



WASHINGTON WATCH

Dependable Information for America's Disability Community

National Governor's Association Considers "Budget Allocation" Proposal for Medicaid Program

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Governors on the 10-member National Governors Association (NGA) Medicaid Reform Task Force are considering a "Budget Allocation" reform proposal that would significantly restructure the Medicaid program. Governors Jeb Bush (R-FL) and Tom Vilsack (D-IA) have encouraged their fellow Task Force members to adopt the proposal which contains numerous provisions that would fundamentally curtail individual entitlement and critical services and eligibility for people with disabilities. Democratic Governor Patton (KY) also reportedly favors the proposal.

The draft proposal is similar in its basic approach to the Bush Administration's Medicaid reform proposal that the governors considered and declined to endorse in February. The major differences between the Administration's proposal and the NGA Task Force draft reflect efforts by the governors to protect states from the fiscal risks posed by a cap on federal Medicaid funding. The essential elements that spell major risk for people with disabilities, however, are equally problematic in both proposals.

The current federal/state financing structure would remain in place for individuals who are in the mandatory eligibility group (generally those on SSI) and for services that are mandatory under the current system (e.g. hospital, nursing facilities, and home health care for people eligible for nursing facilities). Funding would be capped, however, for those services considered optional as well as for beneficiaries in the optional categories of eligibility (generally, above SSI income/resources). Current optional services include prescription drugs, physical therapy and related services, diagnostic, screening, and preventive services, home and community based services (under waiver authority), case management services, prosthetic devices, personal care services, rehabilitative services, dental and vision care, Intermediate Care Facilities for people with mental retardation and related conditions (ICFs/MR) and hospice care.

Two-thirds of current Medicaid spending is for optional services and optional populations. Under the proposal, these would be subject to a cap, rather than the current federal/state funding structure. Therefore, if costs go up, states bear the full burden of the increased costs. Under the NGA proposal, there are exceptions to the cap/budget allocation structure for certain events (e.g. extraordinary increases in employment rates, disasters or other catastrophic acts of God substantially affecting enrollment or benefit use, introduction of significant new technologies/drugs affecting the Medicaid population, detection and treatment of major new diseases or new mandates). The Administration's proposal did not include these exceptions.

As of June 9, Governors Bill Richardson (D-NM) and Bob Holden (D-MO) issued public statements opposing the budget allocation proposal based on concerns about the implications of capped funding. The NGA Medicaid Task Force delayed a vote on the proposed "Budget Allocation" proposal at least until the week of June 9.

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If adopted by the Task Force and the NGA Executive Committee, the budget allocation proposal is expected to be put before the entire NGA membership for consideration. A two-thirds vote of the NGA is needed for passage. There are 26 Republican governors, who are expected to vote for the proposal since they supported the Administration's original proposal. Seven Democratic votes would be needed for passage. As indicated above, two Democratic governors are already in support of the proposal.

House Minority Leader Nancy Pelosi (D-CA) and Senate Minority Leader Tom Daschle (D-SD), along with ranking minority members of Senate and House Committees with jurisdiction over Medicaid, called on Democratic governors to reject any proposals which would cap Medicaid funding. The Arc and UPC, along with advocates for other Medicaid beneficiaries and providers, have voiced similar concerns.

Medicaid Long Term Services and Supports Focus of Congressional Activity in June

On June 5, the House Energy and Commerce Committee Subcommittee on Health held a hearing on the Medicaid Cash and Counseling demonstrations operating in three states (AR, FL, and NJ) with funding from the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation and administered by the Centers for Medicare and Medicaid Services.

The Cash and Counseling demonstrations allow a state to provide a cash allowance to Medicaid beneficiaries who use long term supports and services in place of agency-delivered services.

Witnesses at the hearing were: Kevin Mahoney, Graduate School of Social Work, Boston College; Patricia Gittens, parent, Florida; Terry White, Secretary, Florida Department of Elder Affairs; and Bob Williams, Co-Director, Advancing Independence and Modernizing Medicare and Medicaid.

