



# Economic Outcomes

Among families raising children with intellectual & developmental disabilities

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# Intellectual & Developmental Disabilities

- In the United States:
  - 2.8 million children aged 5-15 years (6.2%) have a disability
  - 1 in every 26 American families reported raising a child/children with a disability

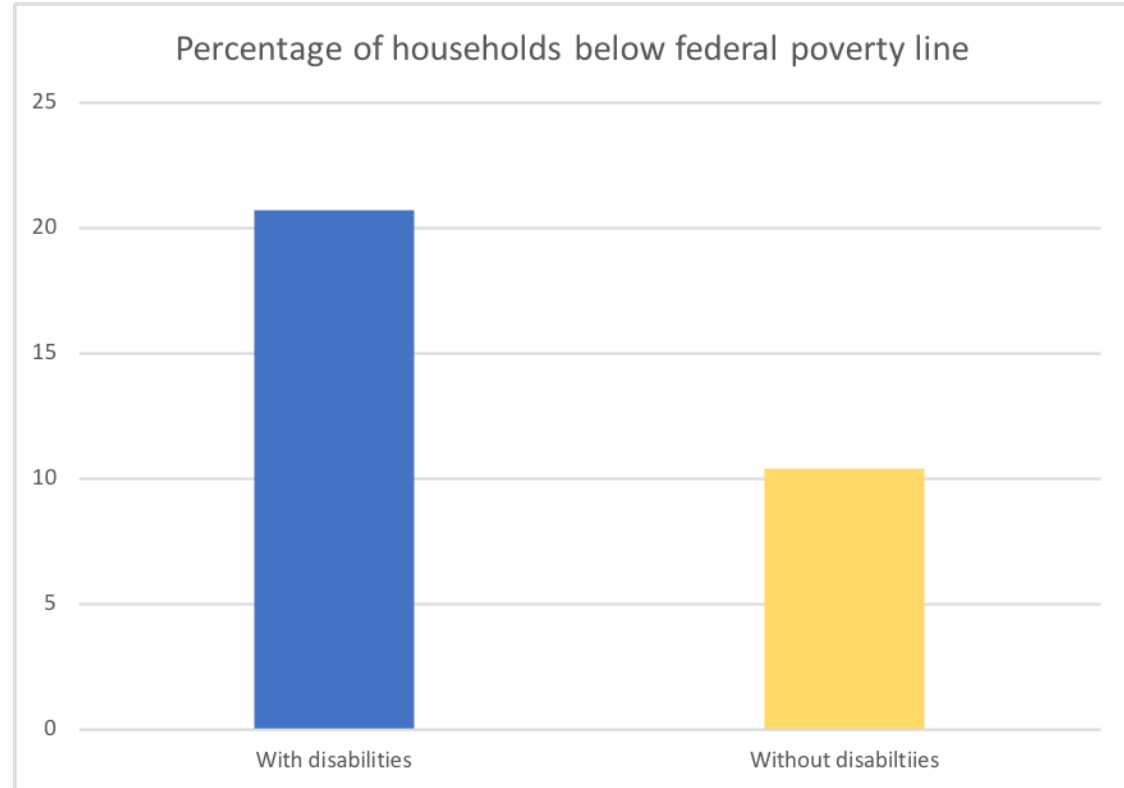
US Census Bureau. Disability and American Families: 2000

Disability	Definition	Prevalence (in US)	References
Autism spectrum disorders	Difficulties with social interaction and communication accompanied by restricted or repetitive patterns of thought and behaviors.	1 in 54 children aged 8 years	Maenner et al, 2020
Cerebral palsy	Difficulty with balance, posture, and/or movements due to a non-progressive injury or abnormality in the brain.	1 in 345 children	CDC, 2020
Intellectual disability	Significant limitation in intellectual functioning and adaptive behavior originating before the age of 18 years. Generally associated with IQ score <70.	1 in 100 children	Zablotsky et al, 2019
Intractable epilepsy	Recurrent seizures not controlled by two or more medications.	1 in 300 children	Skjei & Dlugos, 2011; Zack & Kobau, 2017

**And yet, topics covered in day-to-day clinic visits revolve around struggles obtaining medically indicated and appropriate...**

- Services through school district
- In-home nursing and respite care
- Mobility equipment
- Transportation to and from medical appointments
- Assistance obtaining supplementary income
- Patient behavioral and mental health services
- Parental mental health services

*Reflect upon how these struggles may be affected by where one lives and how much one earns.*



In a study based on US census data from 2000 to 2010, 20.7% of households having one or more members with disabilities were below the federal poverty line, compared to 10.4% of households with no members with disabilities.

## **Life Course Impacts of Parenting a Child With a Disability**

Marsha Mailick Seltzer; Jan S. Greenberg; Frank J. Floyd; Yvette Pettee; Jinkuk Hong

