



Council of State Governments

A Survey of State Disability Policy, 2010

Twenty years after the passage of the Americans with Disabilities Act (ADA), the landmark federal legislation that changed the face of disability policy in the United States, the fight for equality, access, and civil rights continues unabated. While states have become leaders as well as responders to action related to disability policy, it still remains key to communicate and learn from one another. Enclosed is an illustrative sampling of state policy related to disabilities, a selection of state programs and initiatives, descriptions of select federal policy and the primary source documents available to policymakers, legislators and activists of all spectrums.

Rey Fuentes
7/26/2010

TABLE OF CONTENTS

- Executive Summary-----	4
- Methodology and Use-----	8
- Community Integration and Long Term Care-----	9
- Housing-----	18
- Employment-----	20
- Education-----	25
- Health and Co-Occurring Disabilities-----	29
- Disability Awareness, Benefit Counseling, and Access-----	36
- State Programs and Initiatives-----	44
- Federal Policy and the States-----	57
- Summary and Comments-----	61
- Index-----	63

"I long to accomplish a great and noble task, but it is my chief duty to accomplish small tasks as if they were great and noble."

- **Helen Keller (1880-1968)**

Executive Summary

July 26, 2010 marks the 20th anniversary of the Americans with Disabilities Act, what many consider to be one of the most sweeping movements toward advancing freedom, independence, and dignity since the Civil Rights Act of 1964. As long time policy advisor and crafter of the ADA, Bobby Silverstein sums up the comprehensive federal act saying that “it codified common sense and common courtesy. It basically says that people with disabilities should be treated with dignity and respect in the areas of employment, public accommodations, and services provided by state and local governments.”¹

Yet the current state of disability policy in America is one of sobering statistics. As David Stapleton speaks to in his 2006 article, people with at least one disability are twice as likely to go unemployed than their counterparts with no disability². In fact the average reported employment for persons with disabilities in the United States hovers around a meager 39%³. Match these statistics with a rapidly graying baby-boomer population, returning veterans from theatres of war overseas, growing numbers of diagnosed children with Autism Spectrum Disorders, seemingly endless Medicare waiting lists, increased demand for social services and health delivery options all of which are pressing on significant losses in revenue at the state and federal level, and you have a snapshot of disability policy in America that demands action.

“ [The ADA] codified common sense and common courtesy. It basically says that people with disabilities should be treated with dignity and respect in the areas of employment, public accommodations, and services provided by state and local governments.”

- **Bobby Silverstein**

Even after decades of legislative, judicial, and social progress, the intangible portions of the disability debate may be some of the most destructive. As Silverstein mentions, we must accept a “new emerging disability policy framework” that embraces “the precept that disability is a natural and normal part of the human experience that in no way diminishes a person’s right to participate fully in all aspects of society.”⁴ Many policy makers have been quick to accept this emerging approach by redefining their concept of disabilities, accepting “person first” disability language (i.e. “a person with a disability” versus “a disabled person”) and renaming state agencies and programs to reflect a shift away from archaic language (i.e. “retarded” or “handicapped”). Disabled historian Robert Weibe captures this shift in language by describing that, “The words we use to define problems, or to evaluate

potential solutions to those problems, structure thinking by linking concrete situations to moral categories,” making advocates and policymakers responsible for changing the language of disability in tandem with changing the policy.⁵ Only then will there be a chance for society to accept that access and integration are not simply a series of legal and fiduciary obligations, but a matter of civil rights.

Fight for Progress

While setbacks are easy to focus on, successes must also be celebrated. Intel has now developed a portable assistive reading device that allows blind users to take a picture of any text document and have the information read aloud via an artificial voice. The non-profit organization “No Person Left Behind” focuses on independence for persons whose primary vehicle for transportation is electronic wheelchairs the chance to utilize 12 volt, solar powered assistive devices that free them from possible loss of power and subsequent immobilization. Indeed, as Marilyn J. Field and Alan M. Jette state, the “future of disability in America will depend on how this country prepares for and manages a complex array of demographic, fiscal, medical, technological, and other developments that will unfold in the next several decades.”⁶ Without a doubt, doubled efforts toward enhanced coordination, matched with innovation and perseverance, will be the hallmark of success in the arena of disability policy at the federal level and among the states.

While states have become leaders as well as responders to action related to disability policy, it still remains key to communicate and learn from one another. As Assistant U.S. Attorney General Thomas Perez commented during testimony to the Senate Health, Education, Labor and Pension Committee on the enforcement of *Olmstead v. L.C.*, the landmark Supreme Court ruling requiring states to allow institutionalized patients to seek community-based care, states have long suffered from a “stove-piping” effect, having mixed responses to dealing with federal mandates and providing sufficient resources for individuals needing care when disability policy is left to innumerable state agencies and advocacy organizations.^{5,7} Better communication, along with strategies to fund new programs and mandates will be critical to ensuring the best possible environment for persons with disabilities.

Federal Response

In addition to state responsibilities, the federal government has been making progress in terms of disability policy. HR 3101, if passed by the Senate, will allow the Federal Communications Commission (FCC) to create new regulations for online video captioning services and provide for more accessible emergency management updates.⁸ Secretary

Sebelius issued a letter to Governors to encourage them to voluntarily enroll in the expanded Money Follow the Person (MFP) program in an effort to fulfill commitments to community choice care options.⁹ And on this year of the 20th anniversary of the ADA, the Senate has the opportunity to ratify an international convention on disability to help expand human rights globally.¹⁰

Though the ADA, the Individuals with Disabilities Education Act (IDEA), Medicare, Medicaid, Money Follows the Person Demonstration Grants, Temporary Assistance for Needy Families (TANF) and Children Health Insurance Program, among many other policies, have changed the face of disability policy in the United States, the fight for equality, access, and civil rights continues unabated.

Advocates have a chance now to change the face of disability policy to realize full integration, empowerment, and respect. While system wide change must be made, policymakers must constantly pursue and capture smaller victories that create the ripple effects toward tidal change. As Helen Keller is quoted in the beginning of this document, advocates and policymakers can achieve this “great and noble” goal through the smaller victories we continue to pursue.

What direction might there be for a new decade of disability advocacy?

State Action

What follows then is an illustrative sampling of state policy related to disabilities (nearly 149 different entries from 31 states), in an effort to help spread awareness of programs from across the country. In addition there is enclosed a selection of state programs and initiatives, descriptions of select federal policy and the primary source documents available to policymakers, legislators and advocates of all spectrums. What conclusions can be drawn from these state-based policy decisions and what direction might there be for a new decade of disability advocacy? Six themes, while not comprehensive or prescriptive, may be instructive to help move the policy debate forward:

- 1. Progress is progress, no matter how small:** Many states have seen increased success in responding to issues surrounding disability. From name changes to specific state agencies (Idaho) to simply increasing fines for disability parking to fund programmatic enhancements (Washington & Oklahoma), or allowing American Sign Language to be applied as foreign language in post-secondary education (Kentucky); no policy change should be rendered insignificant.

2. **Focus on community:** For decades, disabilities meant exclusion and privation, but with cultural shifts in society at large and court rulings such as *Olmstead v. L.C.*, institutional facilities are on track to be phased out of long-term care plans in many states in exchange for expected lower costs and greater community integration. From recognizing and certifying communities that offer the best environment for long-term care (Oklahoma) to enhanced funding for transition services such as moving companies, furniture, and groceries through Money Follow the Person Demonstration Grants (Virginia), states have recognized and codified movements toward greater community care.
3. **Promotion and awareness:** Going further than passing disability awareness months, or proclaiming a new state holiday, many states have taken steps to produce true awareness movements. Advocates can take part in online communities meant to spread awareness such as www.adaiowa.com (Iowa) or the Youth M.O.V.E. (Motivating Others through Voices of Experience) (Maryland). States have been able to more clearly identify and help citizens interact with people from various backgrounds and life-paths.
4. **Gather Data:** Predicting outcomes and evaluating the success of a policy in place requires robust sources of data. Programs that require state housing authorities to record the number of accessible homes available to persons with disabilities (Nevada) to programs that gather information on employment opportunities (Minnesota), data gathering must become commonplace in any new action taking place around the country. Only then will advocates and policymakers have the tools necessary to advance their cause.
5. **Remember to Evaluate:** Statutorily mandated annual reporting has been beneficial in synthesizing the massive amounts of information and actions taken by stakeholders, agencies, and policy-making bodies and further refining these efforts have given many states valuable tools to organize and effectively communicate successes as well as obstacles to the correct audiences (i.e. California and Florida's statutorily mandated annual report).
6. **Put power in the right place:** Finding the right balance between advice and enforcement has been a delicate matter. Some states have relied extensively on advisory boards to produce information and recommendations, but Massachusetts'

Office on Disability, for example, places informal enforcement in the hands of its Executive Director to enforce specific rules, regulations, policies implemented by the state legislature. Increased enforcement powers and centralized agency enforcement has been an emerging trend as new requirements test state leadership.

Methodology and Use

What follows is a collection of state information that was the result of email and phone coorespondence with various state agencies and legislative officials that engaged with the initial contact, as well as independent research from various online publication and state-sponsored web sources (e.g. state legislative websites) with reliable information on policy action. The Council of State Governments in no way approves of or encourages adoption of any program, policy, or legislation outlined below, nor gives its endorsement to the effectiveness or overall impact of any program. This report is meant to give policymakers, legislators, and advocates illustrative information on select policies that will encourage not only the adoption of new policies that they may find herein, but the continuation and enhancement of the current public discourse surrounding disability policy. While no document can ever seek to be wholly comprehensive and authoritative, any missing program or under-represented geographic region is not a consequence of choice or design, but of limited time and access to data.

The report has been broken down by thematic section illustrated in the table of contents, and a short summary of sub-themes and particularly creative or innovative policies will preface each new section. Each section then lists policies and programs from various states along with the attached primary source document if such documentation is available. Beyond the information compiled, it is the hope that this document serve as yet another step forward on a longer journey toward stronger public policy to enhance the lives of Americans.

Community Integration, Housing, and Long Term Care

After the landmark *Olmstead v. L.C.* Supreme Court Decision, that mandated community placement for institutionalized patients who sought such placement, community based care, along with long-term care options, have become the one of the most salient shifts in disability policy. The Center for Medicare and Medicaid Services (CMS), Medicare Infrastructure Grants (MIG's), and Money Follow the Person Demonstration Grants (MFP's) may prove to be a powerful forces in creating and sustaining community care and full integration. The Money Follow the Person Grants, simply enhanced federal matching assistance for 31 states included in the 2005 Deficit Reduction Act, have since been extended to 2016 and advocates and state officials still await the final verdict on the program's effectiveness in developing sustainable community based care options.

Some states have found success by merging their Long-Term Care (LTC) services and programs into a single "global" budget, such as Washington or Vermont, for more streamlined and cost-effective benefits distribution or encourage increased data collection to better identify and plan for LTC requirements into the future.

Below you will find policies that center on community based care, long term care options and a range of related issues surrounding this theme. Some particular highlights for this section include state focus on "person" or "client" centered planning that shifts the focus from a person in need of government services, to a client in the market for long-term care. Some policies have been designed to regulate the provider market, while others are simply powerful declarations of a state's will to commit it resources to this new paradigm surrounding community-based options. Below is a sampling of these policies.

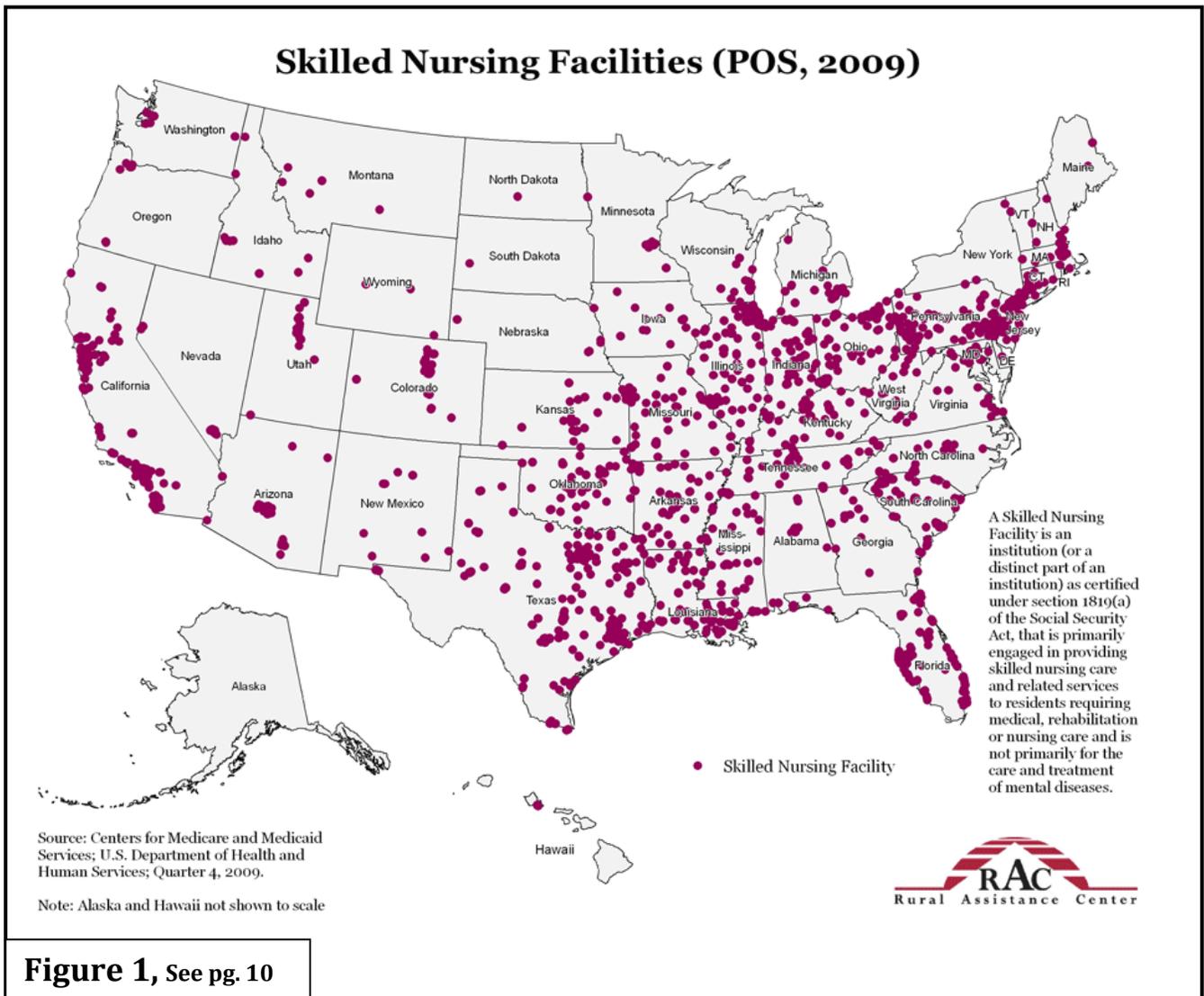
- **New Hampshire, 2008:** HB 717 empowers municipalities in New Hampshire the ability to establish local centers for community care planning boards. [C2]
- **New Hampshire, 2008:** New Hampshire statute (RSA 151-E:4) provides legal support for person-centered planning in the arena of long-term care coverage. [C3]
- **New Hampshire, 2010:** HB 1170 in New Hampshire provides for the regular inspection of home health care providers on an annual basis. [C4]