All four witnesses spoke very favorably of the program and the potential it offers to Medicaid beneficiaries. However, the witnesses also stressed that there are limitations to the cash and counseling approach and that the approach should not be seen as a model for all Medicaid beneficiaries. Mr. Williams went further to note that there is nothing in the demonstration's basic intent, design, or findings that would support the notion that the entire Medicaid program, including medical care and prescription drugs, should be "cashed out" in this way. Williams went on to say that "expecting people to know how to navigate, purchase and manage their entire health and medical care is not only unrealistic, it would be setting many up to take a serious fall or worse."

Members of the Health Subcommittee engaged in lengthy discussions with the witnesses about the benefits and the limitations of a "cash and counseling" approach. Representative Henry Waxman (D-CA) noted that "this kind of approach cannot be done on the cheap" and that cash and counseling is not a model for cost-containment.

Later the same day, Senate and House sponsors of the Medicaid Community-Based Attendant Services and Supports Act (MiCASSA), S. 971 and H.R. 2032, led a rally in support of passage of MiCASSA in the Dirksen Senate office building. The rally was simultaneously broadcast to sites across the country where groups of 20 or more advocates were gathered. Senator Harkin (D-IA) and Representatives Davis (D-IL), Shimkus (R-IL), Hoyer (D-MD), Frank (D-MA), and Langevin (D-RI) all spoke to the overflow crowd.

The MiCASSA bill would create a new mandatory service - community-based attendant services and supports - in Medicaid for people who are eligible for nursing facility services or Intermediate Care Facilities for people with mental retardation or related conditions (ICFs/MR). The services could be provided through traditional agency-directed mechanisms or through consumer-directed models. There would be an enhanced federal match for those states with early coverage to promote and enhance the use of community - based attendant services. The U.S. Secretary of Health and Human Services would award grants to states that have established a Consumer Task Force to assist the state in its development of real choice systems change initiatives. There would also be grant funding for a demonstration project for the purpose of evaluating service coordination and cost-sharing approaches for community-based services and supports to non-elderly individuals entitled to both Medicaid and Medicare.

House Passes IDEA Reauthorization

The U.S. House of Representatives, by a vote of 251-171 on April 30, passed H.R. 1350, the Improving Education Results for Children with Disabilities Act. This bill was strongly opposed by virtually every national disability organization including UCP and The Arc and garnered, by far, the most votes in opposition to an IDEA bill in its nearly 30 year history. Approximately 16% of House Democrats voting joined almost 100% of House Republicans in support of the measure. H.R.1350 contains numerous onerous provisions that will strip students with disabilities and their parents of important rights. If enacted into law, this bill would be a victory for those school officials who seek broader authority to discipline, suspend and segregate students with disabilities who violate school rules. The negatives in the bill far outweigh the few positive changes to IDEA.

Discipline

H.R. 1350 radically reverses many of the carefully developed discipline provisions of the 1997 Amendments to IDEA (IDEA '97). These provisions provide a balanced approach to the issue of discipline of children with disabilities that reflects the need for orderly and safe schools and the need to protect the right of children with disabilities to a free appropriate public education (FAPE). Evidence shows that the discipline provisions of IDEA '97 not only allow school administrators the flexibility to maintain safe and orderly schools, but also protect students with disabilities. H.R. 1350 allows school personnel to unilaterally remove a child with a disability from his or her current placement for the violation of any school rule, while at the same time removing the protection of the manifestation determination to assess whether the behavior is related to the child's disability. Furthermore, H.R. 1350 removes the requirements for functional behavioral assessment, development of behavior intervention plans and review of the appropriateness of the current individualized education program (IEP) and placement. The provisions of H.R. 1350 will potentially increase school dropout rates and delinquency by removing appropriate educational services for students whose school success depends upon these services. Eliminating the manifestation determination will likely lead to a substantial increase in litigation.

Due Process

H.R. 1350 contains several provisions that significantly weaken the ability of parents to get the educational services and supports they need for their children. For example, the bill encourages the use of voluntary binding arbitration. Voluntary binding arbitration and its corresponding limitations are inappropriate in situations where a child's needs change over time. Further legal disputes will arise about how long the arbitration is binding. The bargaining positions of the parties are too unequal to rely on binding arbitration when one party is an individual parent and the other is a school district.