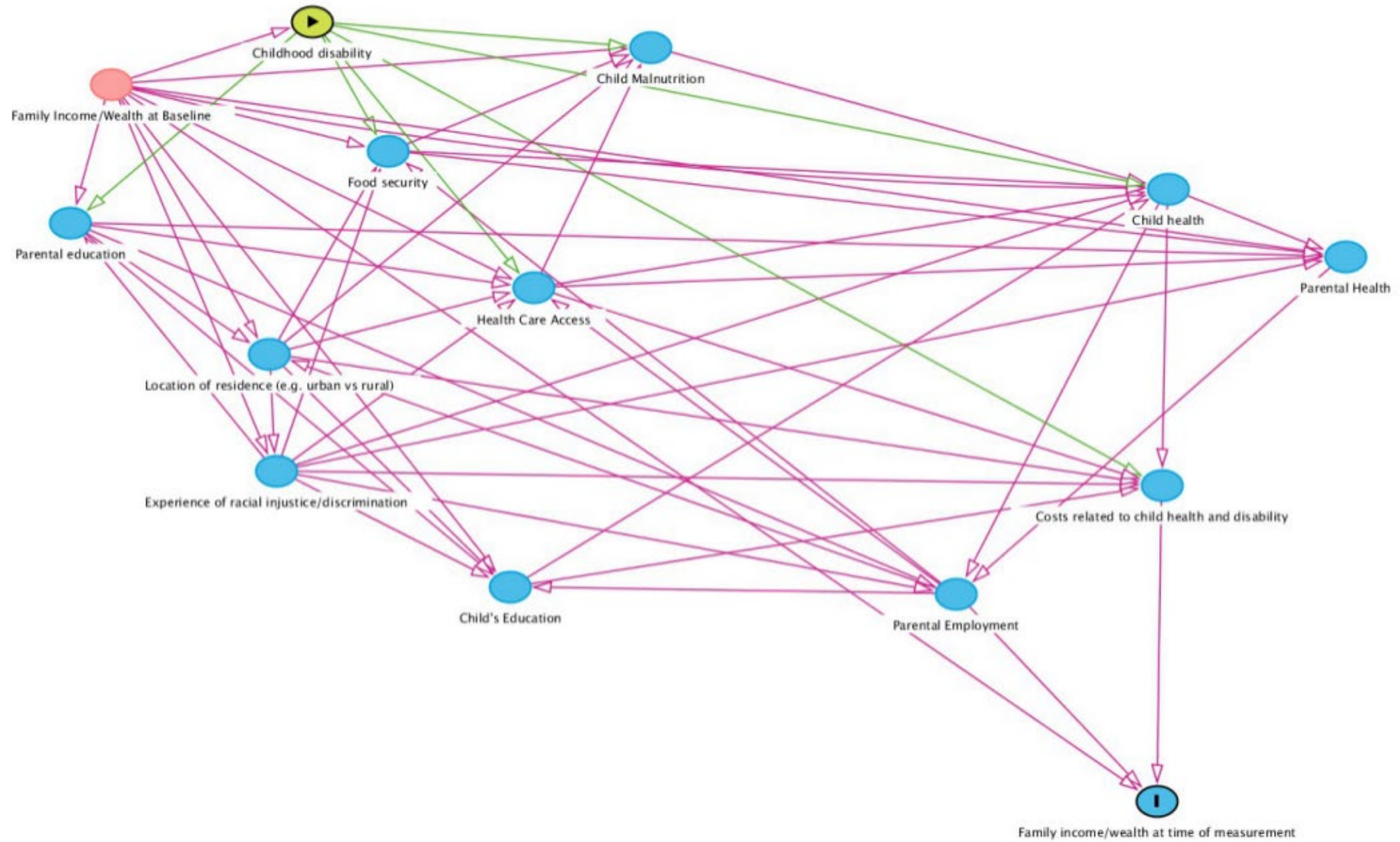
*Am J Ment Retard* (2001) 106 (3): 265–286.

## **Financial Well-being of Single, Working-age Mothers of Children with Developmental Disabilities**

*Susan L. Parish, Roderick A. Rose, Jamie G. Swaine, Sarah Dababnah, and Ellen Tracy Mayra*

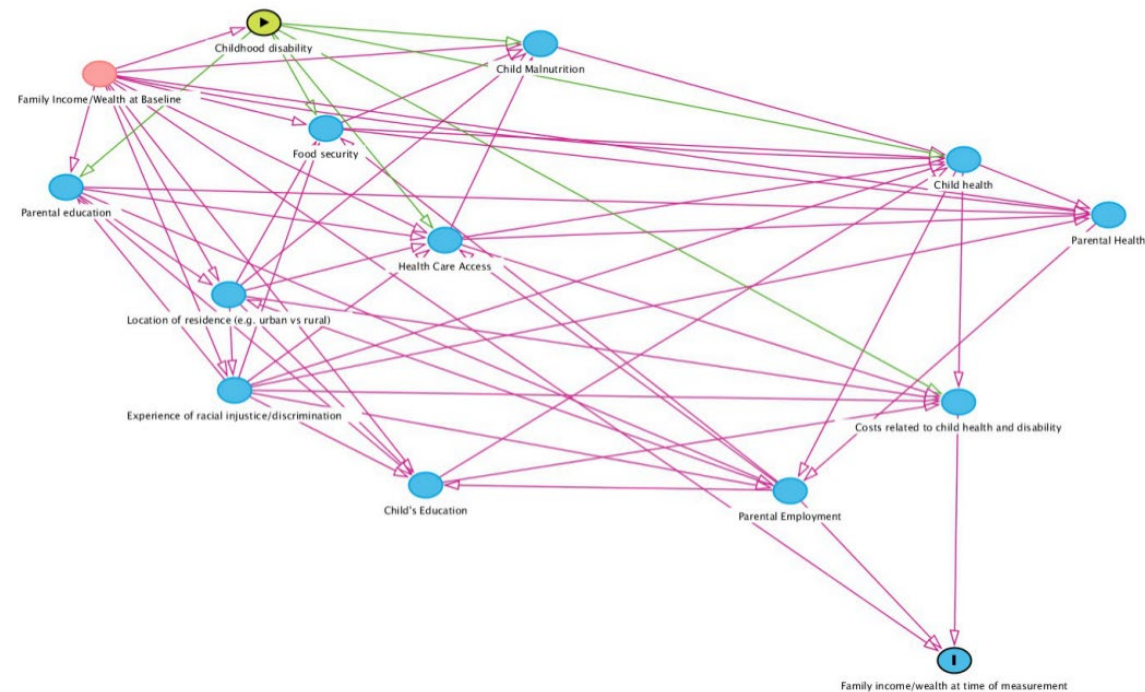
Mothers in the US caring for a child with disability had lower rates of employment, lower savings and lower incomes overall in those families.

