Multiple Perspectives on the Impact of COVID-19 on Persons with Disabilities: Lived Experience, Data, and Policy

Tawara D. Goode
Georgetown University National Center for Cultural Competence
University Center for Excellence in Developmental Disabilities
Center for Child and Human Development
Georgetown University Medical Center

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What do we know about the impact of the COVID-19 pandemic on persons with disabilities?
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A review of selected and recently published literature indicates disproportionate COVID-19 morbidity and mortality among persons with disabilities due to underlying health conditions.

Persons with disabilities experienced delayed and poorer quality of health and mental health care, discrimination and biases by health care professionals and institutions, increased isolation, job loss, and disruption in supports and services.

This literature cites extensive deficits in the nation’s current data collection systems, including the failure to examine COVID-19 related data by disability, race, ethnicity, and languages spoken in states, territories, and tribal nations.

“Statistics are people with the tears wiped away.”
What do we know about the impact of the COVID-19 pandemic on persons with disabilities?

During the early stages of the pandemic, the Georgetown University Center for Excellence in Developmental Disabilities went about the task of talking with persons with disabilities, listening carefully to their stories, and documenting these stories as personal narratives.

Between April and May 2020, GUCEDD faculty interviewed 11 persons with intellectual, developmental, and other disabilities from diverse racial and ethnic backgrounds who reside in the District of Columbia. The interviews consisted of asking four basic questions about their lives during the pandemic.

These narratives captured stories before statistics could wipe the tears away, helping us better understand the socio-cultural contexts of the lives of these persons during COVID-19.
Disparities: A Disability Framework

FULL PARTICIPATION OF INDIVIDUALS WITH DEVELOPMENTAL AND OTHER DISABILITIES in all facets of community life

Health ♦ Housing ♦ Child Care ♦ Recreation ♦ Employment ♦ Education ♦ Early Intervention ♦ Transportation

AVAILABILITY ↔ ACCESSIBILITY ↔ ACCEPTABILITY ↔ QUALITY ↔ UTILIZATION

Public Policy & Resources (Public & Private Sector)

T.D. Goode

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Using the Disability Disparities Framework, the stories revealed:

- That the 11 persons with intellectual, developmental, and other disabilities interviewed experienced disparities in accessibility (9 of 11), availability (8 of 11), acceptability (1 of 11), and quality (1 of 11) of supports and services.

- Each person experienced disruptions in utilization due to the widespread impact of the pandemic, resulting in significant limitations in major aspects of their lives.

- All persons who were interviewed reported disparities in supports and services that included but were not limited to health and medical care, in-home supports, physical and other therapies, public transportation, employment (days worked), performing independent activities of daily living, and facility-based services and closures.

- Access to and the capacity to use technologies (e.g., internet, computers, tablets, mobile phones) were reported as having a significant impact because it was the primary means of conveying information to the public.

- Fear, vulnerability, anxiety, frustration, and isolation were prevalent among the persons interviewed which increased their risk for mental health problems.


Understanding the Impact of COVID-19 on Young Adults with IDD-MH and their Families

An Analytical Framework and Database to Identify Service Experiences and Outcomes Across Diverse Populations in Real Time

A project funded by the Patient-Centered Outcomes Research Institute
RECONCILING THE PAST AND CHANGING THE FUTURE

Engaging Young Adults with IDD-MH and Researchers in Comparative Effectiveness Research

Jessica Kramer
jessica.kramer@phhp.ufl.edu

Tawara D. Goode
tdg2@georgetown.edu

Joan B. Beasley
Joan.Beasley@unh.edu
Convergence of Cultural Contexts:
A Focus on Developmental Disabilities

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The Center for START Services recognized and responded to the urgent need to determine how families were impacted during the initial phases of the COVID-19 shutdown.

The COVID-19 Family Interview was developed to address this need and was administered to 1455 caregivers nationally from March 15-July 31, 2020.

The Convergence of Cultural Contexts Framework is being used to analyze a rich national data set to identify:

- the sheer number of systems and sectors family caregivers navigated in order to meet the needs of children/adults with IDD-MH during the COVID-19 crisis.
- disparities in service system need and use based on race, ethnicity, languages spoken, and other cultural factors.
- the extent to which telehealth and virtual services were available, accessible, acceptable, and utilized by caregivers.
- impact of the pandemic on the person with IDD-MH, caregiver, and family unit as a whole within socio-cultural contexts of the communities in which they live.
A Call to Action on May 14, 2021

Understanding the Political Determinant of Health and their Impact on Persons with Disabilities during COVID-19

Lived Experience: Communities of Color, Disability, and the Physical and Mental Impact of COVID-19

Public Policy and the Governmental Response in a Pandemic: Lessons Learned and Impact on Persons with Disabilities

The Way Forward: What is It?

https://www.ahrcnyc.org/2021-symposium/
Closing Thoughts ...

- COVID-19 is still with us, and will be for months and likely years to come. We still have much to learn about its impact on persons with disabilities.

- If we do not collect, analyze, and report data that are inclusive of race, ethnicity, primary language spoken, gender, gender identity, socioeconomic status, and other cultural factors, we miss the opportunity to improve prevention, treatment, and other services for all persons with disabilities in future public health emergencies.

- It is essential that our knowledge about the impact of COVID-19 on persons with disabilities is not limited solely to quantitative data. We have an obligation to collect qualitative data on a continuous basis which provide in-depth insight and valuable information about the lived experience of people with intellectual, developmental, and other disabilities in order to inform policy, resource allocation, needed supports and services and advance equity.
For every social determinant of health, there was some preceding legal, legislative, regulatory, or other policy decision that resulted in that social determinant of health. And those are the political determinants of health.

Daniel E. Dawes, J.D.
Morehouse School of Medicine
Georgetown University National Center for Cultural Competence
http://nccc.georgetown.edu
cultural@georgetown.edu

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