H.R. 1350 creates a new maze of options and new burdens on parents that, singly or in combination, will severely chill the prospect of many families moving forward with due process. For example, the bill mandates a one-month waiting period before any parent complaint can go to due process regardless of the problem or issue. This provision will cause unnecessary delay. In addition, a new one-year statute of limitations could run out before parents will even discover certain types of violations, especially if their child is unable to report to them when services have not been provided. Moreover, the statute of limitations is inconsistent with child find and will deprive children whose needs are ignored for years with no possibility of remediation.

Another concern is that H.R. 1350 permits the Governor of each state to determine the amount of reasonable attorney fees to be reimbursed to the parents. No other civil rights law allows defendants or those acting in their place to set prevailing plaintiffs' fees. Only parents who prevail in judicial proceedings collect attorneys' fees. The provision in H.R. 1350 will make it even harder for parents to secure their child's rights, and will curtail the number of parents who can access their child's due process protections under IDEA. In addition, the bill does not give the Governor the authority to limit the fees that can be paid to school district attorneys.

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Only fees paid to parents are affected. The bill also includes a provision that requires parents to present their case in a mandatory resolution session without the reimbursement for attorney's fees that is available for due process hearings. If the case proceeds to a due process hearing, the parents can only raise issues that were in the complaint or part of the resolution session. Most parents do not have the legal training that is required to foresee all the issues under IDEA that are available for them to raise at the resolution session. In each of these provisions, the bill places additional burdens on parents.

IEP

H.R. 1350 claims to reduce paperwork for teachers. It threatens annual Individualized Education Program (IEP) reviews due to the new three-year IEP option and eliminates the short-term objectives and benchmarks by 2005-2006 (except for those students taking alternative assessments). This change was made without any scientific research to document that these provisions will reduce paperwork. Many parents report that the short term objectives are the most important measure of progress for their children and the best way to keep schools accountable for progress toward their IEP goals. While this is an optional choice for students and parents, many could either be confused by it or feel coerced to accept this option.

Paperwork Reduction Pilots

H.R. 1350 contains a provision that allows the U.S. Dept. of Education to give approval to up to ten states to waive requirements under IDEA in order to remove paperwork burdens. These pilot projects have no limitations and could result in the loss of IEPs, due process, related services, and other vital protections under the law.

IDEA Funding

H.R. 1350 directs 15% of IDEA funds to finance pre-referral services, support services required by No Child Left Behind and other activities. In addition, 20% of increases in appropriations for the Part B State Grant Program may be used as local funds. Also, nothing in the bill precludes schools from keeping children in a pre-referral category indefinitely. While the activities authorized may have merit, concern remains about funding them with the insufficient supply of Part B funds that does not even sufficiently address the needs of students with disabilities who are currently served under the law. While the disability community supports collaboration and joint funding, in this instance, special education is being asked to finance more than its fair share.

The Education Task Force of the Consortium for Citizens with Disabilities has published a detailed analysis of the many serious concerns about H.R. 1350. The analysis is posted on UCP's and The Arc's websites.

Senate

The Senate, meanwhile, has not yet acted on a bill. Republican and Democratic staff of the Senate Health, Education, Labor and Pensions (HELP) Committee have worked feverishly for months to craft a bipartisan bill to reauthorize IDEA. The latest estimate has the bill being introduced in to mid June, to be followed by a two week period for special education interests to provide comments. The bill, likely amended to incorporate some of the input, would then be marked up by the HELP Committee before the Independence Day recess. There is a reasonable expectation that the bipartisan Senate bill be much improved from the House bill.

Sens. Chuck Hagel (R-NE) and Tom Harkin (D-IA) have introduced S. 939, a bill to secure mandatory full funding for IDEA. This issue will likely be decided on the Senate floor.

Update on Medicaid “Allotments” Reform Proposal

The Administration’s proposal to restructure Medicaid, which HHS Secretary Tommy Thompson originally announced through a FY 2004 Budget press release, has generated much debate among advocates and policymakers in Washington during the past month.