What do we know about economic outcomes for families raising children with IDD?



# Analysis of publicly available data

- Identified the following factors associated with poor economic outcome in families raising children with intellectual & developmental disabilities:





# Part 1: Analysis of publicly available data

Data Source	National Survey of Children with Special Healthcare Needs (CSHCN)	2018 National Survey of Children Health (NSCH)	2018 National Health Interview Survey (NHIS)	2018 American Community Survey (ACS) Public Use Microdata Sample (PUMS)
Conducted By	CDC National Center of Health Statistics	<ul style="list-style-type: none"> <li>•US Census Bureau</li> <li>•US Department of Health and Human Services</li> <li>•Health Resources and Services Agency</li> <li>•Maternal and Health Bureau</li> </ul>	National Center of Health Statistics	US Census Bureau
Year Data Collected	June 7, 2009 – March 2, 2011	June 2018– January 2019	2018	Jan 1 – Dec 31, 2018
Collection Format	Households with at least one child (0-17 age) for detailed phone interview	Web survey OR Mailout/Mailback (household with at least one child)	Face-to-Face interviews in respondent’s home (survey not limited to children)	Person record, Housing Unit Record
Notes	196,159 screening interviews, 40,242 detailed interviews completed	38,140 screeners, 30,530 detailed topical completed (CSHCN oversampled)	N= 8,269 in Sampled Child file EIS/SES Analysis + Neuro DIS Analysis	N=total number of samples

# Part 1: Data Source Profile

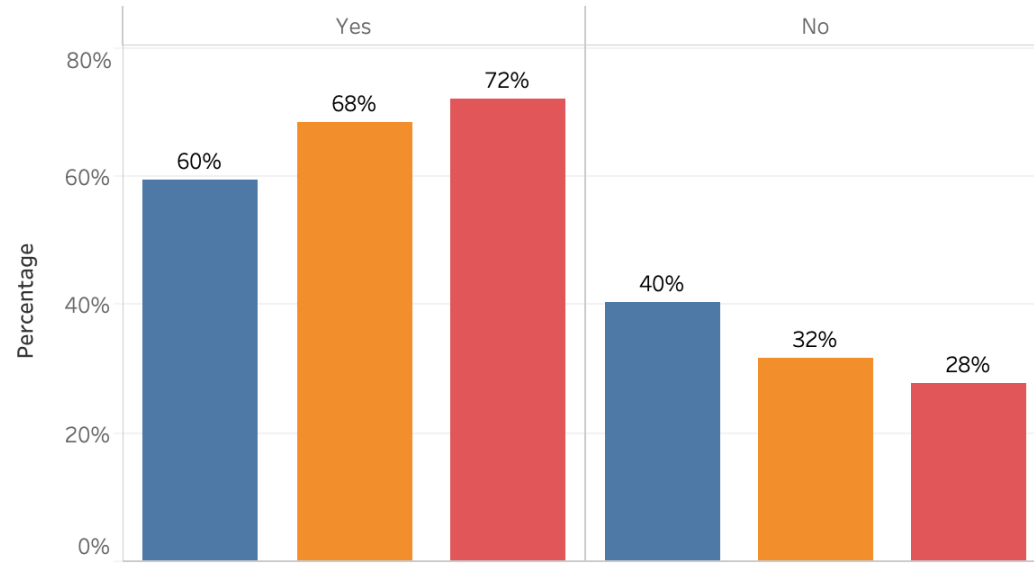
Data Source	CSHCN	NSCH	NHIS	ACS PUMS
Sample Group(Children <= 18 years old)	Children with One of the Neuro Disorder WITHOUT diabetes OR migraines	Children that have AT LEAST one of the Neuro Disorder	Families with child with at least one of the selected Neuro Disorder; Families with child with at least one of the selected Neuro Disorder;	Families with children (<18 y/o) with cognitive disability
Adjusted Sample	2,468,708	3,919,410	4519127; 2054145;	1,951,154
Control Group	Children with diabetes OR migraines WITHOUT having one of the Neuro Disorders	Children that DO NOT have any of the Neuro Disorders, but MAY OR MAY NOT have another SHCN	Families w/o children receiving EIS/SES; Families without child with any Neuro Disorder;	Families with children without any cognitive disability (may have non-cognitive disability)
Adjusted Control	935,057	68,652,440	29442384; 31967083;	28,379,732
Sample Weight Applied	Interview Weight (WEIGHT_I)	Child Weight (FWC)	Family Weight (WTFA_FAM)	Housing Unit Weight
Level of Analysis	Household* (one child per HH)	Child* (each from unique HH)	Family	Household* (one child per HH)

Most of work was done in R Studio with visualization using Tableau.