- **New Hampshire, 2010:** New Hampshire passed legislation to bolster Caregiver Support Services by adopting a “person-centered” planning approach and providing for local coordination of services available for LTC individuals. [C5]
- **Washington, 2006:** Washington State Statute (Sec. 5. RCW 29A.46.260 and 2006 Ch. 207 Sec. 7) of Washington provides for the full incorporation of the rights of people with disabilities to vote, in accordance with the Help America Vote Act. [C6]
- **Washington, 2010:** Washington State, in an effort to provide more comprehensive community based care through county based grant, increased disability parking infraction from \$250 to \$450 to fund several programs, including: Reimbursement for travel, per diem, sign language interpreters, a grant program to fund small, local projects to improve awareness, acceptance, inclusion and access for people with disabilities, technical assistance and training, a web site to share guidance, technical assistance, reference and resources information for counties and public accommodation, and a searchable listing of public accommodations with information on access features. [C7.1, C7.2]
- **Oklahoma, 2010:** Oklahoma’s SB 1640 creates the Certified Retirement Communities Program Act. This bill directs the Department of Commerce to develop a certification to recognize communities that have created conditions favorable to retirees and that would attract older residents and tourists by offering favorable tax provisions, health and safety improvements, public transportation, community services and activities, etc. [C8]
- **Oklahoma, 2010:** Oklahoma’s HB 2596 creates the Empower-OK program which gives seniors and people with disabilities more choice in the long-term care services they receive. Self directed nursing care works by allowing eligible recipients to hire friends, family or a trusted neighbor to provide basic health and wellness services in-home for as long as recipients are able. The bill specifies that other benefits a

As Figures 1 and 2 (pg. 11 and 13 respectively) describe, skilled nursing facilities (as defined Section 1819a of the Social Security Act) and long-term care hospitals (defined by hospitals averaging 25 days of inpatient care) can be few and far between for citizens in rural states and far from urban centers.

person receives shall not be reduced as a result of the person participating in a cash and counseling program. [C9]

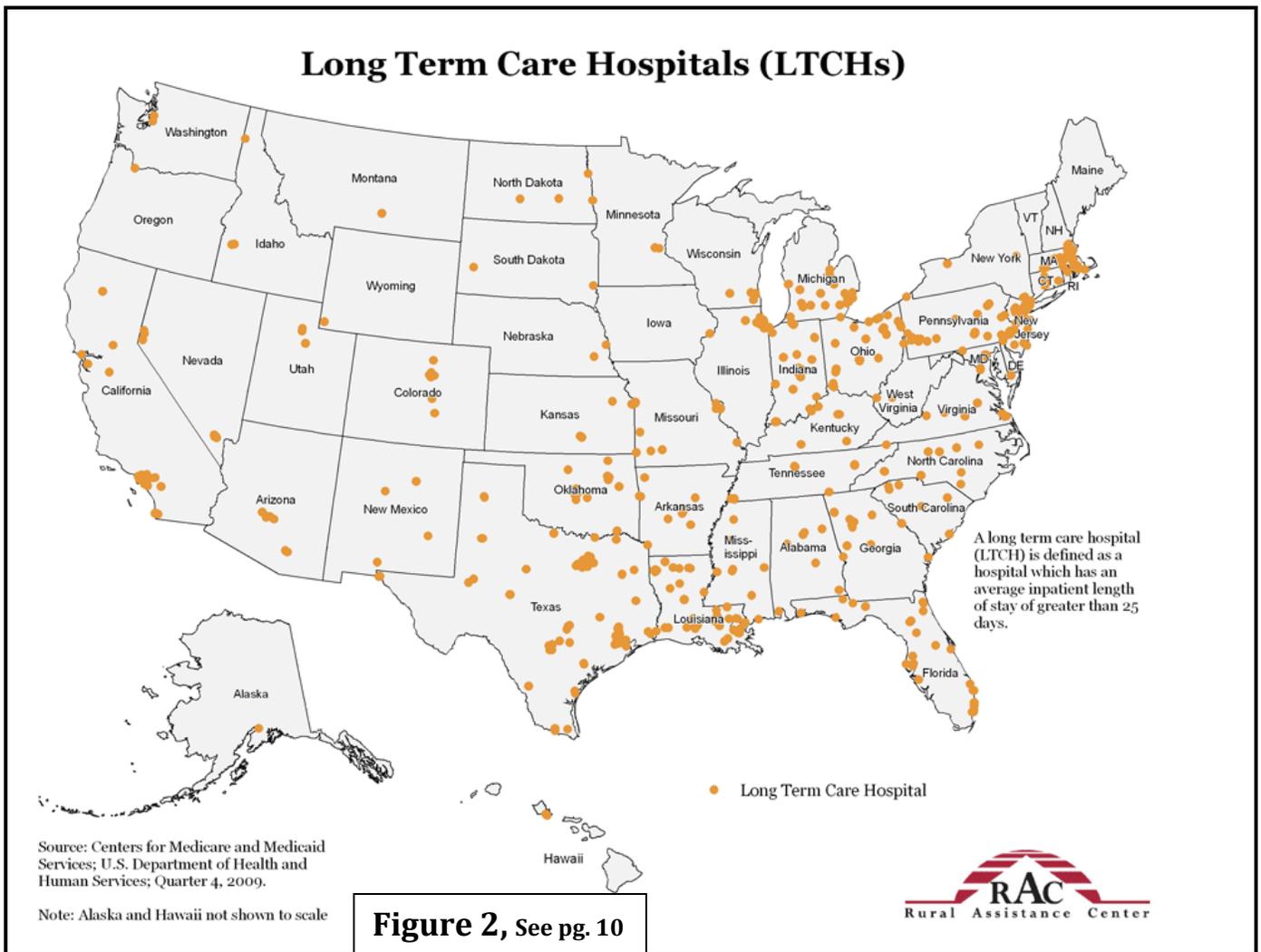
- Oklahoma, 2010:** Oklahoma’s HB-2906 creates the Vulnerable Adult Intervention Team Pilot Program, to be established by DHS if funds are available. The purpose of the program would be to provide interdisciplinary community assistance, intervention and referral services for persons with mental or physical illnesses or disabilities, dementia or other related disease or condition. The interdisciplinary team would have nine members including the directors of DRS, Mental Health, DHS, and Health. This bill died, but some of its provisions were included in SB-1601. SB-



1601. The conference report incorporates the task force provision and adds municipal employees to those required to report abuse, neglect or exploitation of vulnerable adults. [C10.1, C10.2]

- **Virginia, 2008:** In 2008 the Virginians with Disabilities Act (VDA) expanded the kinds of disabilities covered by its service animal provisions under the VDA. Previously, state law protected only the use of service animals by individuals who are blind, hearing impaired, or mobility impaired. The law now says “or otherwise disabled.” This change had positive implications for people who use service animals to assist with less obvious disabilities, such as epilepsy or mental illness. The new law also specifically included people who train service animals. The VDA now defines a “three unit service animal team” composed of the service animal, the person with the disability, and an adult trained to handle the animal. This provides VDA protection to someone with a disability who is only learning to use a service animal but cannot yet use it without another’s assistance. [C11]
- **Virginia, 2008:** In 2008, transition services (up front household expenses) were added to waivers for Money Follows the Person (MFP) participants. Personal Emergency Response Systems were added to the Tech Waiver. Assistive Technology and Environmental Modifications were added to the EDCD and HIV/AIDS waiver for MFP participants.
- **Virginia, 2009:** As a result of several work groups and studies, including those of the Joint Commission on Health Care and the Joint Legislative and Audit Review Commission, the responsibility of the Department of Behavioral Health and Developmental Services (change of name in 2009) was changed to add a coordination of planning and services role for individuals with developmental disabilities, including autism. Previously, the department was responsible by statute only for intellectual disability, mental illness, and substance abuse disorders.
- **Virginia, 2009:** In 2009 the General Assembly passed HB 1853 which expressed the General Assembly’s “intent” to gradually phase in additional slots to end the waiting lists for the ID/DD waivers. Requires the governor to develop a plan to eliminate the urgent waiting list for the ID waiver and the waiting list for the DD waiver by the 2018-20 biennium. [C12]

- Virginia, 2010:** A priority of the Advisory Commission and the Community Integration Implementation Team for a number of years passed. SB 194 provides exemptions to specific sections of the Code of Virginia that will allow an individual to perform state or federally funded health care tasks for a person with a disability under that person’s direction in certain conditions. The tasks must typically be self-performed, and the person with a disability must live in a private residence and, by reason of disability, be unable to perform the tasks but be capable of directing their appropriate performance. [C13]



- Virginia, 2010:** HB 514 designates the Secretary of Health and Human Resources to lead the coordination and implementation of Virginia’s long term care policies. The

Secretary is required to convene, as appropriate, a group consisting of other heads of executive branch secretariats, state agencies, and other public and private agencies and entities to develop a blueprint for livable communities and long term services and supports for older Virginians and people with disabilities through 2025. The blueprint will build upon existing plans and reports and is required to be comprehensive and inclusive of issues related to active, daily life in communities across the Commonwealth. [C14]

- **Virginia, 2010:** SJ 45, a joint resolution originating in the Senate, recognized the issue of abuse of individuals with disabilities and encourages the state Department of Social Services to identify and work with public and private partners to conduct a comprehensive public awareness and education program to identify, prevent, and report abuse, neglect, and exploitation of adults and children with a disability. [C15]
- **Nevada, 2009:** The Nevada State Legislature amended NRS 439A to require reporting by health care facilities to a data repository of individuals at risk of entering a nursing facility, so that community-based alternatives can be explored before a person enters a facility. [Nevada2009]
- **Vermont, 2006:** Vermont has made a major commitment to rebalancing its LTC system by combining nursing home and HCBS funds into a “global budget” that is available to fund a consumer’s entitlement to either nursing home or home and community care. As early as 1996, Vermont began to alter the balance between institutional and HCBS by enacting landmark legislation—Act 160—that required the state to shift to HCBS dollars saved from reduced Medicaid nursing home use. Vermont adopted a 60/40 goal— 40 Medicaid HCBS participants for every 60 Medicaid-funded nursing home residents. A major effort was made to increase the availability of publicly funded services in the home and community, including new residential services. In 1996, when Act 160 was passed, 88 percent of Medicaid long-term care dollars in the state were allocated to nursing home care, and 12 percent went to HCBS. In 2006, the allocation was 68 percent to nursing homes and 32 percent to HCBS. [C16]
- **Vermont, 2005:** Vermont took a large step in October 2005 with implementation of its “Choices for Care” program. After three years of planning and working with federal officials, Vermont received federal approval for a Section 1115 Medicaid

waiver that provides an entitlement to Home and Community Based Services (HCBS). The premise of the program is that people should have equal access to the full array of LTC services, whether a nursing home or HCBS. [C17]

- **Iowa, 2005:** In 2005, the Iowa legislature passed the IowaCare Act (House File 841), also known as Iowa’s Medicaid Reform Proposal. While the Act expands Medicaid health care coverage, it also mandates fundamental LTC reform under a section of the law called “Rebalancing Long-Term Care.” The intent of the LTC provisions is to improve access, expand choices about where and how to obtain services, and build the capacity of Iowa communities to sustain independent living for people with disabilities. The act establishes a higher eligibility standard for nursing homes than for HCBS waiver services, and mandates planning for expansion of HCBS and reducing the population in Iowa’s ICF/MR facilities. The 2006 Department of Human Services budget provided enough funds to virtually eliminate the waiting lists on the state’s HCBS disability waivers. [C18]
- **Washington, 2007:** Washington State has made steady, consistent progress toward an LTC system to the point that, in 2007, more than twice as many people are served under the Medicaid waiver programs for seniors and the disabled persons as are in nursing homes. A single state government agency, the Aging and Disability Services Administration, manages a single LTC appropriation for older people and people with physical disabilities, developmental disabilities and mental retardation. Washington’s assessment and information system, Comprehensive Assessment and Reporting Evaluation (CARE), provides care planning and access not only to Medicaid waiver services but also to Medicaid state plan personal care and state funded services. [See Chapter 388-106 WAC]

