CONVERGE COVID-19 Working Groups for Public Health and Social Sciences Research

Research Agenda-Setting Paper

This paper was written to help advance convergence-oriented research in the hazards and disaster field. It highlights areas where additional research could contribute new knowledge to the response to and recovery from the pandemic and other disasters yet to come. Questions about the research topics and ethical and methodological issues highlighted here should be directed to the authors who contributed to this paper.

Working Group Name:

Disability and COVID-19

Working Group Description:

This Working Group examined the intersection of disability and COVID-19 as a natural hazard—specifically, how the unfolding emergency is affecting access to and use of attendant care, community resources, medical care, mental health services, public health, and social services. The group was also interested in whether people with disabilities but without underlying health conditions were disproportionately experiencing barriers to information and services in relation to COVID; previous research on other disasters suggests that such barriers consistently occur.

Priority Research Topics and Specific Research Questions:

Priority Research Topics	Potential Research Questions
1. Examining existing theory: How does this pandemic expand or change existing conceptualizations of how disasters intersect with disability status?	• RQ1: How do socio-political models of disaster risk, such as the Pressure and Release Model (Wisner et al., 2003), extend to the social and political roots of the current pandemic-related risk as experienced by people with disabilities (PWD)? • RQ2: Is Bronfenbrenner's systems theory appropriate when applied to the current pandemic or does it require modification? (Boon et al., 2012) • RQ3: How does the C-MIST (Kailes) framework apply to pandemics where staying in place is needed for an extended period of time? • RQ4: How do social support and community resources influence resilience of PWD post-disaster? (Boon et al., 2012). • RQ5: In what ways can concepts from the social model of disability or Critical Disability Studies inform disaster risk experienced by people with disabilities, including the politicization of disaster response, stigmatization, segregation, and devaluation?
2A. Critical research questions: What are priorities for future empirical studies?	• RQ1: How have stigma, marginalization, and ablest views held in mainstream society contributed to devaluating deaths that occur in nursing homes, prisons, group homes, and other congregate living facilities that serve people with disabilities?

Stigma and Marginalization	• RQ2: What prevents (or supports, in rare cases) the inclusion of individuals with disabilities in local disaster planning efforts? • RQ3: Among people with disabilities who are Black and Hispanic, do we observe disproportionate impacts from COVID?
2B. Critical research questions: What are priorities for future empirical studies? *Education*	• RQ1: What impact has COVID-19 had on skill maintenance (or regression) of students with disabilities? • RQ2: What knowledge, skills, or supports do preservice SPED teachers/interns need for online instruction? How can SPED teacher prep programs best support them learning these skills? • RQ3: Are districts providing/preparing teachers support on online accessibility? • RQ4: How can school districts utilize UDL for online instruction? • RQ5: Just getting students to access the internet is one issue, but are the materials/online learning materials accessible?
2C. Critical research questions: What are priorities for future empirical studies? *Mental Health and Well-Being*	• RQ1: What impact has COVID-19 had on the social skills and emotional wellbeing of individuals with disabilities? • RQ2: What is the impact of COVID on families of children with disabilities? • RQ3: What are the COVID concerns/issues most relevant for people with I/DD? • RQ4: In jurisdictions (i.e., welfare regimes, countries, and states) offering more generous social welfare benefits for people with disabilities pre-disaster, do we observe better health and socioeconomic outcomes, when controlling for virus spread? • RQ5: Do individuals with disabilities have access to, and are they utilizing mental health supports during COVID-19?
3. Translating research into practice: Evidence-based practices that best support people with disabilities and disability-based organizations	• RQ1: How can information sharing across disciplines readily occur so that known information can be acted upon quickly? (Note that Campbell et al. made recommendations in the public health literature in 2009.) • RQ2: What community and policy level factors may have attenuated the risk of negative health, social, and economic outcomes for people with disabilities? • RQ3: What are examples of successful interventions to reduce loneliness and social isolation for people with disabilities during the crisis? • RQ4: How did communities ensure caregivers were able to provide needed support to people with disabilities during the crisis? What are examples of best practices? • RQ5: Which theories (e.g., Bronfenbrenner, C-MIST, Pressure and Release, etc.) best explain illness and mortality rates for COVID-19 for individuals with disabilities?
4. Policy implications: What do unfolding events reveal with respect to needed policy change and creation?	• RQ1: What existent policies in the pre-disaster environment could have mitigated the risk of COVID 19 for people with disabilities? • RQ2: How might policy change with respect to access PWD have to health care workers and personal care attendants? • RQ3: How might social policies have better supported caregivers to ensure the continuity of care for people with disabilities during the crisis? • RQ4: Given the health and economic crisis, how well did those receiving public disability benefits fare and were their benefits enough to make ends meet? • RQ5: What have we learned so far to prevent further distress as this pandemic continues- or if there is a resurgence of infections?

