

How Genetic Reductionism Conceals Social Determinants: The Case of Down Syndrome and Covid-19

Sara M. Bergstresser, PhD, MPH, MS
Columbia University, Bioethics, SPS

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Overview

- People with Down Syndrome (Trisomy 21) have been at higher risk to develop Covid-19, to have severe illness, and to die of the disease.
- Since then, health researchers continue to seek genetic and biological explanations, but few parallel attempts have been made to address social determinants or to rethink the risks inherent in existing institutional systems.

Combating Biological Reductionism

- Biological reductionism will prioritize the study of hypothetical biological differences over clear examples of social inequality.
- Genetic reductionism not only reduces humans to genes, but it also forms an underpinning of eugenic thinking and its many related harms.
- A disability studies perspective disputes the idea that disability is an individual defect.

Eugenic Thinking

- Disability, genetics, and scientific racism were intertwined in the 19th and early 20th Centuries.
- “Mongolism” was an early diagnostic term for Down Syndrome. This terminology is now recognized to be very offensive.
- Ideas of “degeneracy,” “racial atavism,” and “Mongolian Idiocy” were debated among scientists of the day. (Wright 2011)

Vestiges of Eugenic Thinking

- Even though these ideas are no longer explicitly held within legitimate science, many of the assumptions, tests, and diagnostic techniques show clear and often unexamined historical continuities with earlier eras.
- For example, a biological deficit model as the baseline assumption directs inquiry in particular directions.

Disability Studies Perspective

- A disabilities approach can help us to understand how:
 - Individualizing disability allows social systems and policymakers to offload responsibility onto individuals.
 - Myths and preconceived notions are used for hypothesis formation, leading to lack of inclusion and ignoring many social factors.

Covid-19, Institutions, & Down Syndrome

- In New York, in a study of COVID-19 Outcomes Among People With Intellectual and Developmental Disabilities Receiving Residential Services (Landes et al. 2021)
 - Median age: 57.0 years
 - Highest association with Covid-19 infection: Down Syndrome, Increased Age, Kidney Disease, Larger number of residents in facility

Covid-19 and Down Syndrome 1

- In the UK, a large study of 8 million found (Clift et al 2021):
 - Adjusted for age and sex, the Hazard Ratio (HR) for COVID-19–related death in adults with versus without Down syndrome was 24.94 (January - June 2020; 95% CI, 17.08 to 36.44).

Covid-19 and Down Syndrome 2

- After adjustment for age, sex, ethnicity, BMI, dementia diagnosis, care home residency, congenital heart disease, and a range of other comorbid conditions and treatments (Clift 2021)
- There was still a very strong association between Down Syndrome and death from Covid-19 and hospitalization for Covid-19
- This suggests biological factors are important

Covid-19 and Down Syndrome 3

- After adjusting for demographic and biological factors (including Down Syndrome) (Clift 2021)
- Death from COVID-19 is strongly associated with living in a residential or nursing home
- Hazard Ratios similar to those of chronic kidney disease on dialysis, diabetes, chemotherapy
- This suggests social and environmental factors are important

Responses to Covid-DS Risk

- Can promote Justice and Equity:
 - Advocate for preferential vaccine eligibility based on higher risk and need.
- Or can lead to Injustice and Disparity:
 - Individualizing the problem, such as assuming inability to conform to masking and other protocols, and setting policy based on these unexamined assumptions.

“Less-Noticed” Covid Clusters 1

- During that period, in the US it also became clear that individuals living in nursing homes were at very high risk, but clusters at disability-related residential institutions remained largely ignored
- NY times data counts early outbreaks at Nursing Homes, Prisons, and Colleges separately, lists “Developmental Centers” under catchall “Other Clusters” (formerly “less-noticed coronavirus clusters”)

“Less-Noticed” Covid Clusters 2

- At least 16 “developmental centers” and similar facilities had over 50 coronavirus cases each as of November 9, 2020.
- The center with the most cases was the Ludeman Developmental Center in Illinois, with 356. This number was similar to the highest national nursing home case count of 375 at the time.
- <https://www.nytimes.com/interactive/2021/us/covid-cases.html>

Biological Reductionism and Policy

- Biological reductionism leads to misdirected policy priorities in emergency situations.
- It was clear that during the early pandemic, residential facilities of all sorts had large and deadly Covid-19 clusters.
- When individuals are dying, the focus should be on what can help immediately rather than genetic hypothesis formation.

Biological & Social Determinants

- Real world outcomes result from the interaction of both biological and environmental factors.
- Disproportionate research focus on biological pathways and genetic risk factors with much less focus on social and environmental determinants.
- This is not to say that genetic or physiological differences are not worthy of medical research, but they must be considered in conjunction with social determinants.