- Indiana, 2007:** The secretary of the Family and Social Services Administration adopted a goal of rebalancing LTC funding by the close of FY 2009 through a major expansion of HCBS. The Aging Reform Agenda developed in 2005 and early 2006 called for a “new strategic direction for a comprehensive, integrated LTC system.” The agenda’s objectives were to improve public awareness, increase service capacity, expand access, and rebalance LTC spending. The state integrated all HCBS, nursing facility and hospice services into a single program, Indiana Options for Long-Term Care (OPTIONS). Through a Nursing Home Closure and Conversion Fund, the state has sought to close 1,500 nursing home beds through a combination of incentives and a direct sales effort to the nursing home industry that identified the beds to be closed by July 1, 2007. A major part of the strategy was to increase the number of adult day services and residential alternatives to nursing home care. The state increased the number of certified assisted living providers from 22 on July 1, 2006, to 50 by January 1, 2007. During the same time period, it also increased the adult day service providers from 35 to 38 and the number of adult foster care homes from none to 23. The state had expanded Medicaid waiver slots by 3,500 and reduced waiting lists from a combined total of more than 3,000 to 550 by the end of 2006. [C19]
- Maryland, 2003:** Maryland enacted House Bill 752 during the 2002 legislative session, requires social workers in nursing homes to present residents with information about home and community-based services that might help them live in the community. In the 2003 legislative session, lawmakers enacted House Bill 478, the Money Follows the Individual Act. The law prohibits the Department of Health and Mental Hygiene from denying an individual access to HCBS waiver services due to a lack of funding for the program. [C20]
- Colorado, 2004:** Legislation in 2004, HB 04-1219, added community transition services to the Home and Community-Based Services for the Elderly, Blind, and

“[W]e must not rest until America has a national disability policy based on three simple creeds; inclusion, not exclusion; independence, not dependence; and empowerment, not paternalism.”

~ President Bill Clinton
May 23, 1996

Disabled Medicaid waiver program and provided that such services should not exceed \$2,000 per eligible person per year. [C21]

- **New York, 2009:** A 2009 report by New York’s Health Policy Research Center compares the Long Term Care program in New York State to those in 18 other states (Florida, Pennsylvania, Maine, Massachusetts, Connecticut, Illinois, Michigan, New Jersey, Ohio, Oregon, Vermont, Washington, California, Louisiana, North Carolina, Texas, Virginia and Utah). [C22]
- **Washington, 2010:** Aging and Disability Services Administration (ADSA) in Washington State offers four waivers under Home and Community Services Division (HCS) and four waivers under the Division of Developmental Disabilities (DDD). The waivers are flexible for individuals to receive services in their homes; allowing for nurse delegation, the self-direction of health related tasks to be directed by the person with the disability and provided by paid family or other paid non-licensed personal assistance providers. There are also provisions for home modifications and assistive technology to assist individuals to be more independent in their homes and communities.
- **California, 2010:** California’s Department of Developmental Services (DDS) provides the opportunity to create Individual Program Plan (IPP) for clients to personalize their care direction. IPP Buddies are specially trained San Diego People First members. The buddy will help the self-advocate organize information; identify wants, needs and dreams; and role-play to give the self-advocate greater confidence. The buddy at the request of the self-advocate attends IPP meetings in a support capacity helping to ensure that the members of the IPP team listen to the self-advocate. Buddies follow up with the self-advocate after the meeting to review and assess the actual IPP document and if need be make referrals to advocacy services if unresolved issues remain. There is no charge for the service and all conversations between the self advocates and buddies are confidential.
- **Florida, 2009:** As the Governor’s Council on Disabilities found, basic care in the trauma centers costs the state approximately \$30,000 per individual, per month. Through extensive research, Commission staff provided recommendations to significantly reduce patient rehabilitation services. All of the collaborating parties worked together to establish a Medicaid billing code for a respiratory pacing system

that can replace a ventilator. The respiratory pacing system would allow a large percentage of those presently living in trauma centers due to ventilators to return home or transfer to nursing homes or rehabilitation facilities. There is a one-time cost of approximately \$50,000 for the device and its implantation. If 50 of these Floridians were moved out of the trauma centers, it would save the State of Florida \$1.5 million per month or \$18 million per year and positively impact their quality of life.

- **Maryland, 2009:** MH expanded community service accessibility to individuals with physical disabilities by increasing the maximum age at time of enrollment from age 59 to age 64 and by enhancing waiver service options by adding environmental assessment, nutritional/dietitian services, and home delivered meals in the Living at Home waiver program. Transition services are also being added to the Older Adults Waiver.

Housing

Shelter, next to food and clothing, is a basic need that must be included in comprehensive response to disability reform. Though progress since the passage of the ADA has been



clearly in the direction of providing accessible structures, from housing to public facilities, many homes remain inaccessible to individuals with disabilities.

The lack of accessible housing has serious consequences for individuals and for society as a whole. People with disabilities living in units that lack adequate accessibility features face a greater risk of injury due to falls than those living in units with adequate features. The fear of falling itself reduces the well-being of many older people. Also, people with disabilities living in units without adequate features are more likely to suffer from social isolation

and loneliness. This is a negative impact on life satisfaction, health, and self-esteem (*Aging and Disability Implications for the Housing Industry and Housing Policy in the United States*, Smith, Rayer, and Smith, 2008). Additionally, continued pressure for toward greater community-based care has left many states and municipalities scrambling to find acceptable residences to match their state commitment to care.

In the section that follows, some of the newest developments in housing policy have been updates to accessibility standards, compulsory data collection to anticipate need and housing availability, and novel efforts at certifying housing in varying categories of “visitability,” among others. Below is a sampling of these policies.

- **Nevada, 2006:** Nevada’s 2006 Strategic Plan for People with Disabilities calls for property owners receiving funding from any level of government, and who own accessible and/ or affordable units, report the availability of their affordable or accessible units to the Nevada Housing Registry. [Nevada2009]
- **Texas, 2009:** Texas’ HB 216 (81st) provides for the regulation of certain boarding home facilities and assisted living facilities and requires Health and Human Services Commission (HHSC) to develop and publish model standards, which the local authorities have the option of using when conducting housing construction. [H1]
- **Massachusetts, 2010:** Massachusetts provides a comprehensive listing of federal programs to obtain housing funding and housing assessment tool provided by their federally funded Systems Transformation Grant. [H2]
- **Virginia, 2009:** Further improving a strongly supported but underutilized program in Virginia, the legislature expanded the annual individual limit for the state’s Livable Home Tax Credit from \$500 to \$2,000 and increased the percentage of eligible retrofitting costs from 25% to 50%.
- **Virginia, 2009:** The General Assembly in Virginia approved a requirement that comprehensive plans be posted on a localities website. The impetus to this was public input from the disability community about the difficulty in accessing comprehensive plans in order to provide public comment and participate in the plan development process.

- **Virginia, 2009:** In 2009 for the first time, the Virginia General Assembly made a policy and budgetary decision to allocate capital outlay funds to community housing (\$18.5 million) rather than using all of the capital outlay funds for renovation and rebuilding of state institutions for individuals with intellectual disabilities.
- **Virginia, 2010:** SB 262 requires the Virginia Department for the Aging to post on its website and otherwise publicize guidelines on universal design and “visitability” features that make dwellings and other structures accessible for older Virginians and persons who develop mobility impairment, following a trend among fellow states for similar standards to become widespread. [H3]
- **Virginia, 2010:** HB 192 instructs the Virginia Fair Housing Board to establish, by regulation, educational materials on the Fair Housing Law and require a signed affidavit from persons in the business or activity of selling or renting dwellings that they have read and understood the provided materials [H4]
- **Maryland, 2009:** The Maryland state legislature supported successful HB 54 to permit local tax credits for homeowners that install accessible features in a home.
- **Maryland, 2009:** Widely distributed the Maryland Housing Modification Resource Guide and the Guide for Homeownership to individuals with disabilities who need to modify their homes for accessibility. [H5]

Employment

As David Stapleton mentions in his 2006 article “Dismantling the Poverty trap: Disability Policy for the Twenty-First Century” employment may be one of the most grim realities facing persons with disabilities. Social service programs (Medicare, Medicaid, Social Security Insurance etc.) contain what the authors describe as the “benefits cliff” where working persons with disabilities lose vital social services if they obtain, in some cases, \$1 more than the cut-off for services. This cruel cycle keeps people with even moderate disabilities out of employment and dependent on social services. Add this to the fact that disability unemployment is regularly in the 70% range in most states and this becomes an issue in need of serious attention.

While this scenario is likely in need of a federal response, states can and do play among the most critical roles in responding to and ameliorating disability unemployment.

Employment policies on behalf of individuals with disabilities must focus on, when possible, lifting stringent benefits guidelines, empowering individuals seeking work, and then ensuring they remain responsible to their employment. Many states have reacted by developing programs to better navigate federal benefits programs, removing staff limits in certain state agencies, prioritizing state level hiring for a qualified applicant with a disability and much more. Below is a sampling of those policies.

- **Minnesota, 2010:** Minnesota’s Disability Services Division (DSD) is changing their approach to help people with disabilities make work part of the plan so that they opt out of rather than opt in to employment. Supporting this systemic change is the Disability Linkage Line (DLL) which is a statewide, person-centered, communication system. Within the DLL is an interactive online tool called Disability Benefits 101 (DB101). DB101 helps people with disabilities learn how income and benefits interact so that they can make informed choices about their work, manage their benefits and maximize their potential. The DB101 website offers people consistent information, interactive benefits estimators and real time help. See this [link](#) for more information.
- **New Hampshire, 2007:** New Hampshire’s SB138 provides for a cap on waivers for persons with developmental disabilities at 90 days and provides for a scaled increase in wages for direct staff support and relevant agencies. [E1]
- **California, 2009:** AB 1269 eliminated a number of



restrictions on eligibility, which have limited participation in the Medi-Cal Working Disable Program, which permits individuals with disabilities to continue receiving Medi-Cal and IHSS benefits while earning an income up to 250% of the federal poverty level. The bill also revised the method for calculating premiums participants must pay. [E2]

- **California, 2009:** AB 287 directed the State Council on Developmental Disabilities to establish a subcommittee with representatives from the Department of Rehabilitation (DOR), the Department of Developmental Services (DDS) and other key agencies to make recommendations to the Governor and Legislature for establishing an Employment First policy aimed at increasing the number of persons with developmental disabilities who are gainfully employed in integrated settings. [E3]
- **Texas, 2010:** The State of Texas began the Learning Community Initiative to create learning communities to support employment of people with SMI. Learning communities will include a state-level Steering Group, which will provide high level coordination of policy, elimination of systemic barriers and support to local learning communities, and local learning communities representatives, including representatives from the Texas Workforce Solutions. The initiative will focus on adult clients of the state’s mental health system. DSHS will use funds from two existing grants (Mental Health Transformation and Demonstration to Maintain Independence and Employment) to fund the initiative. The approach is threefold:
 - Provide training and analysis to facilitate the development of state and local “learning communities” intended to help simplify navigation of existing employment and health resources;
 - Provide training and analysis to facilitate use of evidence-based supported employment practices within the existing DSHS case management workforce; and
 - Analyze the initial impact and future potential of the initiative.
- **Texas, 2009:** The Texas Department of Assistive and Rehabilitative Services (DARS) in collaboration with the Health and Human Services Commission (HHSC) was awarded a MIG grant for 2008 to jointly develop the infrastructure for a comprehensive system maximizing competitive employment supports for persons

with disabilities. Texas identified five goals to be achieved in 2009 through the MIG activities:

- Through education and outreach, increase enrollment in Medicaid Buy-In (MBI) by supporting implementation of statewide MBI program.
 - Conduct mapping and analysis of public and private system resources available to assist people with disabilities.
 - Increase partner collaboration.
 - Facilitate establishment of informed consumer base.
 - Facilitate establishment of informed employer base.
- **Virginia, 2009:** The Department of Behavioral Health and Developmental Services, in coordination with the Department of Rehabilitative Services and other partner agencies including local community services boards, is required by HB 1099 to establish specific goals for programs to assist individuals with autism spectrum disorders (ASDs) in obtaining and sustaining employment. These programs will provide initial and ongoing job skills and behavioral training for individuals with ASDs. Employers' awareness and understanding of ASDs and common behaviors associated with them would be expanded to ensure that individuals with ASDs receive the ongoing behavioral and social supports needed to retain successful employment. Programmatic details will be provided in their yearly audit report on November 1, 2010. [E4]
- “Our workforce should look like the people we serve”

- **FEMA Administrator Craig Fugate, NCD Summit 2010**
- **Nebraska, 2009:** Nebraska Workforce Investment Act provides for “locally sourced” services to provide employment counseling and services to qualified Nebraskan citizens [E5].
 - **Oklahoma, 2009:** State Work Incentive Program (DRS, DHS) employment provision established in Oklahoma allows rehabilitation and welfare agencies to hire rehab or welfare clients for entry-level positions, without those positions counting against the agency’s FTE staff limit [E7]

