Heath Disparities and Equity at the Intersections: Disability, Race and Ethnicity

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OUTLINE

1. Disability Introduction

2. Demographic Analysis of People with Disabilities, including Race and Ethnicity

3. Intersections Among Racial and Ethnic Health Disparities, Disabilities, and Health Equity

4. Health-Specific Barriers for People with Disabilities
   • Attitudes About Race and Disability
   • Health Literacy in the Context of Disability, Disparity and Health Equity
   • Compound Disparities for People with Disabilities in Underserved Racial and Ethnic Groups

5. Federal Legislation Related to Disability
   • Healthcare-Related Services, Supports and Inclusion Laws
   • Limitations of Law

6. Various Supports and Services for People with Disabilities
   • Healthcare Access
   • Care Coordination and Care Delivery
   • Accessible Care Delivery

7. Conclusions and Summary of Recommendations
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 characteristic/attribute of person
  - 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 political response or solution
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
NHIS PHYSICAL DISABILITY BY RACE/ETHNICITY 2002-2014
HEALTH EQUITY AND INTERSECTIONS AMONG RACIAL, ETHNIC, DISABILITY DISPARITIES

- **Education**: Individuals with Disabilities Education Act (1975)
- **Economic Stability**: poverty, employment, food security
- **Social and Community Context**: social cohesion, discrimination, incarceration
- **Neighborhood and Built Environment**: safety, transportation
- **Health Services**: access to health care, health outcomes
HEALTH-SPECIFIC BARRIERS

Attitudes: perception of difference, assumption of inability, assumption that disability severely compromises quality of life

- Profoundly affect healthcare communication, health literacy, and ultimately the health of patients with disabilities
- Negative impact on how public health issues are prioritized and researched

Health Literacy: The Institute of Medicine began to shift from viewing health literacy solely in the domain of the individual to include the skill of health care professionals and the capacity of health care systems as well as other entities that provide health information
COMPOUND DISPARITIES

- Adults with disabilities from underserved racial and ethnic groups
  - More likely to report fair/poor health
  - Delayed and unmet healthcare needs

- Children with disabilities in underserved racial/ethnic groups
  - Less likely to have health insurance,
  - Less likely to have a usual source of care,
  - More likely to have been unable to get needed medical care
  - More likely to have been hospitalized or use emergency treatment
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
  o Follow federal funds
  o Explicit application to places of public accommodation such as provider offices, hospitals, and so forth
• *Olmstead v. L.C.*
LIMITATIONS OF LAW

- Fragmented delivery of services and supports needed by people with disabilities, and particularly a sharp division between medical care and Long-Term Services & Supports (LTSS)
- 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
- 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 & SERVICES

• Need for LTSS, rebalancing of home and community-based services versus 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**
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.
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.

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 (HCBS) offerings 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.
- 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.
WE LOOK FORWARD TO FURTHER DISCUSSION OF THESE TOPICS