Preconceived Notions and Myths: Age

- Preconceived notions and myths can drive hypothesis formation in the design of research, policy, and emergency interventions
- Myth: Down Syndrome is only a disease of children
- Children grow up, and while Down Syndrome was once linked to shorter lifespan, things have changed dramatically in the past 50 years

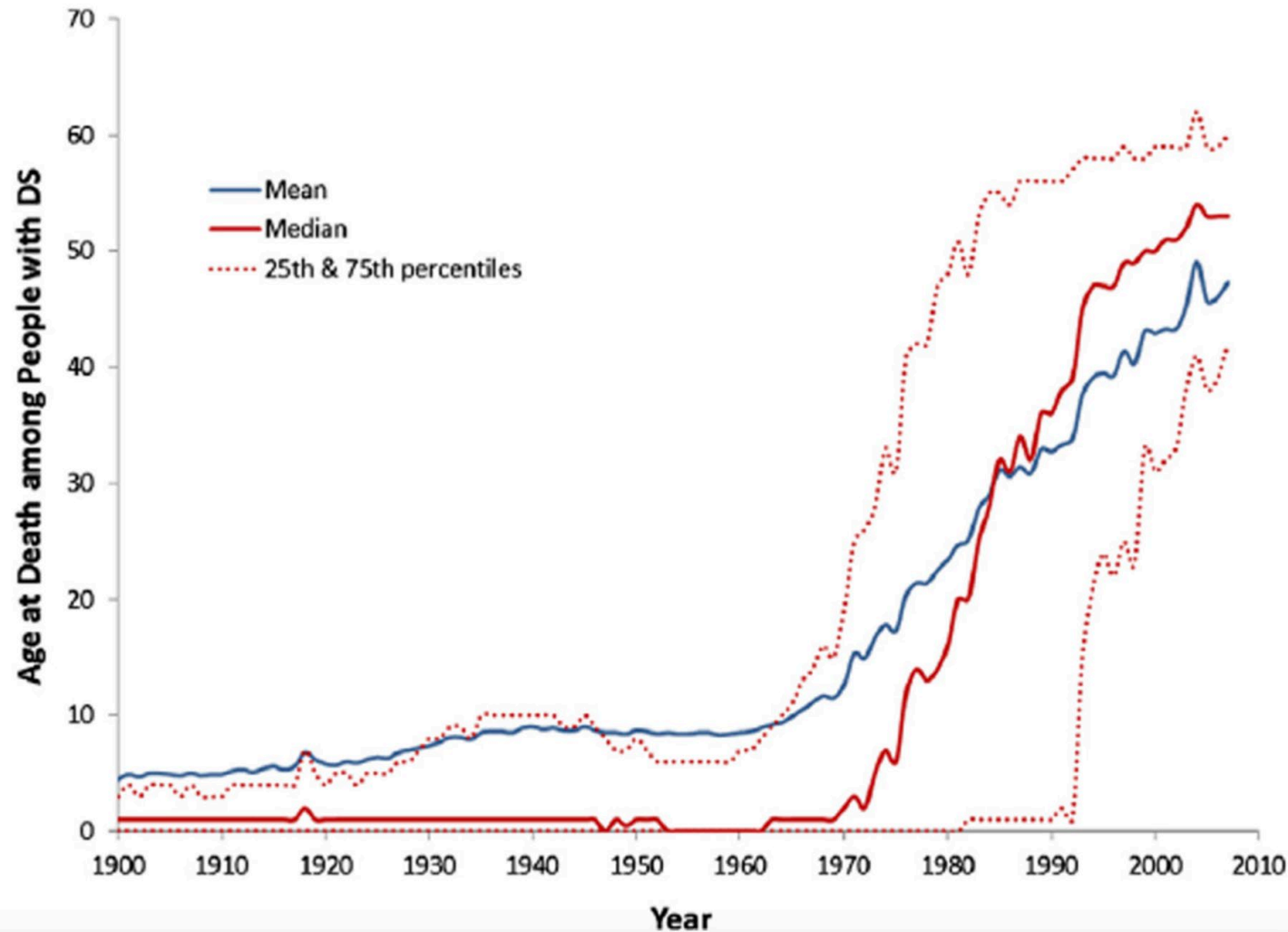
Preconceived Notions and Myths: Age

- Deinstitutionalization – mainly beginning in the early 1970s in the US – also start of dramatic increase in lifespan
- Corresponds to a change in social attitudes towards institutionalization and mass deinstitutionalization
- 1971: Geraldo Rivera exposé "Willowbrook: The Last Great Disgrace."

Preconceived Notions and Myths: Age

- “As surgery became more effective in the 1960s, it was widely acknowledged that cardiac abnormalities commonly associated with congenital conditions – such as the high prevalence of tetralogy of Fallot in children born with Down Syndrome – were not selected for surgery.” (Wright 2016:240)