- **Oklahoma, 2007:** Subsection G & H of Section 74-840-4.12 of “Oklahoma’s Optional Program for Hiring Applicants with Disabilities” allows applicants facing severe disabilities who meet the minimum requirements of state employment to be waived from the formal hiring procedure for competitive and noncompetitive positions. [E8]
- **Iowa, 2010:** Iowa has implemented their Ticket to Work Program (TTW) by implementing the Iowa Workforce Partners Employment Network that has worked to create consumer oriented, “on-stop shop” benefits counseling that has allowed more Iowans with disabilities the opportunity to collect information on employment and access multiple layers of benefits.
- **Washington, 2004:** Washington State took the initiative through RCW 71A.10.015 to create an atmosphere amenable to employment for persons with developmental disabilities to ensure “aid to persons with developmental disabilities through a uniform, coordinated system of services to enable them to achieve a greater measure of independence and fulfillment and to enjoy all rights and privileges under the Constitution and laws of the United States and the state of Washington.” [E9]
- **South Dakota, 2008:** South Dakota statutory language allows Department of Labor waivers to persons with “developmental disabilities” to work below the federally mandated minimum wage. [E10]
- **Virginia, 2008:** The General Assembly eliminated the disparity between the supported employment rates paid under Home and Community Based Medicaid Waivers versus the much higher rates paid by the vocational rehabilitation program. Rates were realigned so that the Medicaid rates are at the same level as the Dept. of Rehabilitative Services rates paid to community rehabilitation programs. Medicaid rates for supported employment will be adjusted when DRS rates are adjusted.
- **Virginia, 2008:** Important data elements were added to annual state agency reporting on employment of people with disabilities was established as a requirement. This was a follow up to Executive Directive # 8 established in October 2007. ED 8 instructed all executive branch state agencies and state funded institutions of higher education to examine their hiring practices and remove any

barriers that may prevent qualified applicants from being employed in state government. [E10]

- **Minnesota, 2007: *Pathways to Employment*** - The mission of the Pathways to Employment initiative is to increase competitive employment of people with disabilities and meet Minnesota’s workforce needs by bringing together people with disabilities, employers, businesses, government and providers. Pathways to Employment is Minnesota’s Competitive Employment Systems – Medicaid Infrastructure initiative, funded through a grant to the Minnesota Department of Human Services from the Centers for Medicare and Medicaid Services. The initiative is a collaborative effort of three state agencies: Minnesota Department of Human Services, Minnesota Department of Employment and Economic Development and Minnesota State Council on Disability. For more information including profiles of those served see this [link](#).

Education

Education, long the cornerstone of disability policy advocates and policy-makers, has taken on renewed strength following Supreme Court cases highlighting the rights of children with disabilities and their families (see *Hendrick Hudson School vs. Rowley* [1982] for a child’s right to individual planning, *Danny R. R. vs. State Board of Ed.* [1989] which centered on a school creating the “Least restrictive environment,” or *Winkelman v. Parma City School District* [2007] on a parents right to advocate for children in Federal court, among many others). Here again, states, as the primary providers of educational services, play a dominant role in shaping education for students with disabilities. Interesting examples of state action in this policy domain include transferable funding to allow students to attend private institutions, providing for the training of



teaching professionals who can work as integral parts of the health and well-being of the child (i.e. teachers trained in Autism Spectrum Disorder identification and intervention strategies), and transition services for students “aging out” of social services. Below is a sampling of these policies.

- **New Hampshire, 2007:** New Hampshire’s HB 661 provided for increased flexibility and funding for the state’s Executive Planning Committee on Special Education to better facilitate students with moderate to severe disabilities in public education. [EN1]
- **Oklahoma, 2010:** Oklahoma introduced HB 3393 that provides a voucher or scholarship for students with disabilities to allow public school funds from state and local sources to be used to send a child to a private school of the parent’s choice. [EN2]
- **Kentucky, 2008:** SB 90 amends KRS 164.4781 to permit the establishment of interpreter training programs for the deaf and hard of hearing at more than one public institution of higher education. “The program shall be exempt from the normal student load requirements for a period of ten years from its implementation or until it can be clearly demonstrated that an adequate supply of interpreters is available in all parts of the state, whichever is later.” [EN4]
- **Kentucky, 2006:** Kentucky statute (KRS 164.478) provides for support services for deaf and hard of hearing students. [EN5]
- **Kentucky, 2006:** Kentucky Postsecondary Textbook Accessibility Act, like a similar California proposal, allows for the access of alternative text material for student with disability. [EN6]
- **Oklahoma, 2010:** Oklahoma SB-1876 specifies curricula for physical education classes in schools. The bill calls for curriculum to offer a variety of activity, and accounts for differences in culture, ability, and gender. [EN7]
- **Oklahoma, 2010:** Oklahoma Governor signed HB-3393 (Nelson; Anderson), a bill to allow schools to meet their obligations under IDEA by providing special educations

students with scholarships, as requested by parents, to attend private schools. [EN8]

- **Virginia, 2008:** The Virginians with Disabilities Act (VDA) added public schools to the “public accommodations” section of the Act. Although the VDA already prohibited discrimination in education, there was some controversy about whether school activities that take place outside the classroom, such as athletic events or school plays, were included. The new law made it clear that all aspects of public schools must fully welcome people with disabilities.

“We will work with schools and enforce laws to ensure that all children, no matter what their race, gender, disability or native origin, have a fair chance at a good future.”

- **Arne Duncan, U.S. Secretary of Education**
Commemoration of the Historic Civil Rights March Selma, Alabama

- **Virginia, 2009:** State legislators took steps to address parents’ concerns regarding proposed changes in the state’s special education regulations. In response to a regulatory change which would have shortened the time to appeal a due process hearing from 1 year to 90 days, the General Assembly enacted a code change ensuring a 180 day statute of limitations for appeals.

- **Virginia, 2009:** The Commonwealth of Virginia allows for a younger age, 14, to begin transition planning for students receiving services under an IEP. Federal regulations changed the minimum age requirement to 16.

- **Virginia, 2010:** Under HB 304, with respect to Standards of Learning (SOL) Alternative Assessment, an annual justification must be provided for each student considered for the Virginia Grade Level Alternative (VGLA) that includes evidence that the student meets the criteria established for that assessment. The student’s Individualized Education Program (IEP) team must review that evidence and determine whether the VGLA is appropriate, and to comply with the Standards of Quality, the school division’s superintendent and school board chairman must certify that there is a justification in the IEP for every student who takes the VHLA. Annual reporting is required to ensure that students are not inappropriately diverted to the alternate assessment. [EN9]

- **Virginia, 2010:** SB 46 empowers Virginia’s Circuit Courts to award reasonable attorney fees to the parent of a child with a disability when he or she is the prevailing party in a special education legal action against the Board of Education or a local school division. In cases where the Board of Education or a local school division prevails, the Court can also award them reasonable attorney fees if it finds that the initial legal filing or continued legal action by the attorney of the parent was frivolous, unreasonable, or without foundation or that that it was presented for any improper purpose such as to harass, cause unnecessary delay, or needlessly increase the cost of litigation. [EN10]
- **California, 2010:** The Transition to Independent Living Program (TIL) at Taft College (TC) in California is a postsecondary experience for developmentally disabled adults emphasizing learning independent living skills. The program stresses the importance of teaching people to accept responsibility for decisions and choices they make. The program currently has a waiting list of about 300 for their two-year program that is only able to accept about 25 students per year. Students participate in the program an average of 22 months. Staff works with each student to establish realistic long-range and short-range goals. Individual Program Plans (IPP's) are then written to assist students in attaining these goals. Instruction is offered in the following areas: meal preparation, money management, shopping, housekeeping, use of appliances, safety, communication, transportation, personal care, and interpersonal relationships.
- **California, 2009:** AB 386 proposes to expand the definition of “non-printed instructional materials” to include audiovisual works, podcasts, and web clips. [EN12]
- **Illinois, 2009:** The Illinois Public Agenda for College and Career Success Board completed and published its new statewide strategic plan, The Illinois Public Agenda for College and Career Success in 2009. The four goals of The Public Agenda address the state need to increase educational attainment, ensure college affordability, address workforce needs, and enhance economic growth and competitiveness. Meeting these goals would enable IBHE and Illinois colleges and universities to eliminate achievement gaps by race, ethnicity, socioeconomic status, gender, and disability, including students with disabilities. The priorities of The Illinois Public Agenda mirror some of the priorities of past strategic plans such as

the previous one, The Illinois Commitment, and Priorities, Quality and Productivity. [EN13]

- **Illinois, 2009:** The Illinois P-20 Council, an integrated system encompassing preschool through graduate schools, public and private colleges and universities, was created by the Illinois General Assembly in 2009. The IBHE and the ICCB are key members of the council. The council is to serve multiple functions, including improving academic achievement, improving the collection and use of educational data and measurements, requiring greater accountability and transparency, and easing the transition to college, as well as college access and success. As envisioned, the data system will include information about of students with disabilities in the different educational sectors. The data should provide enough details to reflect the transition and success of students with different types of disabilities at different educational levels. See this [link](#) for more information.

Health and Co-Occurring Disabilities [M]

From providing successful intervention strategies for Autism Spectrum Disorder patients in their youth, to sustaining health and well-being through adulthood, and further still to providing for adequate medical coverage to either abate or restore function for persons with disabilities, no discussion concerning disability policy is complete without a discussion of health care. In many ways states have taken the full brunt of health delivery, and have taken steps to provide a measure of dignity and respect to individuals with disabilities. One must look no further than state action surrounding expanded insurance coverage, state resource centers for handling health delivery and benefits, and new requirements on the sale and state purchase of assistive technologies to see that the onus, and success in many cases, has been on states. Below is a sampling of these policies.

“The time has come for the Senate to send a loud, clear message across this country: Individuals with disabilities, no less than all other Americans, are entitled to an equal opportunity to participate in the American dream. It is time for that dream to become a reality.”

- *Sen. Orrin Hatch*
September 7, 1989

- **Texas, 2009:** HB 1574 (81st), Thompson Requires the Texas State HHSC to establish and administer an autism spectrum disorders resource center to coordinate resources for individuals with autism and other pervasive

developmental disorders (PDDs) and their families. In doing so, HHSC must consult with the Texas Council on Autism and PDDs. HHSC will conduct a study to determine the costs and benefits to the state of initiating a pilot program to provide services to adult persons with autism and related disabilities with similar needs. The study will determine costs and benefits of a program designed to: encourage employment and community integration through specialized supports, case management, and vocational assessment and training; develop community-based activities for persons who do not have employment as a goal; promote individual development and self-determination; coordinate services and supports across all areas of need; and allow for flexible funding and a flexible array of services to meet individual needs. Requires HHSC to submit a report of the findings of the study to various governmental officials no later than September 1, 2010. [M1]

- **Texas, 2001:** HB 1478 (77th Texas Legislature) convened a workgroup to promote and advocate for public policies that support children with disabilities, including transition services. The Children’s Policy Council’s following report, *Recommendations for Improving Services for Children with Disabilities in Texas*, as required by House Bill 1478, 77th Texas Legislature, is the culmination of months of evaluation, analysis, and development by parents of children with disabilities, health and human services agency staff, and community representatives. The report reflects the issues the Council has identified as requiring priority attention. The most recent initiatives in Texas include:
 - Targeted Funding for Youth with Disabilities Aging Out of Foster Care
 - Improved Permanency and Statewide Training Initiatives
 - Rollout of a Significant Number of Medicaid Waiver Services (slots)
 - Expansion of Consumer Directed Services
 - Workforce Crisis – Shortage of Direct Care Workers [M2]
- **Connecticut, 2010:** Connecticut’s Public Act 09-115 expands health care insurance coverage to ASD. This act broadens what a group health insurance policy must cover regarding autism spectrum disorders. It requires a policy to cover the diagnosis and treatment of autism spectrum disorders, including behavioral therapy for a child age 15 or younger and certain prescription drugs and psychiatric and psychological services for insured's with autism. [M3]

- **Massachusetts, 2010:** Massachusetts’ Department of Mental Health ascribes to a philosophy of Community First, put into practice by their Recovery Learning Communities, which builds upon the nation trend to integrate more community based placement goals into state disability policy. [M4]
- **Texas, 2001:** SB 367 (77th) charged the HHSC and appropriate health and human service agencies with implementing a comprehensive, effectively working plan to ensure appropriate care settings for persons with disabilities, and provides a system of services/support for persons with disabilities. The PIAC’s 2008 Stakeholder Report (http://www.dads.state.tx.us/providers/pi/piac_reports/2009/overview81stlegislature.html) is a combination of: (1) recommendations for Texas’ 2008 Promoting Independence Plan for complying with the U.S. Supreme Court’s *Olmstead v. L.C.* decision (June 1999), (2) information on how Texas is meeting the goals of both its own Plan and the requirements under *Olmstead*, and (3) a statement of the values and principles that underlie all the activities encompassed by the Promoting Independence Initiative. The basis for *Olmstead* and the Initiative is Title II of the Americans with Disabilities Act (ADA) requirement that individuals must have the opportunity to live in the “most integrated setting” (28 Code of Federal Regulations §35.130 [d]), the principles of person centered planning and self-determination, and the independent living philosophy. The PIAC also recognizes 80th Legislature and the Governor’s Office for supporting additional funding for community-based programs. For additional information, please contact Marc Gold, Director, Promoting Independence Initiative, Texas Department of Aging and Disabilities. [M5]
- **Texas, 2010:** The Texas Autism Research and Resource Center (TARRC) will provide enhanced support to individuals with autism and their families by providing information about autism spectrum disorders, associated research, and more centralized information about state and local autism resources. The TARRC will also provide training to professionals who interact with or work closely with individuals with autism.
- **Washington, 2010:** Washington State passed legislation that removes any limits on the number of office visits or inpatient hospital days to treat mental disorders must be removed from all state-regulated health plans, unless the limits also apply to

other health services. M6.2 provides a nation-wide look at mental health parity laws as they exist today. [M6.1, M6.2]

- **Washington, 2007:** Senate Bill 5340 establishes and broadens the definition of disability to include not only known and medically recognized disabilities, but also those disabilities that may be “perceived to exist whether or not it exists in fact.” [M7]

- **Oklahoma, 2009:** HB-2828 establishes the Community-Based Providers Quality Assurance Assessment in Oklahoma, an assessment fee charged to community-based providers that is placed in a special fund of the Health Care Authority and used to match federal Medicaid funds which will be used to pay for community-based services. This appears to be a way to maximize federal Medicaid dollars available to Oklahoma for providing supports and services to individuals with disabilities under Medicaid-funded programs (e.g. home and community based waivers). [M8]

- **Oklahoma, 2010:** HB-2777 started out requiring methods for verifying income of Medicaid applicants, but has been changed to direct DHS and OHCA to offer a self-directed care option to certain Medicaid beneficiaries if CMS approves. The bill makes the existing pilot self-directed care option permanent. Persons on Medicaid home and community waivers would be eligible to use the self-directed option if capable of doing so. [M9]

“We can all take pride in how much the ADA has accomplished, which is evident every time you attend a sporting event, ride the subway, or go to work. Yet, there is always more to be done, which is why it’s good not only to celebrate our successes, but to look forward at what still must be done. As long as we never forget that every life is a miracle and each person has something to contribute, we will finish the job.”