5. Data on the infection rate and mortality rate of people with disabilities from COVID-19	• RQ1: What kinds of data could help to mitigate the disaster risk experience of people with disabilities? • RQ2: Can various administrative agencies serving people with disabilities share their data to facilitate a robust inquiry into the effects of the disaster on people with disabilities? • RQ3: During a pandemics or disasters are there ways to better identify disability and disability types on death certificates? • RQ4: What subsets of individuals with disabilities are most at risk in this pandemic? Intersectionality research suggests that it may be those who are older, of minority status, living in congregate care, etc. • RQ5: What existing nationally representative surveys could shed light on the disaster risk experienced by people with disabilities? Would any be willing to add a special module covering the experiences of people with disabilities during the pandemic?
6. Communication and COVID-19	• RQ1: How can emergency managers, local organizations, and medical facilities provide the best means of communication for people with disabilities? (Brookes et al. 2020) • RQ2: How will people with ID adjust to educational and medical practices involving fewer face to face meetings and more reliance on technological communication? (Courtenay, Enfield, & Haringey) • RQ3: How accessible was disaster crisis information for people with disabilities?

Ethical / Methodological Considerations:

Considerable challenges exist in conducting research on individuals with disabilities. Although people with disabilities make up 26% of the U.S. population, “disability” status actually includes a heterogenic population differing with respect to physical, cognitive, emotional, and health factors. The group is difficult to access due to challenges in communication and privacy protections. Individuals with disabilities are typically considered vulnerable populations by institutional review boards, requiring additional levels of permission, protection, and consent. Self-report data is difficult to obtain from some people with disabilities, necessitating the use of proxies. While the advent of the internet has proliferated online survey research and computer-mediated interviews, individuals with disabilities have less access to the internet and technologies are often inaccessible to some disabilities. Together, these factors limit the type and scope of research conducted on people with disabilities. With respect to the COVID-19 pandemic, people with disabilities make the majority of people in nursing homes, assisted living centers, and other forms of congregate care- all of which disproportionately experience infections and death. As such, for the protection of residents, there is limited or no direct access to these facilities; however, this also means that limited data is accessible to researchers interested in studying this population.

Other Frameworks, Considerations for Collaboration, and/or Resources:

Our group has decided to continue our collaboration through writing at least one academic article. In lieu of writing a summary of our findings and in order to advance this aim, the following section summarizes several focus topics for our continued collaboration.

Topic I: Integrating Findings from Public Health Literature into Disaster Literature

We collectively experienced a large “aha!” moment when we found that the effects of COVID-19 on people with disabilities that have been observed had been predicted and written about in the public health literature, but were not well explicated in the disaster literature. An important article by CDC researchers (Campbell et al., 2009) on how to prepare for a pandemic for people with disabilities and conflagration in congregate settings seems to have been ignored. As a result, many of the preparations described were not followed in practice. Such is the importance of interdisciplinary research—and the danger of research remaining in academic silos.

Purpose: Integrate the disaster risk and public health literatures to understand the nature of the pandemic risk experienced by people with disabilities.