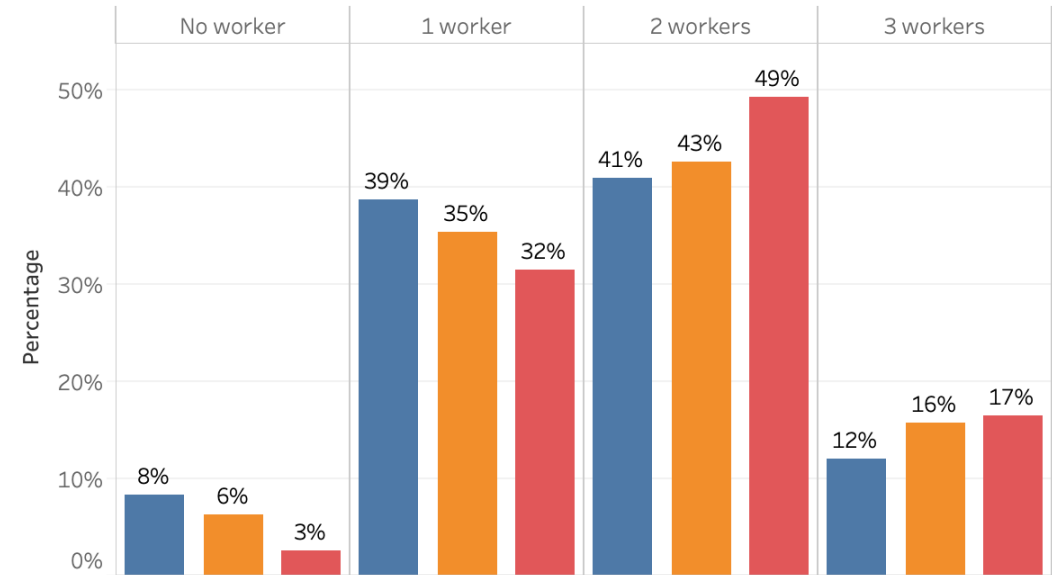
Household types

Neuro disability Other disease Healthy

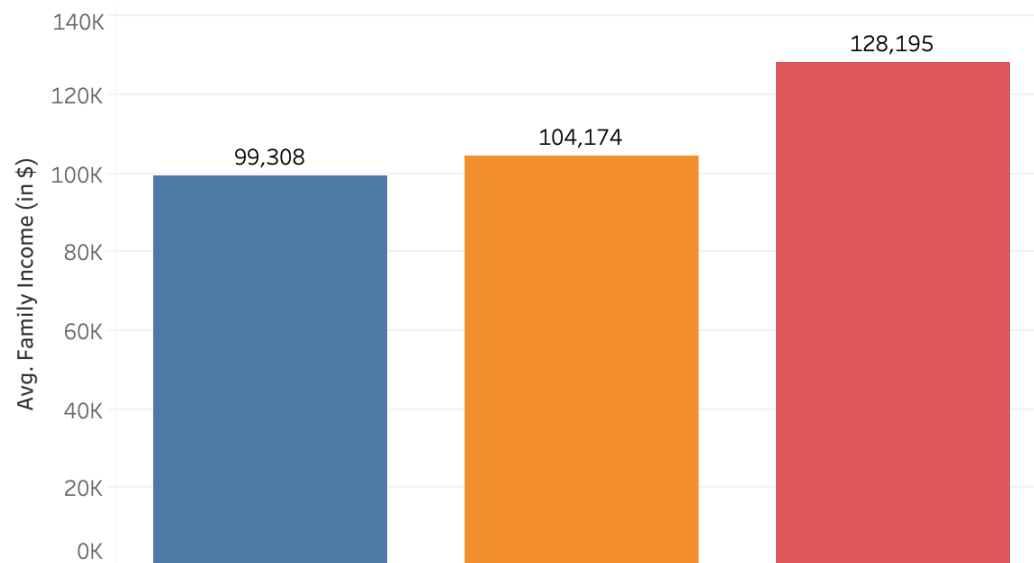
A. Employment during the past year



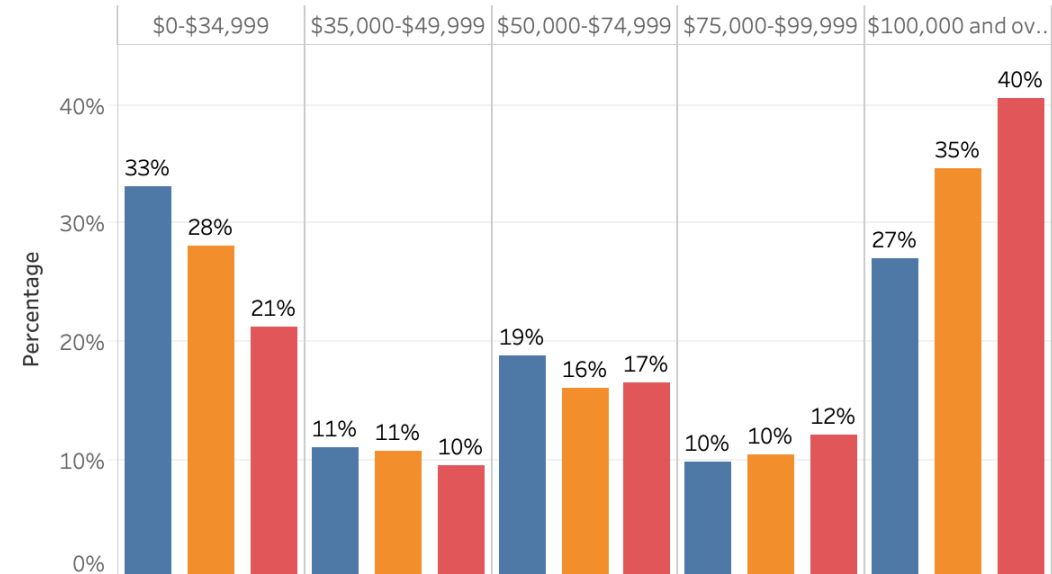
B. Number of workers in the household last year



