

Perspectives

Implications of Health Care Reform for Individuals With Disabilities

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After more than a year of intense debate and nearly a century of previous attempts, President Barack Obama signed into law comprehensive health care reform legislation (P.L. 111–148) on March 23, 2010. The disability community actively engaged in the legislative process and shaped the final outcome. There are many victories to celebrate, lessons to be learned, and work that lies ahead as the process moves toward implementation. Highlighted below are some of the provisions impacting individuals with disabilities, focusing on individuals with developmental disabilities.

Market Reforms and Coverage

Although individuals with disabilities are uninsured at rates similar to the general population, they are more likely to receive coverage through public programs (Altman & Bernstein, 2008; National Council on Disability, 2009). Children with developmental disabilities often receive coverage through their parents' insurance, and a small percentage of adults receive coverage in the private market via employers. However, the majority of adults and many children with developmental disabilities rely on Medicaid. Dynamics influencing this situation include discriminatory practices in the private market, access to specific benefits needed by individuals with disabilities, and affordability. During the health care reform debate, the disability community fought to reduce these barriers while protecting the foundation of public programs.

The final legislation immediately bans discrimination based on preexisting conditions for children and youth under 19 years of age. A similar ban will go into effect for adults in individual and small group markets after the exchange is operational.

Equally important, because individuals with disabilities are among those who use more health services, are bans on lifetime and annual limits. In addition, dependants will be permitted to stay on their parents' insurance until Age 26, which may assist some youth with disabilities during periods of transition from pediatric to adult health care.

Within plans that will be offered in the exchange, the disability community secured important categories of essential benefits for individuals with disabilities, among which include the following: rehabilitative and habilitative services and devices, mental health and substance use disorder services, preventative and wellness services and chronic disease management, and pediatric services, including oral and vision care. Yet, continued advocacy will be needed during implementation to influence the specific definitions and scope of these benefits: for example, to ensure that "behavioral interventions" include positive behavioral approaches that can benefit individuals with autism and other developmental disabilities.

Low-income individuals and families with incomes up to 133% of the federal poverty level (FPL) will have access to Medicaid (FPL is currently \$10,830 for an individual and \$18,310 for a family of three). Furthermore, individuals and families with incomes up to 400% of FPL will receive premium and cost-sharing assistance to purchase insurance through the exchange. These provisions will allow some individuals to earn more and still qualify for Medicaid, allow individuals who do not meet stringent disability determinations to qualify for Medicaid, and assist individuals with disabilities who earn above Medicaid income-eligibility levels to access insurance through the exchange. Even with these changes, the majority of individuals with developmental disabilities will likely continue to rely on Medicaid, particularly

for access to long-term services. However, these reforms present new options, remove discriminatory practices in the private market, and lay a stronger foundation for the future.

Workforce and Prevention

Health care reform includes several new provisions on workforce and prevention that address long-standing issues for individuals with disabilities. Two previous U.S. Surgeon General reports (2002, 2005) have highlighted needs for training of health professionals in the area of disability, particularly for professionals serving individuals across the lifespan. Steps were taken in health care reform to improve clinical training as well as disability cultural competency training. Existing training grants in primary care will be broadened to highlight individuals with disabilities as a priority population. Similarly, individuals with disabilities, and specifically individuals with developmental disabilities, will be highlighted as priority populations within training programs for general, pediatric, and public health dentistry. In addition, grants supporting development of cultural competency curricula will be for the first time expanded to include individuals with disabilities.

The final legislation directs the U.S. Department of Health and Human Services (HHS) to develop new regulations concerning the designation of “medically underserved population.” Although individuals with developmental disabilities meet the majority of current criteria, such as high rates of poverty and infant mortality, as a population, they have never been officially designated as “medically underserved.” Designation is tied to 34 other federal programs, including loan forgiveness programs and targeted training initiatives, which could help address health disparities and access. It will be critical for the disability community to seize this opportunity through public comment and representation on the negotiated rulemaking committee to ensure the needs of individuals with disabilities are recognized.

Another significant victory is the inclusion of disability within data collection on health disparities. The final legislation requires any federally conducted or supported health program, activity, or survey to collect and report data on disability status, including disability subgroups. HHS will also be required to collect new data on the location where

individuals with disabilities access care, providers with accessible facilities and equipment, and providers with training in disability awareness and patient care of individuals with disabilities. This is one of the first times in federal legislation that health disparities for individuals with disabilities have been acknowledged with other minority populations and will assist with advancing future efforts.

In this recent legislation, significant advances were also made in the area of prevention. Perhaps most notable is the direction of the U.S. Access Board to develop standards for the accessibility of medical diagnostic equipment, such as weight scales, X-ray machines, and mammography equipment. This is an area not covered by the ADA and one that poses significant barriers to health care, particularly for preventive care and women’s health. In addition, a prevention and public health trust fund will be established with dedicated funding that begins immediately and scales up to \$2 billion annually. This presents new opportunities for the disability community to advance programs that promote health and prevent secondary conditions, such as the U.S. Centers on Disease Control and Prevention (CDC) Disability and Health state grants, which currently only reach 16 states. Funding could also be used to implement the community transformation grants authorized in the legislation. These new grants—with the purpose of empowering local communities to undertake a variety of prevention and health promotion activities—specifically identify individuals with disabilities as a priority population.

