Disability Rights Education & Defense Fund DREDF

What Will It Take to Get Equal and Effective Healthcare for People with Disabilities?

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Disability Affects Everyone

- Today, approximately 47.5 million US adults (21.8%) are living with at least one disability, and most Americans will experience a disability some time in their lives.

- Almost 14% of children and youth (age 0-17) in the US have a special health care need.

- Over 97% of people with disabilities live in the community (not in a nursing home, institution, or hospital

What is Disability?

The MEDICAL MODEL/Traditional perspective of disability:

- Views disability as a primary personal attribute
  - Caused by disease, trauma or other health condition
  - Requires an intervention to correct or compensate for problem

The SOCIAL MODEL perspective of disability:

- Views disability as a socially created problem not personal attribute
  - Caused by unaccommodating, inflexible social/physical environment
  - Requires systemic political response to alter environment

International Classification of Functioning, Disability and Health

- ICF merges the medical and social models
- ICF explicitly recognizes that external forces contribute to or mitigate disability – including
- physical environments,
- social structures,
- governmental policies, and
- societal attitudes
- Disability , under ICF, is an umbrella term for impairments, activity limitations and participation restrictions

Healthcare Specific Disability Barriers

- Structural inaccessibility
- Lack of accessible equipment
- Programmatic inaccessibility (policies and procedures)
- Insufficient data on functional limitation as a demographic characteristic
- Limited Long-Term Care (LTC) options and Institutional Bias
- Historical Private Insurance Practice
- Lack of universal insurance and employment-based insurance

Legal Framework

Trends in disability law:

- Less diagnostic or situationally specific, more holistic
- Attempts to support deinstitutionalization and rebalancing
- Federal oversight, monitoring and implementation vs. federal deference to “local” state flexibility
- Rise of cross-disability non-discrimination civil rights laws
  - Follow federal funds
  - Explicit application to places of public accommodation such as provider offices, hospitals, and so forth
- *Olmstead v. L.C.*

Limitations of Law

- Even in the single arena of physical and programmatic barrier removal, non-discrimination laws are not self-executing – they rely heavily on individual complaints and lawsuits
- Difficult to address the fragmented delivery of the services and supports needed by people with disabilities, and particularly a sharp division between medical care and Long-Term Services & Supports (LTSS)
- Administrative complexity of U.S. healthcare system factors into both the difficulty of enforcing nondiscrimination and in the delivery of LTSS
- Existing non-discrimination law is a poor tool for forcing systemic change in such critical areas as provider training, interagency-coordination, and intersectional data collection

Supports and Services Issues

- Need for LTSS, rebalancing of home and community-based services verses institutional care
- Critical role of care coordination – among physical and mental health care providers, and between medical care and LTSS providers
- Partnerships between community-based disability and aging organizations and primary care managed care organizations and providers
- Slowly growing attempt to address health of people with disabilities within the context of community-based housing
- Very slow acknowledgement of need for physical and programmatic accessibility in areas such as managed care provider network adequacy, and provider directories

Key Recommendations

1. Improve data collection - mandate use of the ACS six disability questions in relevant population surveys and in electronic health records.
   - Monitor and report health-related differences between groups according to disability, race, ethnicity and other personal characteristics
2. Conduct research-
   - Call for an intersectionality report from CMS
   - Provide focused Funding Opportunity Announcements for independent investigators to examine disability and intersectionality health disparities
3. Systemically include people with disabilities in health equity, health literacy, and clinical trail research efforts, and address the racial, ethnic, cultural, and linguistic diversity among people with disabilities

Key Recommendations (continued)

4. Establish a core training requirement on cultural competence in disability, race, and ethnicity in healthcare, public health, and human service training programs.
5. Disability accessibility laws must be consistently monitored by sufficiently independent federal or state entities given primary responsibility for enforcement
6. CMS has included some disability accommodation language in proposed Medicaid managed care regulations, Medicaid 1115 waivers and various duals demonstration contracts, but practical methods to implement the intent of the language and monitor and enforce are absent. Accessibility requirements must be substantively incorporated within accreditation and funding standards, and healthcare providers and entities must periodically demonstrate compliance.

Key Recommendations (continued)

7. Health Care Finance - Federal health care payment reforms currently under consideration include risk adjustment for socio-economic status in payment and in quality reporting.
8. CMS should strengthen MMCO provider network adequacy standards by requiring a showing of accessibility and capacity to accommodate, and by calling for networks to be expanded if found to be deficient.
9. Activities that increase access and provider capacity to accommodate PWD, including innovative ways to provide services, should be included as a bona fide element in medical loss ratio calculations

Key Recommendations (continued)

10. Care Integration- ACOs, ACCs, and Medical Homes/Health Homes should integrate non-medical community based services and resources into their comprehensive service model of care.
    - Behavior and physical health care services should be integrated across all health care delivery settings, including interoperable health information technology (HIT).
11. Long Term Services and Supports – HHS should encourage and support states in broadening home and community-based (HBCS) to better meet consumers' needs
    - Federal and state policies should promote a stable and appropriately skilled LTSS workforce by improving job quality and should find ways to support family caregivers in continuing to provide the help that consumers need.

Key Recommendations (continued)

- HHS should require, and states should welcome, expanded efforts to measure LTSS quality and outcomes, relying not only on administrative data but also on direct feedback from consumers.
- State agencies should be empowered to monitor quality and enforce requirements for high-quality services. The needs of consumers must be protected by their getting assessed for services fairly by entities without a conflict of interest, getting support in resolving problems encountered in dealing with MCOs, and being given the option of remaining in or returning to a fee-for-service system if needed.
- HHS and the states need to be especially vigilant in ensuring that MCOs retain and enhance the ability for consumers to direct their own services and continue to receive services that are not strictly health care related but are more generally aimed at supporting people in participating fully in their communities.