~ **Statement from Former President George H.W. Bush on the Anniversary of the Americans with Disabilities Act - July 24 2009.**

- **Oklahoma, 2010:** HB-2774 provides a reimbursement incentive to restaurants to become smoke free. Funds for the incentive come from the Tobacco Prevention and Cessation Revolving Fund and are disbursed by the Health Department. The bill also created the Certified Healthy Communities Act. The Health Department is directed to create a program to certify communities as healthy communities if they request it and meet standards. Criteria for certification as a healthy community would include

but not be limited to enforcement of social host bans to reduce alcohol consumption by minors, adopting local ordinances that promote sidewalks and walking, development of recreation facilities and community gardens, and development of incentives to promote community health and mental health services. An advisory committee will help the Health Department establish the range of criteria to use. The bill creates a similar healthy schools certification program. [M10]

- **Maine, 2007:** Maine adds language to existing statute to broaden the definition of disabilities to include mental health and brain injuries. [M11]

Life is an exciting business, and most exciting when it is lived for others.

- *Helen Keller*

- **Virginia, 2008:** The General Assembly enacted a package of reforms that made major changes to Virginia's involuntary treatment laws and enhanced access to services to ensure individuals with mental health disorders get the treatment they need. The most significant of these reforms involved changing the existing "imminent danger" and "inability to care for self" criteria (widely believed to be too restrictive

and vague) to broader and clearer standards based on "substantial likelihood" of causing or suffering harm. Other major areas of reform included new mandatory outpatient treatment procedures, clarification of permitted disclosures, new responsibilities for CSBs for participation in the involuntary process and coordination of care, more specific responsibilities for CSB preadmission screeners and independent examiners, clarification of court procedures, new evidentiary provisions, and other reforms.

- **Virginia, 2008:** Recovery Oriented Systems Indicators (ROSI) added as a requirement for local community services boards to administer annually. The ROSI is a nationally recognized instrument for measuring movement in the areas of recovery-oriented services for individuals with mental health challenges. There is a strong emphasis on inclusion of individuals receiving services measuring their level of service planning and directing their own supports. [M12]
- **Virginia, 2007:** A Children's Services System Transformation Initiative was initiated in late 07 to improve outcomes for children and their families. Programmatic objectives of the policy initiative were to: (1) increase the number

and rate at which youth in foster care move into permanent family arrangements; (2) increase the number of placements of at-risk children and youth with kin and foster parents; (3) devote more resources to community based care; and (4) reduce the number of group care placements. In 2009, an action plan was developed to spread the transformation work statewide. [M13]

- **Alaska, 2008:** Alaska’s Governor’s Council on Disabilities and Special Education organized and oversaw the development and implementation of the Alaska’s Kids Can’t Wait campaign. As a result, the legislature funded a \$1 million dollar increment for the Early Intervention/Infant Learning Program (EI/ILP) services and \$300,000 for EI/ILP workforce development/high qualified staff. [M14]
- **Alaska, 2009:** As a result of the Alaska’s Governors Council’s advocacy, in 2009 the State Board of Education & Early Development added advanced nurse practitioners to the list of medical personal that can make an autism diagnosis for special education purposes. [M15]
- **Nevada, 2009:** Raise the unearned income eligibility limit for the Medicaid buy-in program (HIWA). Issue Summary: Objective 52 of the Strategic Plan challenges the State to “continually expand Nevada’s Medicaid Buy-In Program to equitably provide, by 2008, medical insurance coverage or wraparound to all people with disabilities who, by virtue of becoming employed, have established an income above poverty level, but cannot obtain the health care coverage and services required to terminate reliance on public benefits.” The Health Insurance for Work Advancement (HIWA) program enables people with disabilities who want to go back to work to buy-in to the Medicaid program to ensure that they will not lose health insurance coverage in the process of getting a job. This recommendation has been implemented. The Division of Health Care Financing and Policy budget included an elimination of the unearned income limit for the HIWA program. [Nevada2009]
- **Illinois, 2007:** Illinois passed SB 284 that will establish three group homes for adolescents with autism. “This legislation seeks to remedy the situation of lack of services for autistics aged 13 to 18, and offer some relief to their families as well,” said Representative Dennis Reboletti. The Department of Human Services will provide the funds needed to manage the centers, which will be staffed full-time by adults who specialize in treating children with autism. [M16]

- **Indiana, 2007:** Indiana enacted HB 1428 that requires police officers directly employed by a school to undergo training to deal appropriately with autistic children. Children with this disability may not react as might be expected to many situations, especially stressful ones, and their behavior can be difficult to understand and manage. The law also allows local officials to close schools for up to three days in order to provide similar training for teachers. [M17]
- **South Carolina, 2007:** Legislators in the South Carolina overrode the Governor's veto to enact SB 20, which requires all insurers, including the state's employee and retiree plans, to cover ASD treatment for anyone who was diagnosed before the age of eight. [M18]
- **California, Delaware, Kansas, Illinois, Iowa, Missouri, New York and Washington** have laws that ban or limit the amount of mercury a vaccine can contain based on concern for the possible link in the rise in autism diagnoses. Several studies, including reports from the Center For Disease Control, dispute this link.
- **Minnesota, 2008:** The development of health care homes in Minnesota is part of the ground-breaking health reform legislation passed in May 2008. The legislation includes payment to primary care providers for partnering with patients and families to provide coordination of care. A "health care home," also called a "medical home," is an approach to primary care in which primary care providers, families and patients work in partnership to improve health outcomes and quality of life for individuals with chronic health conditions and disabilities. Further definitions of health care homes from 2009 are available [here](#). [M19]
- **Alaska, 2009:** The Council's five-part autism initiative continues to gain momentum. FY10 funding for expanded diagnostic capacity transitioned from a mix of state general fund dollars and Trust funding to 100% state general fund dollars (\$500,000). An additional \$125,000 in state general funds was secured for workforce development; and for the first time, state general funds (\$150,000) were obtained for the Alaska Autism Resource Center.

- **Maryland, 2009:** An agreement was confirmed between Gallaudet University and the Mid-Shore CSA to provide culturally competent training on mental health needs of the deaf, hard of hearing and deaf-blind individuals to practitioners in Maryland.

Disability Awareness, Benefit Counseling, and Access

Even after decades of legislative, judicial, and social progress, the intangible portions of the disability debate may be some of the most destructive. Persons with disabilities still face hurdles not experienced by their counterparts that, at times, put them at a competitive disadvantage when searching for education, employment, or just simply acceptance. States have taken creative and necessary steps to reduce this trend by changing archaic words and phrases from state departments and programs (i.e. “retarded,” “handicapped,” or “special needs”), partnered with advocacy organizations, provided enhanced legal protection for access to services and technologies, and even issuing policies directly from the executive branch for decades of mistreatment. The policies recognize that structural change is nearly impossible without perceptual changes in the way we view disability and access. Below is a sampling of these policies.

- **Maryland, 2010:** Youth M.O.V.E. (Youth Motivating Others through Voices of Experience): Maryland is the first of eleven states to implement a state chapter of Youth M.O.V.E. – in a partnership of the MD Coalition of Families for Children's Mental Health, the University of Maryland Innovations Institute, and local Core Service Agencies. [MOVE](#) seeks to raise awareness surrounding youth issues “for the purpose of empowering youth to be equal partners in the process of change”
- **Idaho, 2010:** The Idaho House and Senate passed legislation, subsequently signed into law by the Governor on April 6, 2010, revising state statute to reflect respectful disability language. The legislation (S1330a – Removing Archaic and Disrespectful Language from Idaho Law) updates Idaho law by removing the term “mental retardation” and replacing it with “intellectual disabilities” or, in the case of education law, “cognitive impairments”. It also replaces “handicapped” with “disability” and removes outdated words such as “lunatic” and “idiot.” [D1]

- **North Dakota, 2009:** North Dakota Expanded eligibility for SCHIP from 150 to 160 percent net of the federal poverty level, as well as additional funding for outreach to cover more children.
- **Washington, 2010:** Washington State increased funding for its General Assistance – Unemployable (GAU) fund by \$20 million, increasing monthly coverage for individuals temporarily unemployed due to a disability but timing out benefits at 24 months across three years [D3]
- **California, 2006:** AB 768 requires a manufacturer or distributor of touch-screen devices used for the purpose of self-service check-in at hotels, transportation stations, and similar locations to make available touch-screen self-service check-in devices that enable a person with a visual impairment to enter any personal information and to use the device independently and without the assistance of others. [D5]
- **California, 2008:** SB 1608 made a variety of changes to the law designed to encourage compliance with disability access laws, to discourage frivolous lawsuits over access issues and to promote prompt resolution of suits that are filed. [D6]
- **Texas, 2004:** The Texas Technology Access Program, administered by the Texas Center for Disability Studies at University of Texas-Austin, is the state's entity that has carried out the federal Assistive Technology Act of 1998 and earlier versions of the law. Programs improve access, advocacy, and awareness of assistive technology to meet the needs of Texans, including youth, with disabilities. Please see <http://tatp.edb.utexas.edu/>
- **Virginia, 2007:** A full report of Virginia Mental Illness service system, along with proposed policy changes to ameliorate service disparities. [D7]
- **Virginia, 2009:** Person centered planning options and examples as provided by the Virginia Department of Behavior Health and Developmental Services with more information provided by at the following [link](#). This program allows for the development of personalized care plans based on a care professional evaluation. [D8]

- **Virginia, 2009:** Virginia Department of Behavioral Health and Developmental Services issued a position statement on culturally and linguistically appropriate services, advocating for, among other things, the respect of culture in recovery and resiliency and the need to develop well-trained stakeholders. [D9]
- **Texas, 2010:** Texas Executive Order RP42 – Relating to the creation of the Aging Texas Well Advisory Committee, created a comprehensive plan to address and assist again Texans in a way that ameliorates the structural concerns of long-term care and assists in creation a long term care plan. [D10]
- **Oklahoma, 2005:** Title 63, Section 2409 of Oklahoma law provides for sign language interpreters for any defendant in a criminal or civil case or during any agency hearings. [D12]
- **Oklahoma, 2010:** Oklahoma passes House Bill 2567 which increases parking fines in handicapped parking spaces from \$150 to \$500. See the following [link](#) for further information. [D13]
- **Oklahoma, 2004:** Oklahoma passed HB 2197 to encourage local compliance with Section 508 of the Reauthorization Rehabilitation Act that encourages states to begin to make electronic access open to as many people as possible. [D14]
- **Tennessee, 2010:** Tennessee authorizes new annual matching program to reduce costs to health providers and allow current enrollees to keep the same level of basic service. See the following [link](#).
- **Oklahoma, 2010:** HB-2710 provides an option for a taxpayer to donate part of his income tax refund to the Multiple Sclerosis Society. [D15]
- **Oklahoma, 2010:** SB-1373 Mandates Department of Health creates a plan to improve management and treatment of lung disease and increase public awareness of Chronic Obstructive Pulmonary Disease (COPD). The bill in its final form also approved creation of a public trust to act as recipient of grants for use in development of electronic medical records exchange protocols. [D16]

- **Iowa, 2010:** To commemorate the 20th Anniversary of the ADA, an informal group of Iowan advocates create www.adaiowa.com to spread information and awareness of the ADA and strengthen services available to those with disabilities.
- **Ohio, 2009:** The Ohio Center for Autism and Low Incidence, which is a project of the state's department of education, developed and maintains a comprehensive manual designed to help parents access the information they need to care for individuals with ASDs at all stages of their lives. The manual contains 277 pages, is available online, and includes sections that address (1) what ASDs are, (2) screening and diagnosis, (3) living with ASDs, (4) interventions, (5) accessing educational services, (6) social service programs, (7) advocacy and disability awareness, and (8) future planning. The document also includes useful forms and guidance that parents can follow to ensure access to services for which their child is eligible. [D17]