The Administration had hoped that support from the nation’s governors would supply significant momentum for the proposal. Secretary Thompson, along with White House and other HHS officials, conducted several briefings for governors during the National Governors Association’s (NGA) winter meeting in Washington in late February. The group, however, failed to reach a consensus on the Bush proposal. Republican governors, citing support for the proposal's principles, pushed for an endorsement. Democratic governors raised significant concerns about the Administration's unwillingness to share specifics of the proposal's financing mechanisms. In lieu of an endorsement, the NGA agreed to form a bipartisan task force to examine Medicaid reform and work with the White House and Congress to negotiate changes in the program. On March 20, the NGA announced that the task force would be co-chaired by Governor Paul Patton (D-KY), NGA’s chairman, and Governor Dirk Kempthorne (R-ID), NGA’s vice-chairman. Members include Governors Jeb Bush (R-FL), Frank O’Bannon (D-IN), John Rowland (R-CT), Tom Vilsack (D-IA), Robert Ehrlich (R-MD), Bob Holden (D-MO), John Hoeven (R-ND), and Bill Richardson (D-NM).

The first public discussion of the proposal occurred on March 12 during a House Energy and Commerce Committee, Subcommittee on Health hearing on “Medicaid Restructuring – Medicaid Today, the States’ Perspective.” At the outset of the hearing, Subcommittee Chairman Michael Bilirakis (R-FL), noting that the hearing’s focus was limited to the perspective of Governors, made a commitment to hold several hearings on Medicaid reform. The hearing’s witnesses -- Governors Jeb Bush (R-FL), John Rowland (R-CT), and Bill Richardson (D-NM)--agreed that Medicaid requires policy changes but sharply disagreed about what changes should be made. Governors Bush and Rowland strongly backed President Bush's Medicaid reform proposal.

Governor Richardson, however, said that the Administration's proposal could mean block grants and spending limits on health care coverage for low-income people. He said, "You can provide increased flexibility to states without capping federal spending." He also stated that he is concerned that the President's proposal could make it easier for states to remove people from the Medicaid program. Governors Bush and Rowland, citing Congress’ enactment of sweeping welfare reform (i.e. TANF) in the 90’s, urged that sweeping Medicaid reforms be enacted soon.

Governor Bush scoffed at the notion that benefits will be cut, asserting that Florida’s innovative “Cash and Counseling” waiver programs allow people to save state dollars by only purchasing the services they need. However, Floridians report that the Governor’s budget proposals will devastate services for people with disabilities. Governor Rowland applauded the flexibility offered by the Administration’s proposal, stating that it would allow states to expand coverage to working families, without giving them the same “rich benefit package” that Medicaid law currently provides.

During the question period, several Subcommittee Democrats raised concerns about the impact of the Administration’s proposal on people with disabilities and other beneficiaries. Rep. Sherrod Brown (D-OH), the Subcommittee’s Ranking Member, asked, “Who can provide the evidence that people are getting too much under Medicaid?”

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Subcommittee members on both sides of the aisle called for Congress to enact a Medicare prescription drug benefit to relieve states of the prescription drug costs of the “dual eligible” population -- seniors and people with disabilities -- who are eligible for both Medicare and Medicaid.

The Consortium for Citizens with Disabilities’ (CCD) statement, supported by over 50 national organizations, was entered into the record of the hearing. Entitled *Bush Administration’s Medicaid Proposal Decimates Services for People with Disabilities*, the statement notes that the Administration’s Medicaid proposal eliminates the longstanding guarantee that all Medicaid beneficiaries in a state have access to a comprehensive array of services.

Advocates Exploring ADA Restoration

Since 1990, when Congress enacted the Americans with Disabilities Act (ADA), many law suits relevant to the Act have arrived at the doorsteps of the Courts throughout the United States. There have been cases that expand the defenses available to employers against whom discrimination is alleged, cases calling into question the constitutionality of the ADA and cases restricting awards available to ADA plaintiffs. But perhaps the most significant and troubling to people with disabilities are those decisions that have specifically narrowed the scope of the definition of “disability,” causing people with disabilities everywhere to take notice and recently causing advocates and Congressional proponents to consider legislation in the 108th Congress to “restore” the rights that have been diminished.