C. Average family income



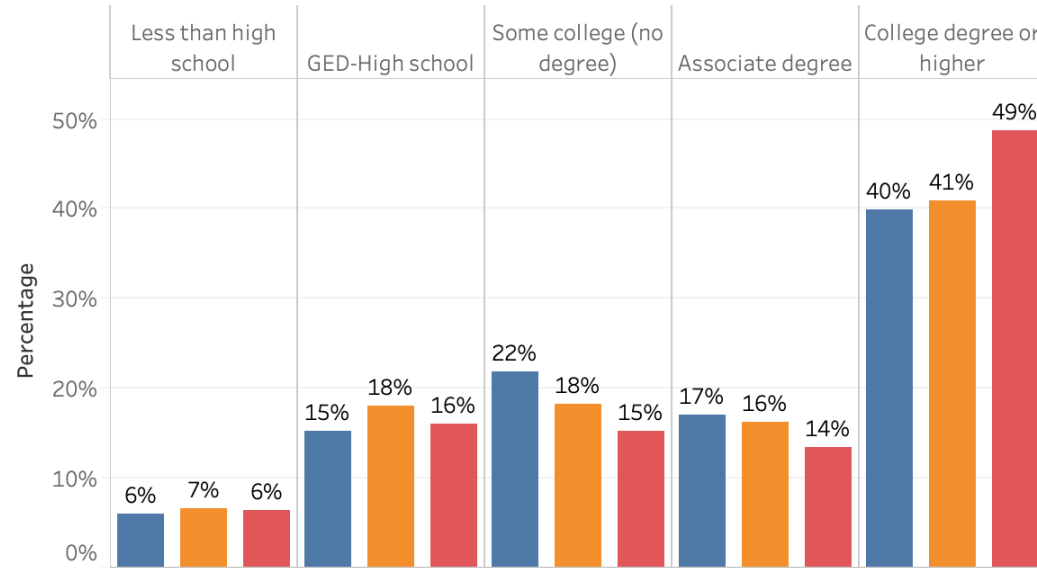
D. Total combined family income



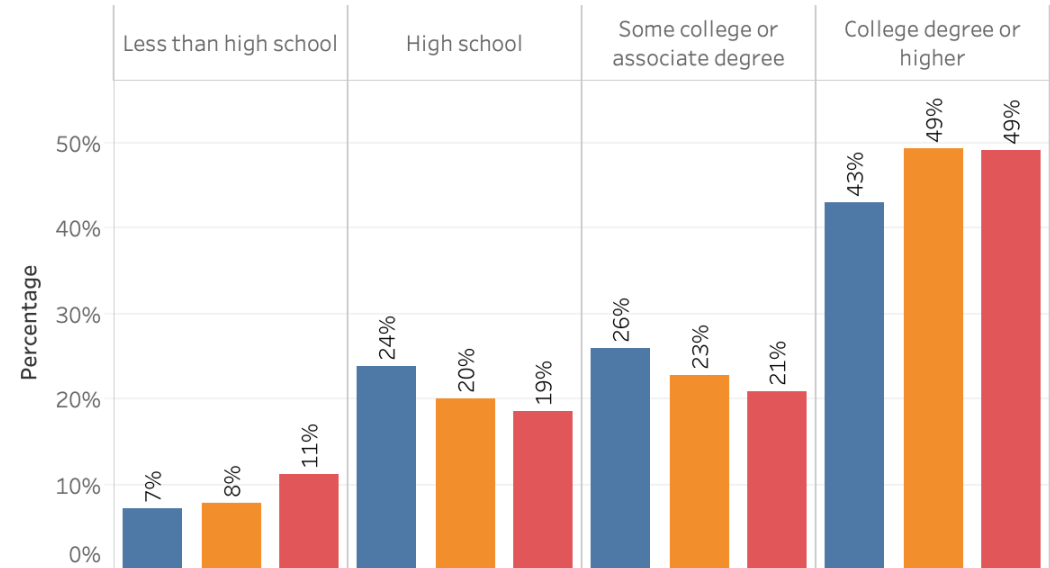
Household Types

■ Neuro disability ■ Other disease ■ Healthy

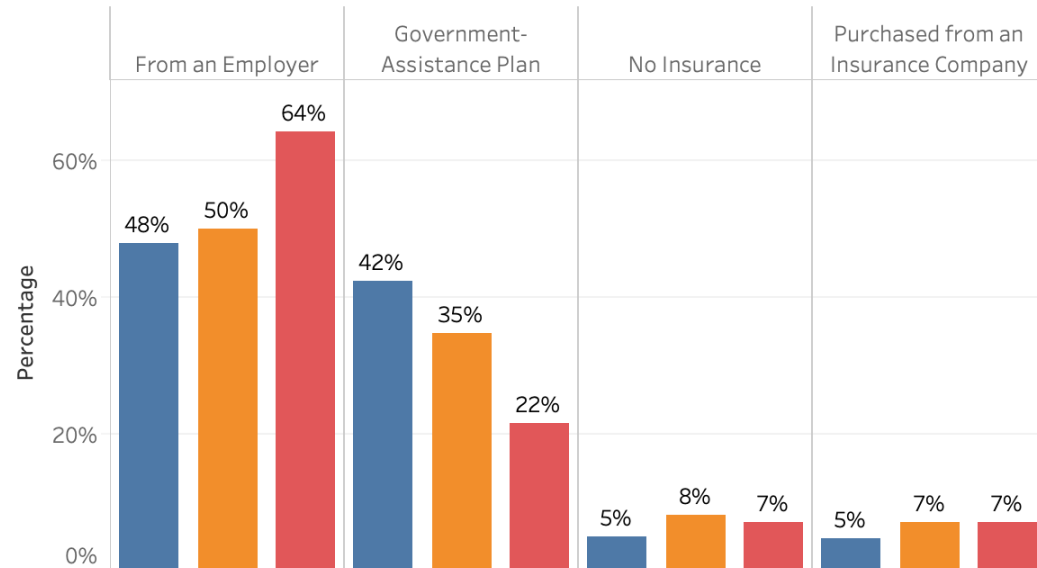
A. Highest educational level among reporting adults



