Health Affairs Blog Post: Challenges for People with Disabilities within the Health Care Safety Net

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Medicare and Medicaid were passed to serve as safety nets for the country's most vulnerable populations, a point that has been reemphasized by the expansion of the populations they serve, especially with regards to Medicaid. Yet, even after 50 years, the disabled population continues to be one whose health care needs are not being met. This community is all too frequently left to suffer health disparities due to cultural incompetency, stigma and misunderstanding, and an inability to create policy changes that covers the population as a whole and their acute and long-term needs.

Nearly 57 million Americans had disabilities in 2010,[1] and this number is likely to grow due to an aging population, advances in technology, and negative health trends such as obesity. While the diversity of the group's demographics and health issues can make it difficult to define "disabled," how it is defined in policy can have significant implications for benefits, as well as stigma. For example, the Social Security Administration narrowly defines disability as "the inability to engage in substantial gainful activity due to a medically determinable physical or mental impairment,"[2] which disregards those who work in spite of their disabilities. Meanwhile, the Americans with Disabilities Act (ADA) defines disability as "a physical or mental impairment that substantially limits one or more major life activities,"[3] focusing on the condition rather than what a person can and cannot do.

The disparities for the disabled community are abundant: in comparison to nondisabled Americans, they are more likely to be unemployed, impoverished, have less than a high school education,[4] and have higher levels of risk factors such as obesity,[5] smoking,[6] and being physically inactive.[7] Moreover, disability

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1. Matthew W. Brault, *Americans with Disabilities: 2010*, U.S. CENSUS BUREAU CURRENT POPULATION REPORTS 4 (2012), http://www.census.gov/prod/2012pubs/p70-131.pdf.

2. SOC. SEC. ADMIN., DISABILITY EVALUATION UNDER SOCIAL SECURITY, http://www.ssa.gov/disability/professionals/bluebook/general-info.htm (last visited Dec. 10, 2014).

3. Americans with Disabilities Act of 1990 § 3, 42 U.S.C. § 12102 (2012).

4. Brault, *supra* note 1, at 22.

5. *Obesity and People with Disabilities: A Tip Sheet for Public Health Professionals*, CTRS.

prevalence is higher in minority groups such as blacks, American Indians, and Alaska Natives.[8] However, their vulnerability does not stem simply from having a disability, but more importantly, like other vulnerable populations, they are not well integrated into the health care system because of certain characteristics.[9] It is this inability to integrate the disabled into the health care system, and in turn society at large, that must be a focus of policymaking, including the Medicare and Medicaid programs, moving forward.

The Affordable Care Act (ACA) has taken steps that should help, such as expanding coverage, but disparities arise from health status and access to care as well. To illustrate, one study looked at disparities between the disabled and nondisabled within Medicare to minimize the effect of coverage. Nearly 50% of the disabled population reported putting off or not seeking care due to cost concerns, and they were more likely to have negative consequences as compared to nondisabled Medicare beneficiaries who delayed care due to costs.[10] Furthermore, disabled beneficiaries were three times as likely to have difficulties finding a doctor who accepted Medicare than nondisabled, and for the lucky beneficiaries that did, 15% had difficulties finding doctors who actually understood their disability or how to treat it.[11] The difficulty in finding access to adequate care is exacerbated by other obstacles arising from inadequate equipment and facilities,[12] and insufficient communication,[13] which is critical to patients' rights of informed consent and bodily integrity.

The ACA contains provisions aimed at tackling some of these barriers to care, including standards for accessible medical diagnostic equipment, and developing trainings to provide culturally competent care to the disabled. Proper

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FOR DISEASE CONTROL & PREVENTION, http://www.cdc.gov/ncbddd/documents/obesity-tip-sheet-_-phpa_1.pdf.

6. *Cigarette Smoking and People with Disabilities: A Tip Sheet for Public Health Professionals*, CTRS. FOR DISEASE CONTROL & PREVENTION, http://www.cdc.gov/ncbddd/documents/smoking-tip-sheet-_phpa_1.pdf.

7. *Physical Inactivity and People with Disabilities: A Tip Sheet for Public Health Professionals*, CTRS. FOR DISEASE CONTROL & PREVENTION, http://www.cdc.gov/ncbddd/documents/physical-inactivity-tip-sheet-_phpa_1.pdf.