- There are strengths and limitations in both literatures. The public health literature provides rigorous analysis of identifiable risk factors for various health outcomes for people with disabilities, while drawing heavily on administrative and survey data. This information is critical for identifying strategies for crisis response but it provides less information as to the kinds of factors that could mitigate the disaster risk experience which are not easily quantifiable (i.e., policies, environmental, and social factors). The public health literature thus tends to be instrumentally- and community-focused, and can lack theoretical and historical depth, which limits its ability to identify the root causes of the disaster risk for people with disabilities. The disaster risk literature, on the other hand, provides a rich theoretical and historical framework that seeks to understand the underlying drivers of the disaster risk experience (see, Wisner et al., 2003) that draws on numerous in-depth studies of disaster events. But the disaster risk literature, with some exceptions, infrequently considers the specific experience of people with disabilities in disaster events. Moreover, the disaster risk literature relies heavily on case studies and requires more robust empirical data.
- This paper will attempt tie together a theoretical frame for public health and disabilities and pandemics. It will incorporate a disability perspective on the disaster risk experience of people with disabilities during the pandemic. This perspective will seek to integrate both the public health and disaster risk literatures and provide a framework that can guide future research. A disability perspective must recognize (a) the distinct social vulnerability of people with disabilities, including the role of social stigma and increased risk for poverty, and how these systemic factors increase disaster risk; (b) the role of the embodied experience and the importance of proximal human supports that make people with disabilities particularly vulnerable in a disaster event such as a pandemic; and (c) the need for an inclusive approach that sees government engaging with a wide range of relevant stakeholders, including persons with disabilities, before, during, and after the disaster event.

Topic II: Stigma, Marginalization, and Exclusion and its Effects on the Disaster Experiences of People with Disabilities

Purpose: Examine the ways in which the pandemic response disproportionately impacted people with disabilities. While social vulnerability frameworks examine political, social, and economic pre-existing disparities, our approach will include the role of stigma confronted by people with disabilities and how this affected public devaluing of people infected by the virus who live in congregate care settings or who require personal assistance by caretakers in their homes. We will warn the public about how the politicization of the response mirrors some of the worst moments in American history with particular discussion of the eugenics movement and the perception that disabled lives are disposable.

- The article will take a critical disability approach and examine the politicization of masking policies, the rhetoric of politicians concerning the impact of the deaths from the pandemic, and examples of unjust social calculations that implicitly devalue the lives of people who are immunocompromised, which includes many people with disabilities, for economic gain.
- In the pandemic, inclusion of people with the disabilities has been lost. When examining re-opening of communities and states, a direct call has been made to those who are “vulnerable” to remain in lockdown. This can be seen as another type of segregation taking place under the guise of protection.

Topic III: Effects of the COVID-19 Pandemic on the Education of Students with Disabilities

Purpose: Examine the ways in which the pandemic disproportionately impacted the education of students with disabilities, as well as the response of educational entities and educators to the needs of their students with disabilities. We will examine the demand for parent involvement in education of students with disabilities, and what educational supports were provided to both students with disabilities and their parents during the pandemic.

- During the pandemic students with disabilities lack consistent access to a Free Appropriate Public Education (FAPE) as required by the Individuals with Disabilities Education Act (IDEA). We will examine how the lack of teacher and school personnel preparedness to provide adequate and accessible learning and services in an online environment disproportionately impacted students with disabilities and their education. We will also be examining how the inequality of educational services received by students with disabilities and intensive support needs using distance technology increased the demand for parental involvement in the education of their child with a disability.

Topic IV: Effects of the COVID-19 Pandemic on the Mental Health of People with Disabilities

Purpose: Before the pandemic, people with disabilities experienced higher rates of depression, social isolation, loneliness, and other negative mental health outcomes. This experience was likely exacerbated by the pandemic. There is thus a need to identify and develop interventions that address mental health issues among people with disabilities.

- This includes an analysis of the ability of people with disabilities to access mental health supports and the ability to receive trauma-informed care. We will analyze how individuals with disabilities with pre-existing trauma will be impacted by trauma experienced during the pandemic. We will analyze data surrounding the impacts of the pandemic on the mental health of individuals with disabilities (i.e., suicide, grief, loss, helplessness, etc.). Specifically, we will analyze the loss of routines and inclusivity around the “protective measures” recommended by governmental entities.
- Therapists are needed with training on IDD populations. Examining how Medicare/Medicaid benefits can be accessed by people with mental health needs.

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