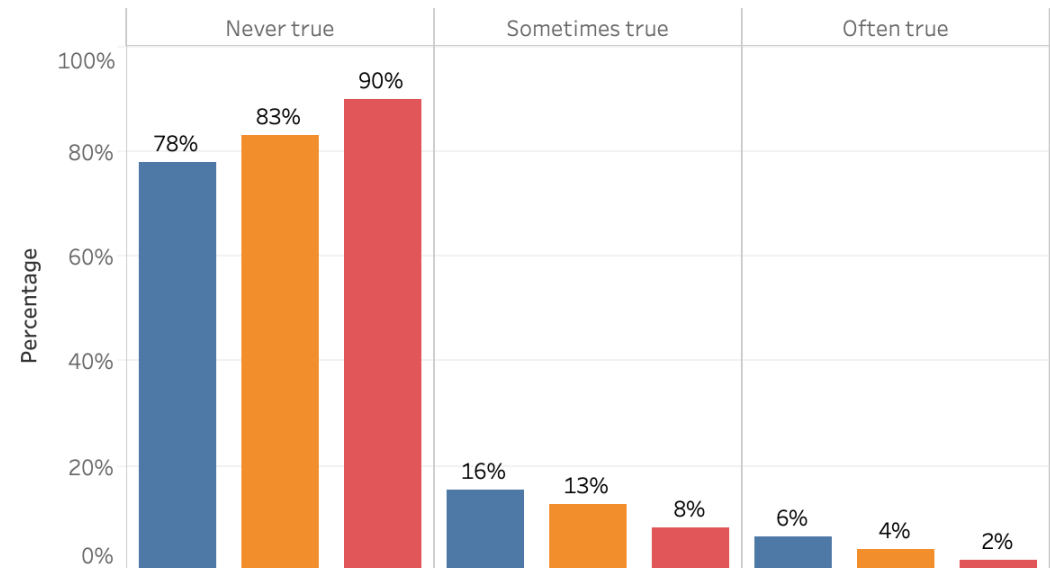
B. Highest educational level among reporting adults