When it passed the ADA, the 101st Congress adopted a definition of the term “disability” that had been used since the 1970s under Section 504 of the Rehabilitation Act. The definition included individuals with a physical or mental impairment that substantially limits a major life activity, individuals with a history of such impairment and individuals who are regarded by others as having such impairment. The legislative history of the ADA shows that Congress was clear about its intent that this definition protect a wide range of people, such as individuals who experience epilepsy, diabetes, mental health conditions or HIV/AIDS. Also included in Congressional intent were amputees and rehabilitated substance addicts, as well as those who can mitigate the effects of their specific disabilities but still encounter discrimination in the workplace and other settings due to fears, misconceptions and stereotypes about disability.

In the thirteen years since the ADA was enacted, several recent Supreme Court decisions and hundreds of decisions in lower courts have chipped away at the protected class by adopting narrower and narrower rules for the statutory definition of “disability.” Rather than validating the civil rights concept and interpreting “disability” broadly as Congress intended, the Supreme Court has determined that the term should be interpreted strictly, creating a high burden of proof for an individual to qualify as “disabled.” As a result, it has become difficult for individuals with certain conditions to establish that they have a disability for purposes of the ADA.

Because of these decisions and their chilling effect on enforcement of the ADA, many people believe that it is time to rewrite the ADA’s definition of “disability,” clarifying and emphasizing Congressional intent and restoring protections to the millions of Americans who experience disability-based discrimination.

Legislative language has not yet been agreed to by the disability community for restoration legislation, although several approaches are under consideration. The concept and the scope of what might be possible and practical is under discussion on many fronts, including on Capitol Hill.

While it has only been 13 years since the ADA was enacted, there has been a significant shift in the makeup of the Congress. In fact, in the 108th Congress, only 100 of the original supporters (about 25%) remain in the House of Representatives and 51 in the Senate. Additionally, current House leadership, Speaker Dennis Hastert (R-IL) and Majority Leader Tom DeLay (R-TX), were “nay” votes during the original passage of the ADA. Moreover, the Administration of President George W. Bush, despite the fact that it was his father, President George H.W. Bush, who signed the Act into law, has been silent, both on the possibility of restoration and on the outcomes of court cases related to the law. Furthermore, Bush Administration judicial nominees have been heavily criticized on many fronts as not being conducive to upholding the letter and intent of the law. Also, proponents will be wary of business groups and others who might take the opportunity, if the Act is re-opened, to weaken critical provisions. Thus, in addition to looking at technical language, supporters have to explore the politics of the situation, and carefully assess the chances of success before a campaign is launched.

Congress Slow to Act on Fiscal Year 2004 Appropriations

Despite the Congress having adopted a FY 2004 budget resolution in late April, House and Senate Appropriations Committees have not yet begun to develop the thirteen bills necessary to decide on discretionary spending levels for the next fiscal year which begins on Oct. 1, 2003. There are several reasons for the delay. Most obvious has been the Congress' recent focus on tax cut legislation that was finalized in late May. A second and more direct reason for the delay is the recognition that the budget resolution, in order to make room for the tax cuts, set a discretionary spending limit that is about \$3 billion below what the Bush Administration requested. The budget resolution allows \$785 billion in discretionary spending, roughly split in half between domestic and defense spending.

Disability related discretionary spending includes programs such as the Individuals with Disabilities Education Act, Vocational Rehabilitation, Workforce Investment Act, Developmental Disabilities Act, Assistive Technology, Maternal and Child Health and other programs. Discretionary spending is limited to the amount available in the budget resolution. This differs from entitlement spending, where spending levels for those programs, including Medicaid and Medicare, are not set by annual appropriations spending limits. Instead, the Federal government spends according to the number of individuals who qualify for the entitlement services.

Once the overall discretionary amount is set by the budget resolution, the Appropriations Committee divide the amount available among the thirteen appropriations subcommittee. This is called the 302(b) process. By far the largest amounts are doled out to the Subcommittee on Defense and the Subcommittee on Labor, Health and Human Services and Education. Since Republicans control both Houses, leaders of the House and Senate Majority are trying to reach agreement on the 302(b) allocations, with no success thus far. One suggested approach is to shift some funding (amount not specified) from defense to domestic programs. Most of the shifted funds would be allocated to the Subcommittees dealing with Labor-HHS, and Education, VA-HUD, and Homeland Security. The Congress could then add back the lost defense spending via a supplemental appropriations bill later in the year.