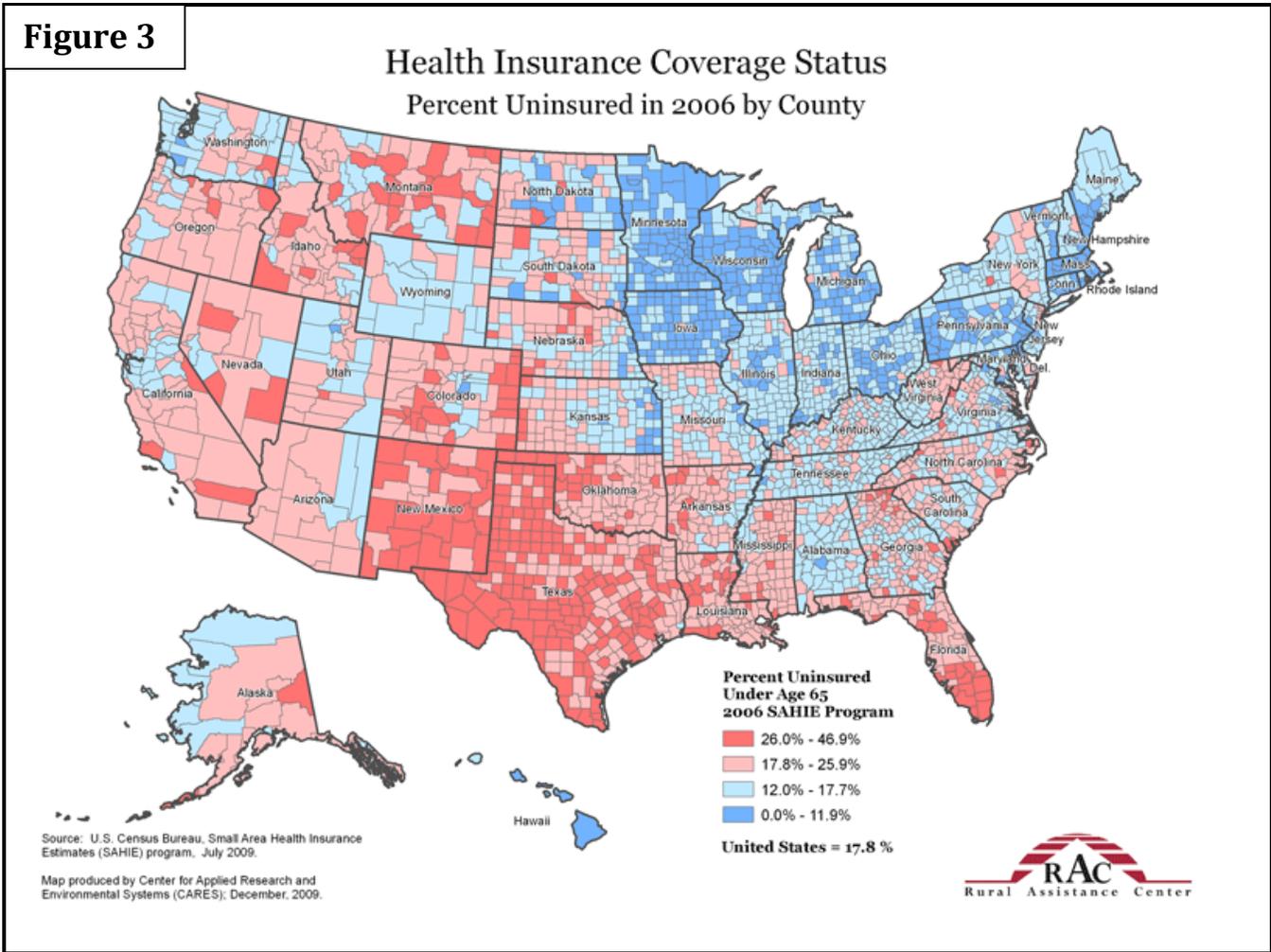
- **California, 2007:** California's Kern Regional Center (KRC) recently implemented an Individual Development Account (IDA) program that allows individuals to save money without affecting their SSI benefits. The individual develops a plan with a savings goal and places earned income into the account. After achieving the savings goal (maximum of \$2,000) the individual also gets the



accrued interest on savings plus a match for each dollar saved from a community partner bank. In the KRC program, it's a three-dollar match for every dollar saved. That would mean over \$6,000 for those who save the maximum. Monies must be used to buy a house, go to school or start a business. As far as KRC knows, this is the first IDA plan specifically focusing on people with developmental disabilities to be approved by the Social Security Administration. [D18]

- **Nevada, 2009:** The Nevada Legislature passes legislation that will require the use of “people first” language in the Nevada Revised Statutes and Nevada Administrative Code when referring to people with disabilities (i.e. removing archaic language and referring to the person before the disability such as “person who uses a wheelchair” v. “a wheelchair user”). [Nevada2009]
- **Nevada, 2007:** Nevada passed AB 629 in 2007 to fund its 2-1-1 automated benefits counseling system after a pilot program in 2005 proved successful. With a fully functioning 2-1-1 system, anyone in Nevada will be able to dial 2-1-1 on their telephone and receive help finding the assistance or information they need which creates a single source benefits phone line dedicated to connecting Nevadans to specific resources in the state. [D19]
- **Multi-State Compact, 2003:** Alaska, Colorado, Georgia, Hawaii, Idaho, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Hampshire, New Mexico, North Carolina, Ohio, Oklahoma, Pennsylvania, Puerto Rico, Rhode Island, South Carolina, Tennessee, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming are currently members in the Interstate Insurance Product Regulation Commission which seeks to create a uniform insurance market across states. A history of the program and related congressional inquiry can be found at the following [link](#). [D20]
- **Minnesota, 2009:** Advocating Change Together (ACT) and Remembering with Dignity (RWD), two self advocacy grassroots organizations working to advance human rights for people with developmental disabilities, secured the passage of Resolution 4, which calls for a formal apology from the State of Minnesota to former residents of the Minnesota State institutions. For most of the twentieth century, persons with mental illness and developmental and other disabilities were institutionalized in Minnesota; their treatment was often less than humane and frequently very cruel. Asking for this apology has long been a part of the work of Remembering with Dignity project, which is housed at Advocating Change Together. [D21]

- Minnesota, 2010:** Minnesota’s disability advocacy community, led by the Arc of MN, successfully worked to pass “Community Counts” legislation during the 2010 legislative session. Community Counts is an initiative to set statewide goals and benchmarks for services and supports for people with disabilities, reflecting the notion that a comprehensive plan is needed to determine if MN is achieving our goals, both for individuals and for our system of supports.



- Illinois, 2007:** In October 2004, the IBHE approved a resolution that urges Illinois public universities to continuously improve student access to the Worldwide Web and other forms of digital communication. Also, Illinois public universities are obligated to comply with the August, 2007 *Illinois Information Technology*

Accessibility Act which reinforced the purposes of the resolution. Although the resolution and the act were intended for public universities, in practice community colleges and private colleges and universities have and continue to respond to the resolution by improving their services to students with disabilities. See the following [link](#) for more information.

- **California, 2008:** SB 1451 and SB 426 Required the Director of the Governor's Office of Emergency Services (OES) to appoint representatives of the disability community to serve on pertinent Standardized Emergency Management System (SEMS) committees and Technical Working Groups. The bill also required the Director to prepare a report to the Legislature by January 1, 2009, with recommendations regarding preparedness, planning, procedures, and provision of accessible information on evacuations regarding the needs of people with disabilities. [D22]
- **Florida, 2009:** Florida state officials, with assistance of an Able Trust grant, are in the process of designing a comprehensive clearinghouse on the web to maintain and enhance the list of links to national and state resources on disability information and services available through the Florida Clearinghouse on Disability Information. Each state agency will then be required to link to the site.
- **Florida, 2008:** Florida state officials will establish a single statewide registry of persons who may need to be served in a special needs shelter in an emergency event. They hope to make the registry accessible by all local emergency management agencies, county health departments, and agencies responsible for the operation of special needs shelters.
- **Maryland, 2009:** Infused a philosophy of "*Nothing about me, without me*" by routinely involving people with disabilities in problem solving - resulting in a 30% increase in consumer satisfaction in the paratransit system.
- **Maryland, 2009:** Secured \$2.6 million in federal funding to expand the Assistive Technology Guaranteed Loan Program, guaranteeing the solvency of the program to

at least the year 2020. This program provides people with low interest loans underwritten by the State to purchase assistive technology or home modifications.

State Programs and Initiatives

What follows, listed in no particular order or rank, are policies and programs that serve as examples of unique state responses to disability policy issues. State programs were chosen by the author with no particular methodology other than a level of depth or uniqueness that presented itself during the research phase of this document. Provided herein are descriptions of those programs from across the country that cover issues of statutory power of state officials in policy enforcement, technological access plans, and community-based care programs, among others. It is hoped that the programs below will add additional depth and nuance to the public policy discourse and allow for a closer look at select state programs.

STATE POLICY 1:

Minnesota's Comprehensive Assessment (COMPASS) Project [SP1]

COMPASS Project Overview:

In 2004, DHS in collaboration with stakeholders began to work on what is currently known as the Minnesota Comprehensive Assessment (COMPASS). This new process and data collection tool was developed to ensure greater consistency and access to the right service at the right time across populations that receive Long Term Care assessments.

The 2009 Minnesota Legislature approved funding for the Minnesota Department of Human Services, Continuing Care Administration to implement the Minnesota COMPASS beginning January 2011.

The Minnesota Comprehensive Assessment (COMPASS) will take the place of all Long Term Care assessments that are currently required including:

- Developmental Disability Screening

- Long Term Care Consultation (LTCC)
- Medical Assistance Health Status Assessment for Personal Care Assistance Services
- Private Duty Nursing Assessment

COMPASS Project Framework:

The COMPASS initiative is developing standards and protocols, a common web-based data collection tool, and recommendations to best utilize the tools to improve the reliability and equity of service provision, with careful regard given to the possible impact on service funding structures. The COMPASS Project has four distinct projects within the COMPASS framework including Project Sponsors, Project Owners, a Steering Committee, Project Leads and work groups. The four distinct projects within COMPASS include:

- Compass Systems Technology Project ~ designed to provide technology solutions for standardizing the assessment process and collection of assessment data for Long Term Care services.
- Policy Revision ~ designed to implement legislative reform which will require policy review, revision and implementation.
- Payment Project ~ designed to develop a new payment methodology for all processes in the COMPASS business process model.
- Certification and Training ~ designed to develop training curriculum and ensure identified assessors are trained and certified within established time lines.

COMPASS Project Outcomes and Vision:

The Minnesota COMPASS is a new Web-based tool using a person-centered approach designed to:

- Allow for timely consideration of support options beyond what is reimbursed through Medical Assistance long-term care programs
- Combine Long Term Care assessment processes
- Provide additional data to evaluate outcomes
- Simplify and standardize face-to-face assessments

The vision of COMPASS is to have a comprehensive assessment process that supports improvements to the quality and efficiency of supports including:

- Assessment standards and protocols that includes all ages and disabilities
- Flexibility to address eligibility, payment of service and case management needs

- Recognition of available informal caregivers and supports

STATE POLICY 2:
Texas' Promoting Independence Initiative and Plan [SP2]

The Texas Promoting Independence Initiative was implemented in direct response to the United States Supreme Court decision in *Olmstead vs. L.C.* (June 1999) and Governor George W. Bush's Executive Order GWB 99-2. The purpose of the initiative is to promote an individual's choice to live in the most integrated residential setting and to receive appropriate long-term services and supports. While this is an HHSC initiative, daily management of the initiative has been delegated to DADS, through Health and Human Services (HHS) System Circular-002: The Promoting Independence Initiative and Plan.

Executive Order GWB 99-2 required that a report be submitted to the Governor's Office by January 2001 to make recommendations regarding services for individuals with disabilities. HHSC established the statewide advisory committee, Promoting Independence Advisory Committee (the Committee), to guide the development of this report, named the "Texas Promoting Independence Plan" (the Plan).

The latest Plan is the "2008 Revised Texas Promoting Independence Plan", published in 2009. A new Plan will be submitted in December 2010, prior to the 82nd Legislative Session. The Committee meets quarterly to promote community-based programs for individuals who are older and/or have disabilities, and to provide a discussion platform for current HHS enterprise-wide issues that may be a barrier to an individual's choice to live in the most integrated setting desired.

Several collaborative, interagency initiatives that DADS will be continuing or initiating involve HHSC and the other HHS agencies that support individuals with disabilities living in the most integrated residential setting. These initiatives promote choice and self-determination.

One major systems change that resulted from this initiative is the "Money Follows the Person" (MFP) policy which began on September 1, 2001 as the result of a rider, and was codified in statute effective September 1, 2005. This policy helps individuals who are receiving long-term services and supports in a nursing facility (NF) return to the

community to receive services without placement on certain Medicaid waiver program interest lists. In order to access the MFP program, an individual must be: Medicaid-eligible; living in a Medicaid-certified NF for 30 days; and meet all the program eligibility criteria for the community-based waiver program. The MFP program has been very successful: since the program's inception, 20,300 Texans have used the program to relocate back to their communities to receive long-term services and supports.