C. Distribution of child's insurance type

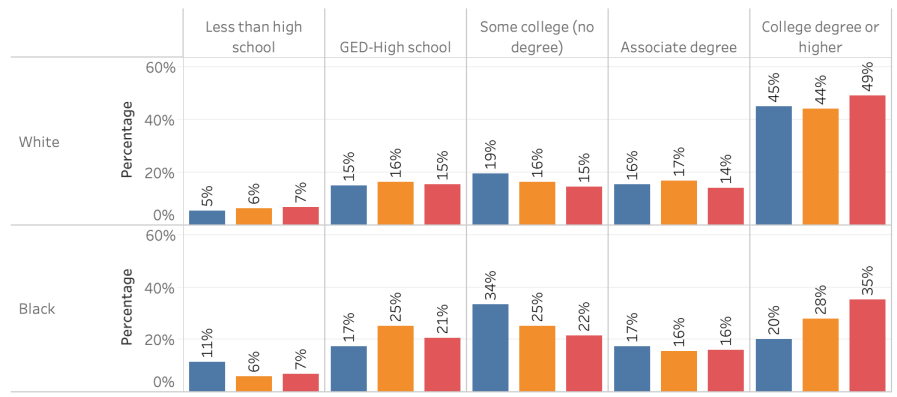


D. Food did not last before had money to get more

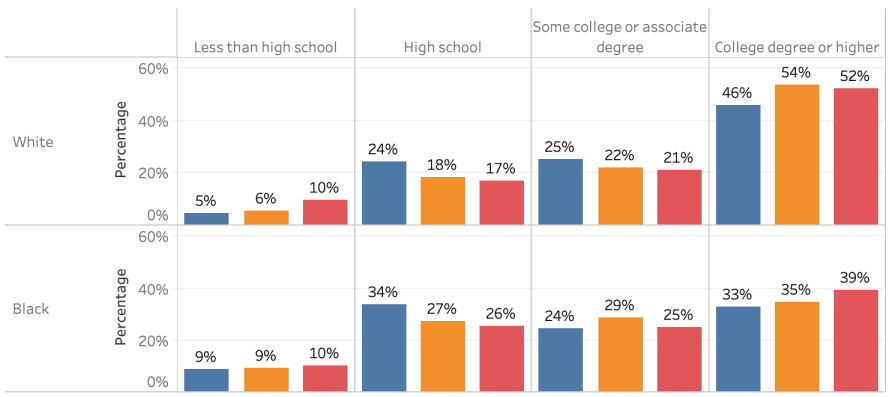


Household types  
■ Neuro disability ■ Other disease ■ Healthy

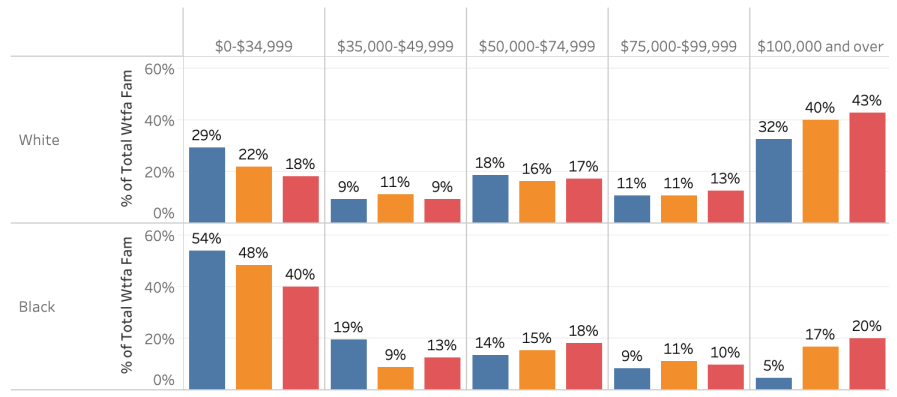
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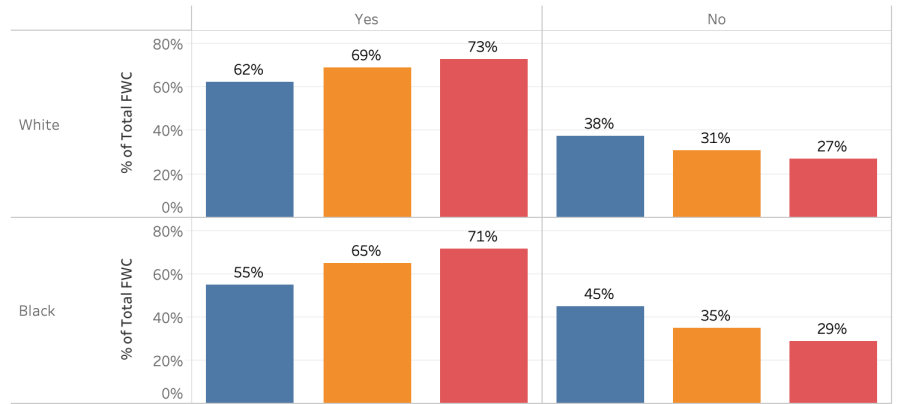
B. Highest educational level among reporting adults



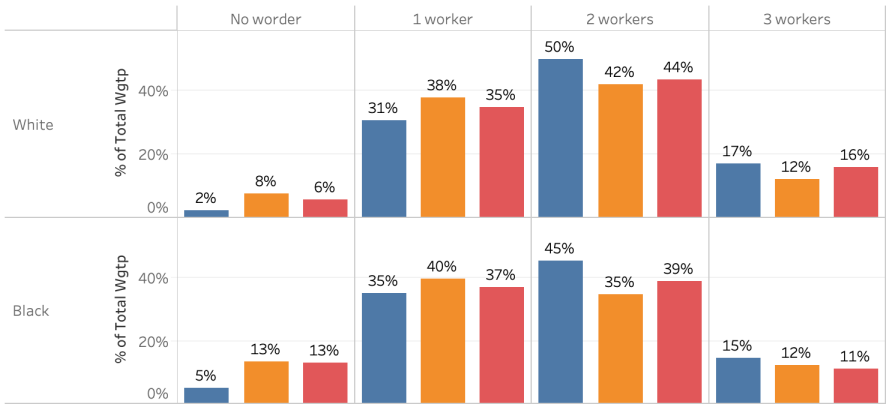
C. Total combined family income



E. Employment during the past year



F. Number of workers in the household last year



Epilepsy Research (2013) 103, 279–287

## Racial and socioeconomic disparities in epilepsy in the District of Columbia

Barbara L. Kroner<sup>a,\*</sup>, Mansour Fahimi<sup>b,1</sup>, Anne Kenyon<sup>c,2</sup>,  
David J. Thurman<sup>d</sup>, William D. Gaillard<sup>e,3</sup>

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

ORIGINAL ARTICLE

## The role of socio-economic status and perinatal factors in racial disparities in the risk of cerebral palsy

MAUREEN S DURKIN<sup>1,2,3</sup> | MATTHEW J MAENNER<sup>3,4</sup> | RUTH E BENEDICT<sup>3,5</sup> | KIM VAN NAARDEN BRAUN<sup>4</sup> |  
DEBORAH CHRISTENSEN<sup>4</sup> | RUSSELL S KIRBY<sup>6</sup> | MARTHA WINGATE<sup>7</sup> | MARSHALYN YEARGIN-ALLSOPP<sup>4</sup>

Many publications have commented on racial disparities in the prevalence or outcomes of various neurologic diagnoses. For example:

- Black Americans developed epilepsy at a 1.74 higher rate than Whites, when adjusted for age, education, and income (Kroner et al, 2013).
- Black children were reported to be 50% more likely to have a diagnosis of spastic cerebral palsy than White children (Durkin, et al, 2015).

This literature may promote the belief that there are biological differences associated with cultural constructs of "race", when they may actually illustrate that the *experience of racial injustice* is a significant element leading to the observed disparities in health outcomes in the US.