Appropriations Subcommittee could start marking up their bills immediately since the 302(b) allocations are not required until full Committee markup. Nonetheless, no subcommittee has attempted to mark up a bill. With Congress slated to be in recess for the entire month of August, only three months remain to complete the FY 2004 appropriations process.

WIA and the Rehab Act Update

On May 8, 2003, the House of Representatives passed H.R. 1261, the Workforce Reinvestment and Adult Education Act of 2003, nearly along party lines. This bill reauthorizes both the Workforce Investment Act of 1998 (WIA) and the Rehabilitation Act of 1973, as amended, and is critical to improving employment and training opportunities for individuals with disabilities.

In 1998, Congress enacted WIA to consolidate, coordinate, and improve employment training, literacy, and vocational rehabilitation programs. The legislation created One-Stop Delivery Systems (One-Stops) to offer employment training, counseling, and resources to individuals who need such services in order to become gainfully employed. WIA also integrated several partners to improve the previously fragmented employment and training system, including Vocational Rehabilitation (VR), in order to better serve individuals with disabilities.

The Arc and UCP strongly believe that One-Stops can play a vital role in the lives of many individuals with disabilities, a contention bolstered by the fact that the public VR system only has sufficient funds to serve approximately 20% of the eligible population. Despite provisions in the original WIA legislation requiring universally accessible services at the One-Stops, however, individuals with disabilities cannot physically access many of the centers.

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Further, when they can literally get in the door, it is reported by individuals and families that most One-Stops do not offer programmatic supports and services necessary to assist individuals with disabilities enter or re-enter the workforce. Thus, a number of improvements are necessary to ensure that the One-Stop workforce development system is accessible to and serves the needs of individuals with disabilities.

In addition, reauthorization of the Rehabilitation Act provides Congress with the opportunity to improve the VR system. First, we know that the VR system is woefully underfunded. Congress could use this opportunity to increase funding to better serve individuals with disabilities and help them find and retain employment. Second, Congress needs to improve programs for students with disabilities transitioning from school to adult life. Third, the VR system must be better coordinated with other employment, educational, and human service programs. And fourth, Congress must maintain the specialized programs within the Rehabilitation Act, such as Supported Employment, Projects With Industry, Migrant and Seasonal Farmworkers, and Recreation projects.

Fortunately, H.R. 1261 maintains authorization for these specialized programs contained in the Rehabilitation Act. Unfortunately, the House did nothing else to improve employment and training opportunities for people with disabilities when it passed H.R. 1261. In fact, the bill fails to authorize adequate funding for either the WIA One-Stops or the Vocational Rehabilitation program. Both of these programs would continue to suffer from a lack of adequate funding.

H.R. 1261 also fails to address the lack of physical and programmatic access for many people with disabilities to employment and training services available at the One-Stops. To the contrary, the bill could cause substantial harm to the efforts of people with disabilities who are trying to enter or re-enter the workforce. H.R. 1261 allows a governor to strip funds from programs for people with disabilities, in particular the VR program, to pay for costs associated with operating the One-Stops. It allows a governor to do so without any assurance that the funds will be used to increase access or improve services for people with disabilities.

H.R. 1261 also fails to make any substantial improvements to the VR program and fails to strengthen transition programs for students with disabilities. Rather, it eliminates a substantial amount of funding for youth training programs for students. H.R. 1261 would completely eliminate funding under WIA for in-school programs, and redirect the funds to serving “at-risk” youth (only 30% of which could be used for students still in school) in out-of-school settings only. This proposal to eliminate funding for in-school youth programs could have a devastating effect on youth with disabilities trying to transition from school to independence and self-sufficiency. We believe that students with disabilities in school that do not have adequate post-secondary transition planning are “at-risk” – at-risk of being jobless and dependent on SSI.

The reauthorization of WIA and the Rehabilitation Act should be an opportunity to improve employment and training services for individuals with disabilities, as well as transition services for students with disabilities. Rather than adopting a bill that would improve the opportunity for people with disabilities to be gainfully employed and therefore less dependent on public assistance, the House passed a bill which, at best, does very little to help individuals with disabilities prepare for and retain productive employment, and, at worst, could cause substantial harm.