The initiative also allows individuals in nine-or-more-bed private community ICFs/MR or in State Supported Living Centers (SSLCs) to have expedited access to the HCS waiver. Individuals in SSLCs may access an HCS slot within six months of referral, and those residing in private community ICFs/MR may access an HCS slot within 12 months of referral.

Texas MFP is anticipated to receive up to \$30 million in enhanced Medicaid funding through 2012 for a Texas MFP Demonstration. Texas was one of the original grantees to receive funding from the \$1.8 billion national demonstration program allocation that was included in the Deficit Reduction Act (DRA) as the MFP Rebalancing Demonstration.

The Texas MFP Demonstration has set a benchmark to relocate 2,999 additional individuals who are current residents of the following institutions:

- NFs;
- Nine-or-more-bed private ICFs/MR;
- State Supported Living Centers; and
- Nine-or-more-bed private ICFs/MR whose providers want to close their facilities.

In addition to targeting the above-mentioned populations, four specialized projects are part of the Demonstration.

- Behavioral Health Pilot: Individuals in Bexar County receive two new Demonstration services: cognitive adaptation training and adult substance abuse training services. The Department of State Health Services (DSHS) coordinates this initiative.
- Post-relocation contacts: Relocation specialists are providing intensive post-relocation contacts with individuals to provide outside support and continuity with the relocation.

- Overnight Companion Services: Individuals in all fee-for-service counties in Region 11 and all counties in Region 4 who have complex functional or medical needs are able to hire an attendant during normal sleeping hours to be available for emergency situations and assistance with daily living activities, such as toileting.
- Voluntary Closure of Nine-or-More-Bed Community ICFs/MR: Providers of these facilities have an opportunity to work with DADS to voluntarily close their facilities. All residents of these facilities are given freedom of choice on where they want to live in terms of community settings or another ICFs/MR.

The *Patient Protection and Affordable Care Act of 2010* (Act) has extended the MFP Demonstration program’s original appropriations an additional five years through 2016. The Act also reduces the eligibility requirement for a participant to be in an institution from 180 days to 90 days before relocation can occur within certain guidelines.

These new provisions have a possibility to greatly impact Texas’ Demonstration. The extension of the program and the decrease in the eligibility criteria will allow more individuals to participate in the Demonstration which, in turn, allows Texas to receive more enhanced federal medical assistance percentages (EFMAP). It was anticipated that Texas would receive an estimated \$30 million in EFMAP through calendar year 2012; this figure should more than double because of the Act. In addition, the new federal appropriations allow Texas to propose additional pilots or test different services/supports to assist in the relocation process and help to promote a more successful relocation and avoiding re-institutionalization.

STATE POLICY 3:
Virginia’s Report on Autism Spectrum Disorder [SP3]

House Joint Resolution 105 of the 2008 General Assembly directed staff of the Joint Legislative Audit and Review Commission to study autism services in the Commonwealth. Specifically, staff were directed to assess the availability and delivery of services to Virginians with autism spectrum disorders (ASDs), examine the provision of these services in other states, and identify ways to better serve individuals with ASDs in the Commonwealth. Staff findings, totally over 250 pages, were presented to the Commission on June 8, 2009. Some of the conclusions based on the report follow below:

- Multiple research studies evaluating the effectiveness of treating children with ASDs have documented that most young children who receive intensive interventions experience improved functioning and require fewer supports over time. In addition, several studies have used these results to determine that the provision of intensive ASD interventions can yield significant savings as a result of a decreased need for special education and long-term care services. The costs for providing Early Intensive Behavioral Intervention (EIBI), generally characterized as 35 to 40 hours per week of ABA-based treatment for two to three years, are estimated to range from \$23,000 to \$60,000 per year (depending on the design of the treatment program), and are typically incurred for two to three years. Research suggests that most children with ASDs who do not receive intensive early interventions are likely to remain in an intensive special education classroom up to age 22 at an average cost that will vary by state, but was \$21,450 in Virginia in 2008.
- A study published in a national journal found that Pennsylvania could save an average of \$187,000 to \$203,000 on each child who received three years of EIBI relative to one who received special education services until age 22. The Pennsylvania study also suggested that cost savings would likely continue to accrue after children exit the school system. The study found that the state could save from \$656,000 to \$1.1 million per child if expenditures up to age 55 are included. Another study published in a national journal found that Texas could save an average of \$208,500 in education costs for each student who received three years of EIBI relative to a student who received 18 years of special education from ages four to 22.
- System wide coordination is necessary to achieve monetary savings and intervention success. Prior to 2009, no State-level entity has been responsible for coordinating the multiple programs and agencies that serve Virginians with ASDs. Each agency has traditionally overseen the delivery of services and development of public policy strictly as they relate to their target population, but no entity has been tasked with considering the broader system of care formed by existing programs.
- More training is necessary for public safety and public service employees who interact with individuals with ASD, as most have not received even basic instructional direction.

- If states chooses to address issues affecting the delivery of services to individuals with ASDs, several strategies could be followed to achieve meaningful results while acknowledging fiscal constraints. These strategies have been either used or recommended in several other states that have recently explored options to improve their service delivery system.
 - Start with “quick hits” that require limited resources and have a short implementation timeframe to begin helping families right away;
 - Build upon existing programs whenever possible in order to minimize the need for ramp-up in knowledge and resources, and expedite implementation;
 - Implement pilot projects to identify successful initiatives which can be expanded when funding is more widely available;
 - Focus efforts on specific programs or populations as a starting point;
 - Increase the number of Individual and Family Developmental Disabilities Support (DD) and Mental Retardation (MR) waiver slots could help many individuals with ASDs receive comprehensive care during all life stages;
 - Utilize funding from the American Recovery and Reinvestment Act (ARRA), Virginia has focuses \$250 million toward services and treatments vocational rehabilitation, independent living, and ASD intervention, among others;
 - Require local matching funds for new services;
 - As of May 2009, 13 states (Arizona, Connecticut, Florida, Illinois, Indiana, Louisiana, Montana, Nevada, New Jersey, New Mexico, Pennsylvania, South Carolina, and Texas) had enacted legislation requiring comprehensive mandated health benefits covering all ASD-related therapies, including speech, occupational, physical, and behavioral interventions. Bills had been introduced in another 25 states in 2009, including Virginia. Further, a bill was introduced in the U.S. Congress in April 2009 that would compel comprehensive coverage of research-based, medically necessary ASD therapies (including applied behavior analysis) by health insurance plans not governed by State laws;
 - Require the contribution of personal resources based on ability to pay.

Further information and study conclusions can be found at [SP3]

STATE POLICY 4:
Support Intensity Scale for Person Centered Planning [SP4]

When it launched in 2004, the Supports Intensity Scale caught the attention of many U.S. states as a tool that assures fair, just, and equitable supports to people with developmental disabilities. Endorsed by many state officials, the program is developed to assess an individual's necessary level of support and assistance to conduct daily activities in order to “enhanced personal independence and productivity, greater participation in an interdependent society, increased community integration, [and] improved quality of life.” The program is designed specifically to develop individual plans for long-term care and an example of the program can be found here [SP4.1] along with a power-point describing the program here [SP4.2]

The Supports Intensity Scale is an assessment tool that evaluates practical support requirements of a person with an intellectual disability. Available in print and electronic formats, SIS consists of an 8-page Interview and profile form that tests support needs in 87 areas, and a 128-page User's Manual. SIS is comprehensive and engages the clients in an interview process covering the following topical areas including 57 life activities and 28 behavioral and medical areas including:

- Home Living Activities
- Community Living Activities
- Lifelong Learning Activities
- Employment Activities
- Health and Safety Activities
- Social Activities
- Protection and Advocacy Activities
- Necessary Medical Supports
- Necessary Behavioral Supports

The Scale ranks each activity according to *frequency* (none, at least once a month), *amount* (none, less than 30 minutes), and *type* of support (monitoring, verbal gesturing). Finally, a Supports Intensity Level is determined based on the Total Support Needs Index, which is a standard score generated from scores on all the items tested by the Scale.

Traditionally, a person's level of developmental disability has been measured by the skills the individual lacks. SIS shifts the focus from lacks to *needs*. The Scale evaluates practical supports people with developmental disabilities need to lead independent lives.

SIS gives professionals direct and reliable measures of practical supports required in daily living activities. The interview forms rank support requirements by *frequency* (none, once a

month, and more), *daily support time* (none, less than 30 minutes, and more), and *type of support needed* (none, monitoring, verbal prompting, and more). The SIS User's Manual provides detailed instructions on how to score and administer the Scale.

More information can be found at:

<http://www.siswebsite.org/page.wv?section=Product+Info&name=Product+Info>

STATE POLICY 5:
IOWA'S SEVEN DEPARTMENT PARTNERSHIP MOU [SP5]

To better coordinate state efforts to care for and serve individuals with disabilities, Iowa has developed a memorandum of understanding (MOU) among seven state agencies. Below is an excerpt of that agreement and their stated strategic goals:

The purpose of this agreement is to strengthen employment services for Iowans with disabilities. To accomplish this goal, collaboration and coordination of career and employment services must occur among the Partners and among their local offices.

Partners to this Agreement

- Iowa Department for the Blind
- Iowa Department of Education
- Iowa Department of Human Rights, Division of Persons with Disabilities
- Iowa Department of Human Services
- Iowa Governor's Developmental Disabilities Council
- Iowa Vocational Rehabilitation Services
- Iowa Workforce Development

Strategy A. Maintain a State-level Support Team to advocate for and facilitate collaboration among Partners at the State and local level.

Strategy B. Identify and assess barriers to collaboration at all levels of service delivery.

Strategy C. Resolve collaboration issues, promote innovative policies, procedures, and practices in service delivery and communicate those consistently statewide to local partners.

Strategy D. Evaluate the success of fostering and supporting collaboration in achieving employment outcomes for Iowans with disabilities when the Partners share customers, resources, and information.

This agreement will develop system wide coordination, understanding and evaluation recognized relevant areas of legal responsibility and seeks to create an arena of understanding in the state of Iowa.

STATE POLICY 6:
Massachusetts Office on Disabilities [SP6]

Massachusetts, in a move that is distinct among states, has created through statute its Office on Disabilities, “in order to bring about full and equal participation in all aspects of life by all persons with disabilities in the commonwealth” and “strive for the advancement of legal rights and for the promotion of the maximum possible opportunities.”

The office has been charged “to identify, analyze, evaluate and monitor public policies, programs, services and regulations that affect or may affect persons with disabilities...utilize a system of collection of information for the purpose of identifying inadequate or inaccessible programs and services, inadequate coordination of programs and services, unnecessary programs and services, and duplication of programs and services...make recommendations and to provide comprehensive coordination and support, and identify and recommend to state and local agencies, departments and organizations appropriate sources of state and federal funds which are available for expanding or improving services and programs for persons with disabilities,” among other duties.

While no provision expressly allows for the Office of Disabilities to regulate departments in the state, their long record of achievements, their recognized legal status as an independent office, and their closeness to other power centers in the state allow it to exercise strong informal powers.

Full statutes can be found at M.G.L. - Chapter 6, Section 185-189.

STATE POLICY 7:
Wisconsin Medicare Infrastructure Grant Programs [SP7]

Medicare Infrastructure Grants (MIGs) allow states to develop the necessary programmatic aims that are structured toward populations receiving Medicare services. Below are three examples of Wisconsin programs funded by MIG's:

Mental Health Transition Project

Project Description: This pilot will address issues surrounding youth with emotional/behavioral disabilities who have poor post high school outcomes including employment. Youth with mental health disorders who receive special education services often do not continue services post-high school because of gaps between school-based services and the adult service system. Their risk of not accessing training, education, or employment at ages 19-21 are greater than their peers without emotional/behavioral disabilities. Although effective connections are often made during acute crises, they aren't routinely available during post high school planning. This project will develop a model of service providing assistance to youth with mental health disabilities, with the opportunity to access the adult provider system prior to leaving the school setting.

Asset Development and Economic Self-Sufficiency

Project Description: There are many programs available to assist individuals develop assets, but historically, most of them are focused on the population of people who qualify for Temporary Aid for Needy Families (TANF). As a result, when it comes to promising practices for and lessons learned about strategies that maximize resources for self-sufficiency, the disability movement can benefit greatly from the foundation paved by the TANF population. This project not only aims to increase access to a variety of benefit options for people with disabilities, but also works in tandem with economic development initiatives intended to promote the development of progressive policy in the areas of disability and employment.

National Marketing Campaign and Wisconsin Marketing Campaign

Project Description: In 2010 the NCHSD and its partner Wirestone will produce the basic elements of a national marketing campaign reaching out to the national employers. The theme of this project is "Look beyond the Label". In 2010 this campaign will undertake large media buys in major media markets and through a variety of mediums. Wisconsin MIG will contribute funding and expertise to the NCHSD planning group.

Further program details and contact information for Wisconsin MIG's are available here [SP7].

STATE POLICY 8:
State Mental Health Parity Laws [SP8]

Published by the National Alliance on Mental Illness for July 2009 gives a 50 state review of Mental Health Parity Laws, grouping states into sections based on the level of coverage mandated based on mental health condition from Comprehensive Coverage to No Parity Law. Mental health parity refers to state policies that require equal coverage for mental health related care (i.e. bipolar disorder, post-traumatic stress disorder, severe depression etc.) in relation to other physical/surgical equivalents. This information may be utilized to assess a states movement toward mental health parity and allow policy-makers to access the primary source information connected to each law here [SP8].