Long-Term Services and Supports

The health care legislation contains a robust package of reforms on long-term services and supports, including the Community Living Assistance Services and Supports (CLASS) Act and improvements in Medicaid. The vision of Senator Edward Kennedy, the CLASS Act will not only revolutionize the way long-term care is financed but will drive future debates and the realm of policy options for years to come. It establishes a new, voluntary national insurance program for workers 18 years of age and older. Workers who enroll pay monthly premiums. Following a vesting period of 5 years, participants who have or acquire functional needs receive a self-directed cash benefit of at least

\$50 a day to assist with purchasing long-term services.

The CLASS Act will benefit individuals with developmental disabilities in at least two fundamental ways. First, individuals with disabilities can enroll in the program and, after the vesting period, receive benefits while continuing to work. Unlike in the private market, there is no underwriting, and, unlike Medicaid, the program does not require individuals to impoverish themselves to receive benefits. Although only about one quarter of adults with developmental disabilities are competitively employed (Butterworth et al., 2008), the work requirement is minimal enough to allow many of these individuals to enroll. Individuals below the poverty level will pay only a nominal premium. Moreover, it establishes a pro-work framework that will complement future efforts to support individuals with developmental disabilities in competitive employment.

Perhaps to even a greater extent, the CLASS Act will benefit individuals with developmental disabilities indirectly. Over the next few decades the number of Americans who need long-term services and supports will more than double due to the aging of the population. This will present enormous strain on state budgets and an already-stretched Medicaid system, where nationally more than 393,096 individuals are on waiting lists, the majority of whom are individuals with developmental disabilities (Kaiser Commission on Medicaid and the Uninsured, 2009). Establishing alternatives to Medicaid and the failing, private long-term care insurance market (which serves only 4% of the population), the CLASS Act will help relieve pressure on Medicaid. The Congressional Budget Office estimates that the program will save Medicaid at least \$1.6 billion during the first 4 years that benefits begin paying out and substantially more in subsequent decades. These saving can be reinvested in Medicaid to make much-needed improvements.

The final legislation includes several incremental improvements to Medicaid long-term services and supports. Although there was a lack of political will to mandate equal access to community-based services, the Community First Choice (CFC) option will incentivize states to provide “community-based attendant services and supports” through a 6% increase in their federal match. States taking up the option as part of their state plans will not be permitted to impose caps and maintain

waiting lists for these services. They will also be required to provide a broad range of flexible services based on functional need. While individuals with developmental disabilities may require additional services, and internal shifts within states could occur, the new option will likely assist individuals on waiting lists. Health care reform also makes improvements to the Medicaid 1915(i) home and community-based (HCBS) state plan option to provide states with additional flexibility. One key change will allow states to provide the full range of benefits currently available under the 1915(c) HCBS waiver. States will be allowed to target certain populations, such as individuals with developmental disabilities under this option, but will not be permitted to maintain waiting lists for such services.

A new grant program will provide some states with additional incentives to provide home and community-based services. Over the 5-year grant period, states currently providing less than 25% of their total Medicaid long-term care expenditures on home and community-based services can apply to receive a 5% enhanced federal match to balance their systems; states that spend less than 50% can receive a 2% enhanced match. In addition, the Money Follows the Person demonstration is extended for an additional 5 years to assist individuals in moving from nursing homes and other institutional placements to the community. The required length of residence in a nursing home is shortened from 6 months to 90 days. Last, incremental advances are made to support the direct-support professional workforce. A new grant program is authorized to provide training opportunities in exchange for 2 years of service in the field. In addition, as part of the CLASS Act, a new Personal Care Attendant advisory panel is established within HHS, and states will be required to assess their direct-support professional workforce and infrastructure.

Conclusion

The disability community has much to celebrate. The Consortium for Citizens with Disabilities (CCD), a coalition of over 100 national disability organizations, provided a strong, sustained voice throughout the process. CCD set forth a guiding principle that challenged policymakers to judge proposals through a universal prism of

disability: If proposals are good enough for people with disabilities, they will most likely be good for all Americans. Moreover, the disability community challenged the very concept of *health*, moving the discussion beyond narrow confines of acute care to a more inclusive framework of functioning, well being, and community participation. To this end, long-term services and supports, which were absolutely nowhere on the initial policy agenda, are included in the final legislation.

Victories achieved did not come easy and most often came only through grassroots organizing and collaboration. Over 100 cross-disability organizations joined together to urge Congress to address health disparities and wellness for individuals with disabilities. The disability community also forged relationships with other minority communities to collaborate on these issues. However, perhaps the most significant outcome of health reform was the unprecedented collaboration between the disability and aging communities. Early in the process, CCD joined forces with the Leadership Council of Aging Organizations, the national coalition of national aging organizations. The two communities, which have traditionally worked in silos, came together. Over 275 national aging, disability, and faith-based organizations coordinated an advocacy campaign on long-term services and supports, generating literally thousands of calls, e-mails, faxes, and visits to Congressional offices—a force that could not have been mounted alone and one that could not be ignored. Although the rhetoric of health care reform in the popular media focused on the politics of division, there are powerful lessons to be learned in the disability community about working together to effect change, lessons we must carry forward as we move forward to implementation and “the work begins anew.”

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