Nebraska Consortium for Citizens with Disabilities

ELIMINATING HEALTH CARE DISPARITIES FOR PEOPLE WITH DISABILITIES

Policy Brief on Health Care

By

Nebraska Consortium for Citizens with Disabilities

Accessing affordable health care is as important to people with disabilities as it is to those without disabilities. However, the current system fails to recognize the importance of accessibility. Health care reform and the financial incentives available to transform the delivery system provide Nebraska the unprecedented opportunity to ensure that health care is accessible, affordable, coordinated, and continuous for all Nebraskans, especially for those with disabilities.

Recommendations[1]

- Increase the meaningful involvement of people with disabilities in all aspects of care
- Ensure access to insurance coverage for people with disabilities whose income puts them in the eligibility gap for tax credits
- Define habilitation and rehabilitation in the Essential Benefits Package so that they include autism services and peer support and adopt the federal definition of "developmental disabilities"
- Enforce the relevant accessibility guidelines and standards and require disability cultural competence in professional medical education programs
- Ensure coverage for services and devices typically used by people with disabilities
- Provide health care and related services in the community to eliminate unnecessary segregation of persons with disabilities
- Maximize federal match and performance bonuses and improve compliance with federal regulations

"***Nothing about us without us***" is a rallying cry for people with disabilities. With the expertise of those with lived experience, "invisible" barriers can be identified. The Center for Disease Control's (CDC) August 30, 2013 Grand Rounds reports, "Experiences at the local and state levels suggest that the key ingredients for success [in eliminating health care disparities] are building strong and long-lasting collaborations with diverse stakeholders and partners, identifying common goals, and integrating persons with disabilities into all facets of public health activities, including planning, surveillance, programming, education, and evaluation."[2] With full participation, health care disparities can be further reduced and quality of care improved.

Historically, individuals with disabilities have faced many barriers to obtaining health care and health insurance coverage. Persons with disabilities have often been rejected for coverage or have been charged exorbitant premiums due to pre-existing conditions. Insurers have dropped others after an illness or disability. Current reforms prohibit these practices[3]. Yet insurance may still not be financially feasible.

In a 2009 survey conducted by the CDC, people with disabilities were more likely to have reported delaying seeking health care or not getting needed health care because of cost than people without disabilities.[4]

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1 The Social Security Administration has a more rigorous definition of "disability" than the Americans with Disabilities Act. The American Community Survey relies on self-report.

2 http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6234a3.htm

3 http://www.hhs.gov/healthcare/rights/http://www.hhs.gov/healthcare/rights/

4 http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5944a7.htm?s_cid=mm5944a7_w

In 2010, 29 percent of people with disabilities report unmet health care needs compared to 12 of people without disabilities.

Health insurance exchanges, or marketplaces, have been developed to support consumers choosing insurance policies and allow them to compare prices and benefits. To enable poor Americans to afford policies, tax credits may be applied to lower premiums. However, credits for an individual are only available if you have an income between $11,490 and $45,960[5].

The 2013 American Community Survey reported that an estimated 21,900, or 23.7 percent, of Nebraska's 21-64 year-olds who experience disabilities live below poverty threshold[6]. (The threshold for an individual was $11,490. The threshold for a household of two adults was $15,510 that year.[7]) If the Social Security Administration has determined these adults to have a disability, they may be able to obtain Medicaid.

If not, they are not eligible for Medicaid in Nebraska[8] or premium tax credit relief. They must pay the full amount. This highlights the impact of poverty on the acquisition of health care. Policy makers should develop a remedy for that to make health care financially available for people with disabilities who live in poverty.

"Essential Health Benefits" (EHB) must be included for a plan to be offered in the marketplace. These 10 minimum standards include "habilitative" and "rehabilitative" services and devices. Their definitions are critically important to individuals with disabilities. States have the option to develop their own definitions.

Nebraska should adopt the federal definition of "developmental disability"[9] and include autism services as habilitative as have Ohio[10] and Michigan.[11] Examples of rehabilitation include peer supports and services, that have been shown to improve recovery, address workforce shortages, and more effectively use financial resources.[12]

The standards and guidelines detailed in federal disability legislation and policy are not being fully enforced. Nebraska should bring health care services into compliance with The Accessibility Guidelines;[13] the Standards for adaptive devices and equipment[14]; the Culturally and Linguistics Appropriate Services Standards (CLASS)[15], and others in order to place people with disabilities on a level playing field with others.

In its strategic plan to reduce health care disparities, the Center for Disease Control includes "accessible messages and communication services … [and] providers with disability knowledge, respectful attitudes, and expectations of good health for people with disabilities."[16]

While many environmental obstacles may be easy to identify, attitudinal barriers are more difficult to discern.