8. Lisa I. Iezzoni, *Eliminating Health and Health Care Disparities Among the Growing Population of People with Disabilities*, 30 HEALTH AFF. 1947, 1947–48 (2010).

9. *Vulnerable Populations*, URBAN INST., http://www.urban.org/health_policy/vulnerable_populations (last visited Dec. 7, 2014).

10. Juliette Cubanski & Patricia Neuman, *Medicare Doesn't Work as Well for Younger, Disabled Beneficiaries as it Does for Older Enrollees*, 29 HEALTH AFF. 1725, 1729 (2010).

11. Kaiser Family Foundation, *Medicare and Nonelderly People with Disabilities: Fact Sheet*, http://www.kff.org/medicare/upload/8100.pdf [hereinafter *Medicare and Nonelderly*].

12. *Disability Healthcare Access Brief*, DISABILITY RIGHTS EDUC. & DEF. FUND (2007), http://dredf.org/healthcare/Access_Brief.pdf.

13. Iezzoni, *supra* note 8, at 1948.

training is critical as many of the health disparities that the disabled suffer are due to the fact that the health care system is not designed to care for this population effectively. The disabled suffer from others' belief that they lack the ability to achieve high-functioning lifestyles, which is illustrated by the fact that health care staff rarely, if ever, emphasizes health promotion.[14]

This is not to insinuate that the issue of coverage, or coverage of the needs of the disabled, has been rectified. A combination of states' right to implement eligibility criteria, Medicaid being a target for budget cuts, and the disabled costing more than any other group,[15] has left many in the disabled community without much needed coverage. The ACA originally expanded Medicaid to anyone at 133% of the federal poverty line (FPL), but the Supreme Court made this optional. With 23 states still not moving forward on expansion,[16] there is a need for advocacy and persuasion to try to limit the force of partisan politics. While other safety net features are available, Medicaid can offer assistance to the disabled through long-term care as well as standard necessities. Medicare on the other hand requires nonelderly disabled individuals receive Social Security Disability Insurance (SSDI) benefits for at least 24 months, where they must be unable to engage in gainful activity for at least 12 months to qualify for SSDI, and long-term institutional or community-based services are uncovered.[17]

This perverse incentive to avoid work, or punish those that do work, is an issue the disabled community faces all too often. Expanding employment options for the disabled is important not only monetarily, but also to enhance their ability to live independently and interact with their social environment. Too often they are cut-off from large parts of society, which undoubtedly lead to their higher rates of depression and mental illnesses.[18] The Community Living Assistance Services and Supports (CLASS) Act aimed to help alleviate some of the concerns over long-term care,[19] but it was ultimately deemed unsustainable.[20] Nevertheless, with the disabled population growing, leaving their long-term medical needs to linger until they become more costly is not an economically efficient solution.

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14. *Id.* at 1950.

15. *Medicaid Moving Forward*, KAISER FAM. FOUND. (2014), http://kff.org/medicaid/fact-sheet/the-medicaid-program-at-a-glance-update.

16. *Status of State Action of the Medicaid Expansion Decision*, KAISER FAM. FOUND. http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act (last visited Dec. 10, 2014).

17. *Medicare and Nonelderly*, *supra* note 11.

18. Cubanski & Neuman, *supra* note 10, at 1727.

19. Kaiser Family Foundation, *Health Care Reform and the CLASS Act*, Focus on Health Reform (2010), http://kaiserfamilyfoundation.files.wordpress.com/2013/01/8069.pdf.

20. Lexie Verdon, *HHS Halts CLASS Act*, KAISER HEALTH NEWS, Oct. 14, 2011, *available at* http://kaiserhealthnews.org/news/hhs-halts-class-act/.

The safety net that Medicare and Medicaid aimed to create fifty years ago is still filled with far too many gaps when it comes to the disabled. The ACA has taken some important steps, but more needs to be done to ensure the health care system, including Medicare and Medicaid, reduces its barriers to health. Coupling policy changes with better information and training should also contribute to a much needed normative change, so that we no longer perceive those with disabilities as having something wrong with them or unable to function "normally." It is essential that as a country we recognize that health disparities for the disabled are associated less with their disability and more with our inability to structure the societal and health care framework to allow them to function optimally.

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