UCP and The Arc are working very closely with other members of the disability community to make sure that when the Senate takes up the reauthorization, it will produce a bill that actually improves physical and programmatic access for people with disabilities at the One-Stops, increases funding for and improves the VR program, and strengthens transition programs for youth with disabilities.

Assistive Technology Act Up for Reauthorization

The Assistive Technology Act (P.L. 103-218), originally enacted in 1988 and reauthorized in 1993 and in 1998, is again due for reauthorization in 2003. State grant programs are due to “sunset” this year, and all of them will phase out by the end of 2004 if the sunset is not lifted through reauthorization – or if an extension is not granted.

The Assistive Technology Act was a landmark for individuals with disabilities of all types. It was very much ahead of its time in predicting that technology would play an increasingly critical role in the lives of people with disabilities in education, in the workplace and in the community.

For fifteen years, programs funded under the Act have made a significant impact on the lives of people with disabilities throughout the United States who depend on assistive technology. The state Assistive Technology Act programs have been instrumental in the dissemination of information on the value and availability of assistive technology for people with disabilities, and state Protection and Advocacy systems have provided advocacy services to individuals with disabilities of all ages who have been denied necessary technology by school systems, public and private insurance sources, employers and others.

Currently, language is being drafted and Congressional co-sponsors sought for a reauthorization bill that will preserve the vital programs under the Act as well as enhance it's effectiveness for consumers by adding provisions that will afford some more tangible benefits for people with disabilities.

In addition to the reauthorization, funds must be appropriated to keep the Assistive Technology Act programs afloat. In fact, even if the Act does not reach final reauthorization in this session of Congress, the opportunity still exists for Congress to appropriate funds to maintain, or even enhance, the programs the Act authorizes. With the programs under the Act in jeopardy of drastic de-funding under the President's budget proposals for three straight fiscal years (FY 2002, FY 2003 and FY 2004), Congress moved forward on its own and preserved them in FY 2002 and FY 2003 by appropriating funds the President did not recommend. The President's FY 2004 budget recommends no funds whatsoever for these programs. Advocates, therefore, are busy on the appropriations front, as well, to ensure the viability of the crucial Assistive Technology Act programs and services.

Senate Committee Passes Genetic Non-Discrimination Bill

Soon scientists will have deciphered the entire human genetic code, providing more information about an individual's health than ever before. Already, tests are available that can detect genetic traits associated with particular diseases, and the use of such tests is predicted to increase dramatically in coming years. Genetic testing can improve lives by providing information on how we can prevent future health problems and cope more effectively with unavoidable conditions. But the ability to predict disease through genetic testing and family history opens troubling questions about discrimination, particularly in employment and health care. Without adequate protections, the potential exists for genetic testing to result in discrimination against people with mental retardation, cerebral palsy and related developmental disabilities.

Currently, people must make some difficult decisions about genetic testing. They are forced to choose between learning genetic information vital to their lives and health, and the possibility of losing health insurance coverage and possibly employment because of the results of those tests.



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In the health care arena, the Act says that insurance companies and health plans cannot use genetic information, or even evidence of a request for genetic information, to refuse enrollment or to charge higher premiums, in either the group or individual markets. Doctors or other health care professionals may inform an individual consumer of the availability of genetic testing and may even request that an individual undergo such testing, but no medical professional may require such testing.

In the workplace, the Act says that an employer may not refuse to hire a person because of genetic information; nor may an employer fire a person or in any other way discriminate, with respect to compensation, privileges, job duties, work sites or opportunities for advancement based on genetic information.

Advocates are still concerned about the recourse available to someone who may experience genetic discrimination, particularly in the health care arena, where the remedies are all at the "administrative" level, and an individual is not granted the right to litigate. In the employment arena, an individual can litigate, if necessary, under Title VII of the Civil Rights Act.

The HELP Committee action is an initial step. The bill must be approved by the full Senate and go through the entire process in the House of Representatives. The Congress will be encouraged to adopt more meaningful enforcement provisions on the health care side. Also, it is worth noting that while the bill prohibits discrimination against individuals with genetic markers, it does not cover individuals who develop health conditions related to their genetic makeup, a distinction that has become important in the judiciary's narrowing of the scope of the ADA's coverage.

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