Preconceived Notions and Myths: Age



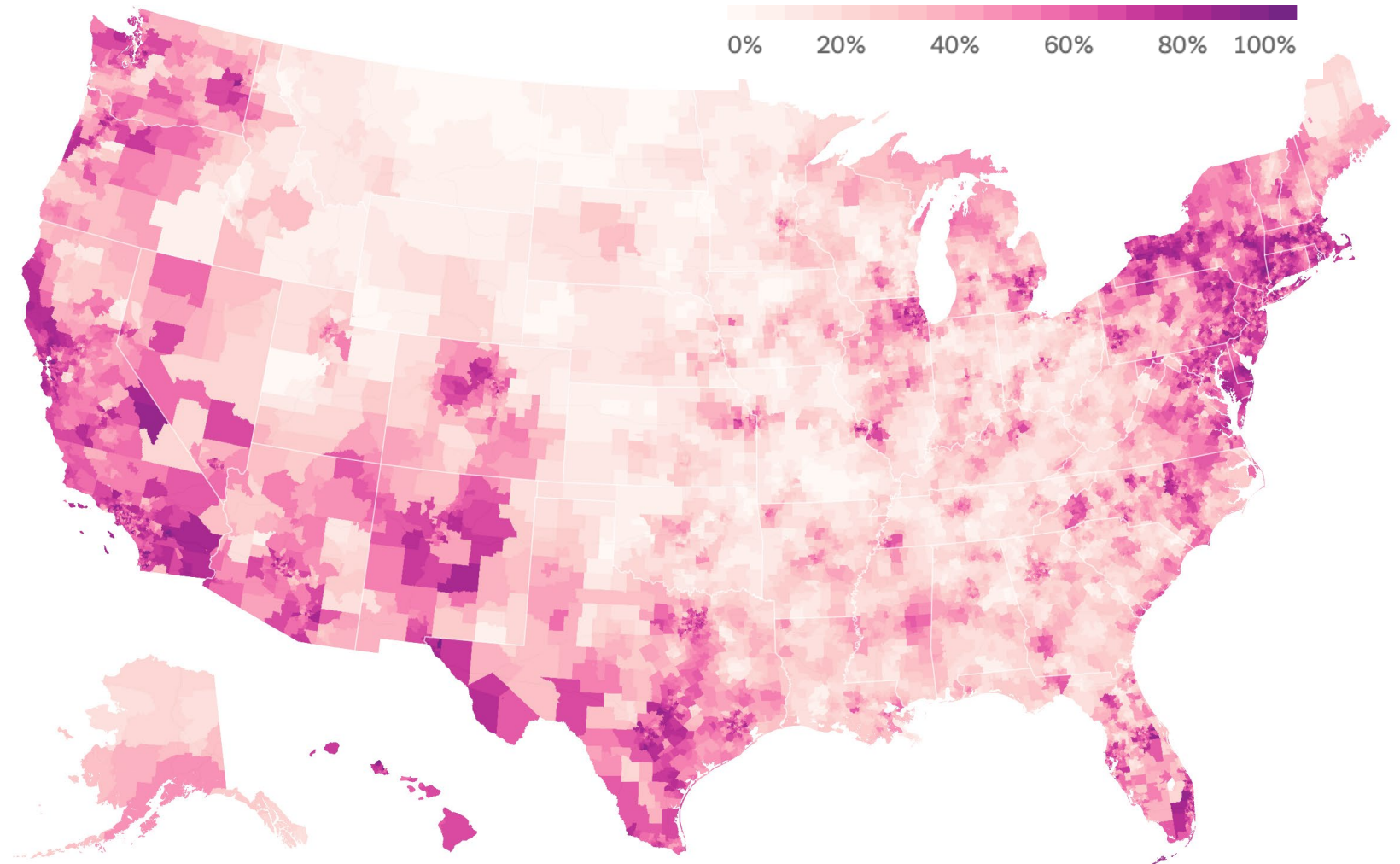
Mean, median, and 25th and 75th percentiles for age at death in persons with Down syndrome, US, 1900–2007 (Presson et al. 2013)

Unexamined Exceptionalism 1

- For individuals with disabilities, there was a focus on noncompliance with masking and other protocols without noting the widespread noncompliance with these measures in the US general population.

“Chance all five people are wearing masks in five random encounters”

- A Detailed Map of Who Is Wearing Masks in the U.S.
- July 2020
- New York Times
- <https://www.nytimes.com/interactive/2020/07/17/upshot/coronavirus-face-mask-map.html>



Non-Reductionist Genetic Research 1

- Genetic Research Need Not Erase Social Determinants
- Statistically controlling for social situations so as to conceal the effect of social situation and to sharpen focus on presumed biological difference

Non-Reductionist Genetic Research 2

- Reductionism erases obvious connections between Covid-19 infection and under-resourced residential facilities with carceral components. For example, locked wards in residential facilities for individuals with disabilities.
- Preventing family contact during Covid also conceals substandard or abusive situations in these facilities.

Conclusions 1

- Biological reductionism and medicalization continue to be used to conceal or deny systemic structural inequality for individuals with DS and other intellectual, developmental, and psychiatric disabilities.
- Inequality is routinely normalized based on presumed or hypothetical biological differences while social and structural constraints are often dismissed or ignored.

Conclusions 2

- Awareness of social determinants of disease is necessary for Disability Justice, Equity, and Inclusion.
- Genetic reductionism threatens the integrity of scientific research since it relies on preconceived notions for hypothesis generation, slowing understanding of real-world complexity and the interactions between genes and environment.

Thank You!

Contact:

Sara M. Bergstresser, PhD, MPH, MS
Lecturer, Bioethics
Columbia University, SPS

SB2715@columbia.edu

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