STATE POLICY 9:
Michigan Web Standards [SP9]

Federal requirements for web accessibility for people with disabilities (found in Section 508 of the ADA) have become state responsibility. In an effort to provide uniform services and allow state programmers the ability to access uniform procedures and standards, Michigan developed its *Look and Feel Standards for e-Government Applications* from its Department of Information Technology.

Some of the programs that the Michigan document covers include:

- World Wide Web Consortium (W3C) regarding ADA accessibility and compliance at <http://www.w3.org/WAI>. This organization provides guidance and tools to develop, execute, and manage web accessibility.
- Full check list of accessibility items to encourage complete compliance at <http://www.w3.org/TR/WCAG10/full-checklist.html>
- Provide goals and standards to develop accessible web pages, including:
 - Provide text equivalents for all non-text elements
 - Alternative Text (Alt text) for images.
 - Use the Name and ID attributes.
 - Use Labels on form fields

- Use of JavaScript in applications
- Creating accessible PDF documents
- Screen-reading software compatibility
- Central control of all state websites for conformity in design and compliance
- Web development that respects differing client needs and preferences
 - Having options for color blind accessibility
 - Designing titles and links in appropriate fonts
 - Allowing alternate file formats in website design (i.e. HTML documents versus PDF versions)

Greater web accessibility is a mandatory duty of state agencies to help provide information and resources to all its citizens, particularly in a time where web-based government resources are rapidly become standard. More information can be found at [SP9].

STATE POLICY 10:
Becoming a Person-Centered Organization [SP10]

Project Background

In October 2007, the Centers for Medicare and Medicaid Services (CMS) awarded funding for a six-state collaborative of developmental disabilities (DD) agencies to incorporate person-centered planning (PCP) tools and practices as integral components within the infrastructure of each state’s service delivery system (Oregon, South Dakota, Georgia, North Carolina, Tennessee, and Virginia). This collaborative was part of a 16-state funding initiative from CMS called Person-Centered Planning Implementation (PCPI) grants.

Support Development Associates (SDA) and the National Association of State Directors of Developmental Disability Services (NASDDDS) provide leadership to the six-state collaborative. The project complements efforts currently underway in the six-states to facilitate organizational change and to provide training and technical assistance to promote person-centered practices. The project is based on the implementation of a model process for “Becoming a Person-Centered Organization” (BPCO) that results in changes at three levels:

- *Level 1:* changes in day-to-day practice that impact persons’ lives and their relationships with formal and informal supports;

- *Level 2:* changes in provider agency management and leadership affecting organizational policy, practice, and program outcomes; and
- *Level 3:* changes in service delivery system infrastructure statewide resulting from changes in regulation, state policy, and system design.

Additionally, a “Community of Practice” assists participating states to: (a) strengthen and expand the use of existing PCP models and practices, (b) assure existing person-centered processes incorporate both formal and informal support and community network assessment tools, and (c) share learning to improve the training furnished to professionals, direct support staff, and others in person-centered practices and policies.

This project is a compilation of inputs (resources and funding) from multiple sources. In addition to time from state, regional, and local staff members, each state provides supplemental funding to complete the “model” process (person-centered thinking, coaches and leadership training and support) in sites throughout their respective states. From PCPI grant resources, each state annually receives \$25,000 through NASDDDS for coordination of the BPCO work, Virginia Commonwealth University receives \$160,000 for project evaluation and contract coordination (of which \$25,000 is for coordination of BPCO work in the commonwealth of Virginia), SDA receives \$293,158 for training, technical assistance, and consultation in states, and NASDDDS receives \$265,000 (of which \$125,000 is granted to 5 states) to promote communication among participating states through an annual meeting and the community of practice and to create and disseminate products related to person-centered systems change.

Provided in this report are the summary of experiences of six states (South Dakota, Tennessee, Oregon, Georgia and Virginia) that provides some of the programs they have developed with the PCPI grant money and challenges they have faced to implementation.

Federal Policy and the States

While state governments has an irreplaceable role to play in policies throughout the United States, there is no question that federal programs, initiatives, and specifically dollars play heavily into the shape and direction of disability policy. For nearly 40 years, the federal government has taken an active role in disability policy and since the passage of the Americans with Disabilities Act, the future of disability policy has been indelibly tied to the

federal policy direction. What follows is a description of some of the most impactful federal programs and a brief overview of changes effecting states. From matching funds for social services to programs enhancing emergency response management, the federal government is a serious stakeholder in the current discussions surrounding disability policy development.

- **July, 26, 2010 Executive Order:** On July 26, 2010, President Obama signed an Executive Order “to establish the Federal Government as a model employer of individuals with disabilities.” As the Order states, “Individuals with disabilities currently represent just over 5 percent of the nearly 2.5 million people in the Federal workforce.” With this order, strategies will be developed to capture a new population of federal employees, and increase retention rates for persons with disabilities. For more information, see the following [link](#). [F1]



- **Letter from Secretary Concerning Money Follows the Person Grants:** To encourage more commitment to community based

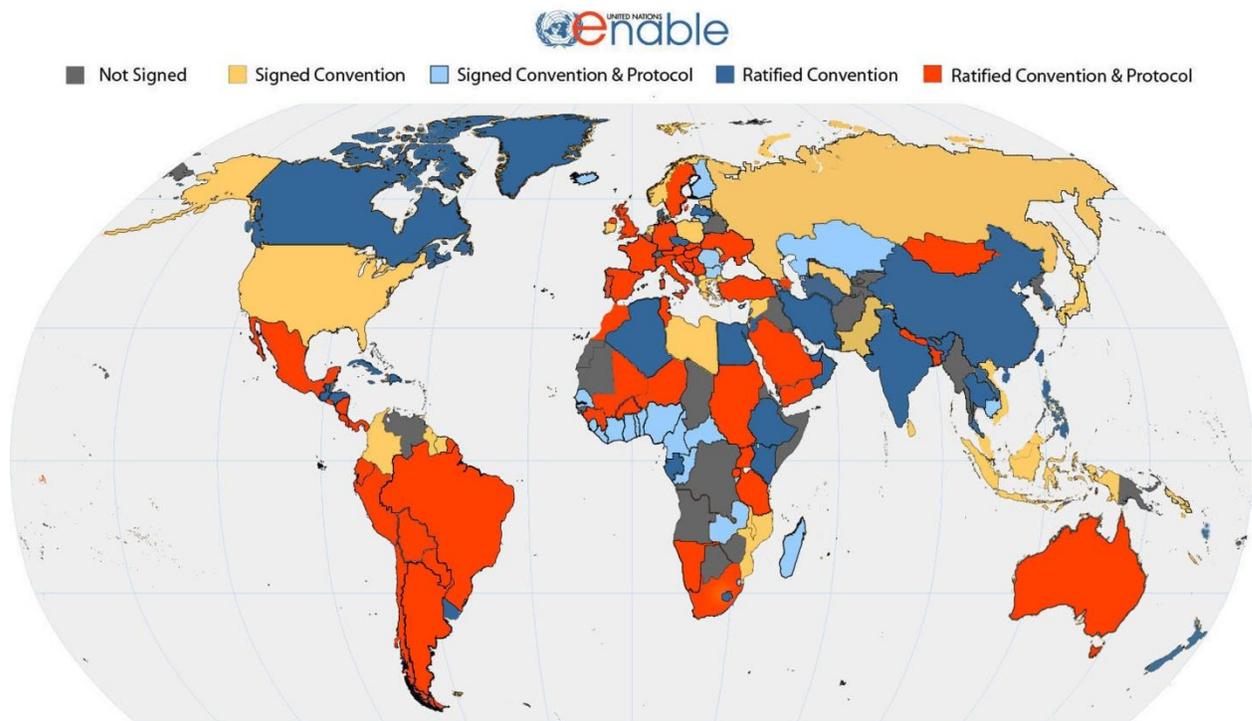
care, HHS Secretary Kathleen Sebelius invited states to join the Money Follow the Person Grants (MFP) and announced an additional \$2.25 billion dollars for the program that was extended to 2016 under the Patient Protection and Affordable Care Act. Under the MFP demonstration, states will receive an enhanced Federal Medical Assistance Percentage (FMAP) for a one-year period for each individual they transition from an institution to a qualified home and community-based program. States will be able to transition multiple population groups including the elderly, people with intellectual, developmental or physical disabilities, mental illness or those who have a dual diagnosis. The enhanced FMAP funding will then be used by states to expand services and supports. In addition, states receiving a MFP

grant award will focus on re-balancing their long-term care systems needs by increasing the use of home and community-based services and decreasing the use of institutional care. [F2]

- **Communications and Video Accessibility Act of 2009:** With the possible passage of HR 3101, the FCC will have new enforcement powers to begin making the Internet more accessible for persons with disabilities. Under the proposed law, the FCC will be able to develop captioning services for online video content, develop enhanced emergency management alerts, and fulfill its authority under Section 255 of the federal Telecommunications Act to provide access to people with disabilities, among other policy changes. [F3]
- **Mental Health Parity:** Mental Health Parity, long a goal of people in the disability community, has gotten a lift from legislation mandating new levels of parity in insurance coverage to make certain that certain mental illnesses. The Mental Health Parity and Addiction Equity Act of 2008 amends the Employee Retirement Income Security Act of 1974, the Public Health Service Act, and the Internal Revenue Code to require a group health plan provide both medical and surgical benefits, and mental health or substance use disorder benefits to ensure that deductibles and co-payments for mental health or substance abuse services are no more restrictive than what is applied to medical or surgical care. Also, see this link from the [New York Times](#). [F4]
- **Pre-existing Condition Insurance Plan:** HHS announced the creation of Pre-existing Condition Insurance Plan (PCIP) that will offer coverage to uninsured Americans who have been unable to obtain health coverage because of a pre-existing health condition. The Pre-Existing Condition Insurance Plan, which will be administered either by a state or by the Department of Health and Human Services, will provide a new health coverage option for Americans who have been uninsured for at least six months, have been unable to get health coverage because of a health condition, and are a U.S. citizen or are residing in the United States legally. Created under the Affordable Care Act, the Pre-Existing Condition Insurance Plan is a transitional program until 2014, when insurers will be banned from discriminating against adults with pre-existing conditions, and individuals and small businesses will have access to more affordable private insurance choices through new

competitive Exchanges. In 2014, Members of Congress will also purchase their insurance through Exchanges. [F5]

- **U.N. Convention on Disability:** With 10% of the world’s population are persons with disabilities (over 650 million persons), 80% of whom live in developing countries, the United Nations has sought to bring countries together to ratify a new convention on disabilities, adding to a global dialogue on disabilities. The Convention sets out the legal obligations on States to promote and protect the rights of persons with disabilities. More information is contained here: [F6]. Below is a global map on the progress of the Convention.



- **Emergency Preparedness:** FEMA Administrator Craig Fugate has committed to honoring the federal government’s pledge to hire more persons with disabilities and ensure planning steps are made for persons with disabilities. [F7]
- **“I Am Norm” Campaign:** In January 2010, twenty young people, with and without disabilities, flew from various locations across the United States to meet in Washington, DC. They designed an initiative to promote the acceptance, respect, and

full inclusion of youth with disabilities in schools and communities by challenging what it means to be normal and live with a disability. Their work is driven by a Youth Inclusion Taskforce and supported by a coalition of youth-serving partner organizations. They can be found at www.iamnorm.org.

- **FMAP Funding in Peril:** The Federal Medical Assistance Percentages (FMAP) was not extended in the HR 4213, the Unemployment Compensation Extension Act. Many states have developed budgets under the assumption of reauthorization and are seeking remedies in the chance that the funds remain unavailable. CSG has developed a succinct review of state implications concerning FMAP extension at www.csg.org.
- **The Council on Postsecondary Education:** Since 2007, The Council on Postsecondary Education has been a partner in the Fund for the Improvement of Postsecondary Education (FIPSE)-funded Project GOALS (Gaining Online Accessible Learning through Self-Study). See the following [link](#) for more information.

Summary and Comments

As any observer to the great policy struggles that occur in the United States can describe, the work is never done. Policies will falter and money will always be short, but creativity and tenacity are tangible goods in the policy-making arena and necessary for the process to continue to create fundamental, systemic change. Without a doubt, this essential progress must be made, since the issue of disabilities stretches across every boundary, every agency, and every policy that is created by government. It is the *human* nature of this issue and its broad, cross-cutting nature that requires it to be on the forefront of policy action in this country.

Challenges and issues facing disability policy, though, are numerous. State and federal governments continue to struggle developing policies surrounding housing, employment, and independent living as described in this document, but many reforms, while still extremely impactful, are very acute. Some of these possible policies challenges include:

- Moving state and federal enforcement away from the complaint driven process, which puts the onus on victims of bias and discrimination to seek remediation and justice;
- Continuing to identify persons with disabilities in an effort to build a cohesive bloc of individuals for a common purpose;
- Removing stigmas from and placing protection on new groups of individuals with disabilities (i.e. epilepsy, diabetes, HIV/AIDS etc.);
- Developing and implementing “Universal Design,” or the process of producing buildings, products, and environments that are usable and effective for every person, regardless of disability status; and
- Creating comprehensive state-based emergency management plans that ensure that all people, regardless of disability, have access to life saving services.

This document is purposed to help deliver its stated aim, which is to provide states with the information on policies that they can pursue in their own states. This illustrative information, while in no way prescriptive, should be helpful in bridging the policy making disconnect among states.