The 2009 CDC publication, *The Current State of Health Care for People with Disabilities*,

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5 https://www.healthcare.gov/will-i-qualify-to-save-on-monthly-premiums/
6 http://www.disabilitystatistics.org/reports/acs.cfm?statistic=7
7 http://aspe.hhs.gov/2013-poverty-guidelines
8 http://kff.org/medicaid/state-indicator/medicaid-income-eligibility-limits-for-adults-at-application-effective-january-1-2014/
9 http://www.md-council.org/resources/dd_definition.html
10 http://www.insurance.ohio.gov/Consumer/Pages/FederalHealthReformFAQs.aspx
11 https://www.michigan.gov/documents/lara/1.7.13_Order_No_13-003-M_EHB_Habilitative_Services_407955_7.pdf
12 http://www.governing.com/news/state/sl-peer-specialists-can-aid-states-obamacare-mental-health-expansion.html
13 report/executive-summary
14 https://www.disability.gov/u-s-access-board-releases-report-accessibility-medical-equipment/
15 http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15
16 http://www.cdc.gov/ncbddd/aboutus/healthcare-disability.html

reports that, “The absence of professional training on disability competency issues for health care practitioners is one of the most significant barriers that prevent people with disabilities from receiving appropriate and effective health care.” [17] Traditionally, medical practices use medical intervention to cure an illness or injury.[18] Yet, disabling conditions do not always result in poor health[19] and many cannot be “cured”.

Another model, championed by many advocates, is the “disability model.”[20] Disability is seen as a normal part of life. This perspective recognizes the influence of the environment, social determinants[21], and attitudes towards disability. It utilizes the expertise of peers with lived experience to provide linkages and supports and to improve insurance coverage, access to accommodations for effective services, and cultural competence.[22]

Traditional insurance often excludes coverage of adaptive devices, assistive technology, and support services on which many people with disabilities rely to address environmental factors in health care. Most coverage requires that these be “medically necessary” as determined by the insurer. The term is loosely defined and often includes a disclaimer that a physician’s prescription does not guarantee coverage.[23]

Some aides are excluded outright. For example, although Medicare covers walking canes as “durable medical equipment”, white canes are not covered.[24] Private insurers often follow Medicare’s guidelines.[25] Restrictive processes also hinder obtaining these items and services, including obtrusive pre-authorization processes and administrative quantity limits.

Medicaid is a federal/state program of Center for Medicare and Medicaid Services (CMS.) In 2012, the program provided medical coverage to 152,297 children; 31,742 adults with dependent children; 17,768 aged, and 35,736 individuals with disabilities in Nebraska.[26] To participate, the state receives federal matching dollars but also must cover certain mandatory services and has the option to offer additional services.

Past attitudes about people with disabilities fused and created an “institutional bias”, a preference for institutional care. As a result, people with disabilities have been placed in state hospitals, nursing homes, assisted living facilities, and intermediate care facilities. In fact, nursing home care is a mandatory Medicaid service.

The Supreme Court’s 1999 decision in *Olmstead v L.C.* determined that “unjustifiable segregation” violated the Americans with Disabilities Act (ADA) and requires states to provide services in the community, as appropriate, when not opposed by the people affected.

Accessible health care, adaptive devices, assistive technology, supports, and services are necessary for many people with disabilities in order to remain in their homes in the communities of their choice.

In order to decrease the state’s institutional bias, Nebraska has participated in Money Follows the

17 http://www.ncd.gov/publications/2009/Sept302009#Health%20Coverage%20and%20Benefits
18 http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm
19 http://www.who.int/mediacentre/factsheets/fs352/en/
20 http://www.accessiblesociety.org/topics/demographics-identity/dkaplanpaper.htm
21 http://www.cdc.gov/socialdeterminants/Definitions.html
22 http://www.ncd.gov/publications/2009/Sept302009#Disability%20Community%20Advocacy
23 https://www.nebraskablue.com/providers/resource-center/glossary/
24 http://www.medicare.gov/coverage/canes.html
25 http://seniorhealth.about.com/library/weekly/aa093000a.htm
26 http://dhhs.ne.gov/medicaid/Documents/Medicaid%20Annual-Report-Draft-2013.pdf

Person (MFP)[27], a CMS program that provides an enhanced Medicaid match for the first year after a person is moved out of a nursing home or other institution.

The ACA extended funding for MFP through September 30, 2016.[28] A "virtual" Aged and Disabled Resource Center[29] is being launched to help folks find help. Programs like these redistribute long-term care funds and allow people to remain in their own homes.

There are too many waivers, initiatives, and programs available to be included in this statement. CMS.gov is an invaluable source of information on many. The Center for Disease Control also offers states support for health care efficacy for people with disabilities.[30] The state must take advantage of these programs, but there are also ways to maximize the programs we already are using.

For example, since 2009, performance bonuses have been awarded to states that strengthen the Children's Health Insurance Program (CHIP) "to support enrollment and retention of eligible children in Medicaid and CHIP and helping to defray the costs associated with increasing enrollment of the lowest income children."

In closing, NCCD believes Nebraska has opportunities to improve health care for people with disabilities, as well as the financial and technical support to do so. By decreasing health care disparities and envisioning a broader health environment, Nebraska would enable many with disabilities to become employed or enhance their employability, thus increasing their economic contribution and reducing reliance on public assistance.

NCCD would be happy to provide additional information and advocacy to policy makers.

27 http://dhhs.ne.gov/medicaid/Pages/med_moneyfollowstheperson.aspx
28 Support/Balancing/Money-Follows-the-Person.html
29 http://adrc.ne.gov/
30 http://www.cdc.gov/ncbddd/disabilityandhealth/programs.html