## Timing of the Diagnosis of Autism in African American Children

John N. Constantino, MD,<sup>a,\*</sup> Anna M. Abbacchi, MS,<sup>a,\*</sup> Celine Saulnier, PhD,<sup>b,c</sup> Cheryl Klaiman, PhD,<sup>b</sup> David S. Mandell, ScD,<sup>d</sup> Yi Zhang, MS,<sup>a</sup> Zoe Hawks, MA,<sup>a</sup> Julianna Bates, PhD,<sup>a</sup> Ami Klin, PhD,<sup>b</sup> Paul Shattuck, PhD,<sup>f</sup> Sophie Molholm, PhD,<sup>a</sup> Robert Fitzgerald, PhD,<sup>a</sup> Anne Roux, MPH,<sup>f</sup> Jennifer K. Lowe, PhD,<sup>g</sup> Daniel H. Geschwind, MD, PhD<sup>h</sup>

### RESEARCH ARTICLE

Autism Research 13: 464–473, 2020

## Disparities in Documented Diagnoses of Autism Spectrum Disorder Based on Demographic, Individual, and Service Factors

Lisa D. Wiggins , Maureen Durkin, Amy Esler , Li-Ching Lee, Walter Zahorodny, Catherine Rice, Marshalyn Yeargin-Allsopp, Nicole F. Dowling, Jennifer Hall-Lande, Michael J. Morrier , Deborah Christensen, Josephine Shenouda, and Jon Baio

Black children with neurologic disabilities may experience delays in diagnosis and service access. For example:

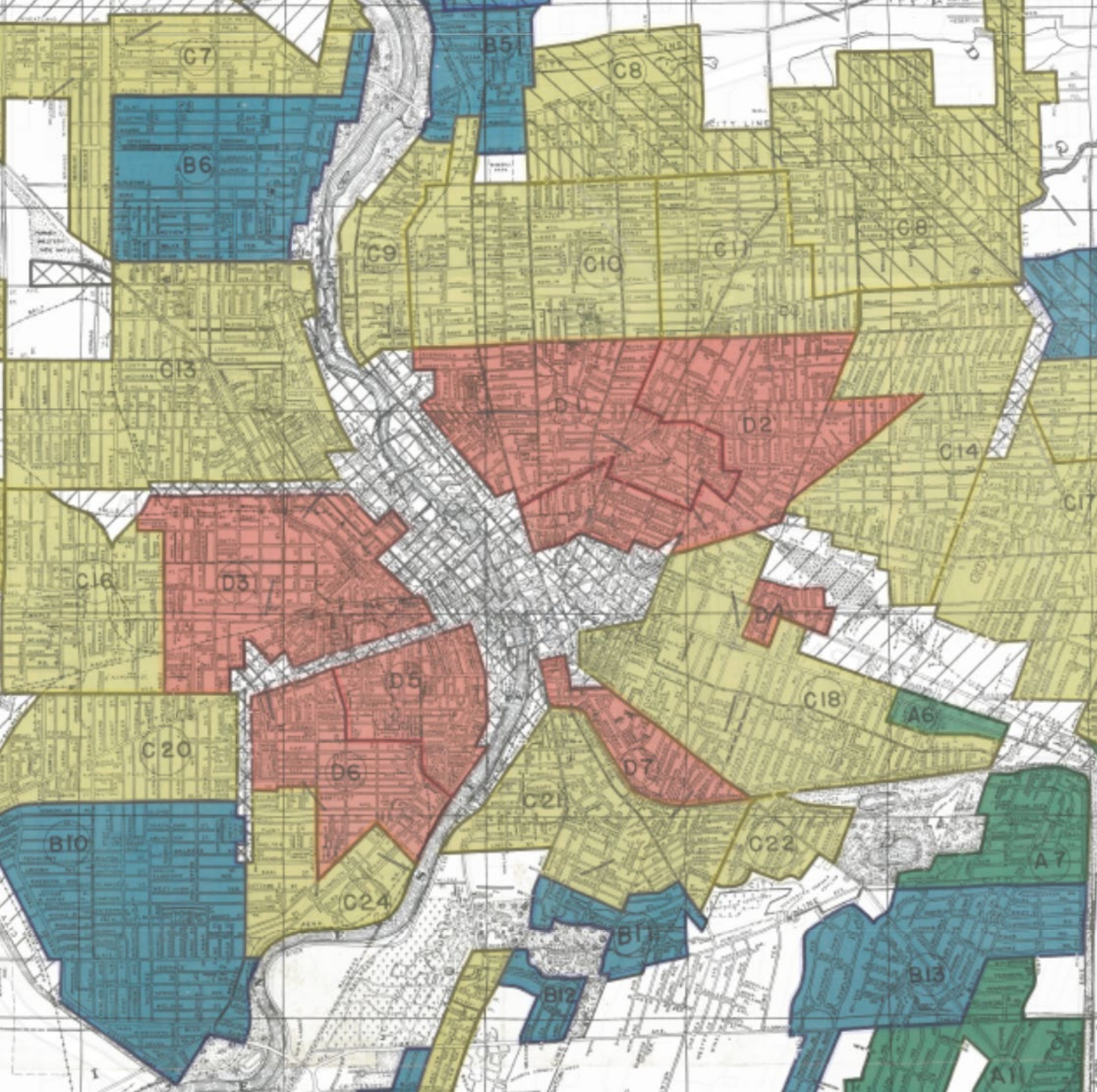
- Black children with autism were diagnosed on average 42.3 months after their parents' first reported concerns about their development (Constantino, et al, 2020)
- Factors associated with *not* having a diagnosis of autism spectrum disorder (despite meeting diagnostic criteria) include non-White race (Wiggins, et al, 2020).



**Jacob Lawrence *The Migration Series***

- The Great Migrations of Black Americans (1915-1930 and 1940-1970) from the rural south to industrialized northern cities associated with disproportionate relocation of White Americans to suburban neighborhoods, leaving decreased urban public spending with consequences on disparities in access to education, healthcare, and other public services that remain to this day (Boustan, 2007; Tabellini, 2018).
- Black Americans migrating to northern cities faced redlining, the practice of restricting lending in certain neighborhoods based on skin color, and restrictive covenants that prohibited sale or rental of property to members of certain groups, practices outlawed by the 1968 Fair Housing Act and the 1974 Equal Credit Opportunity Act (Boustan, 2013).





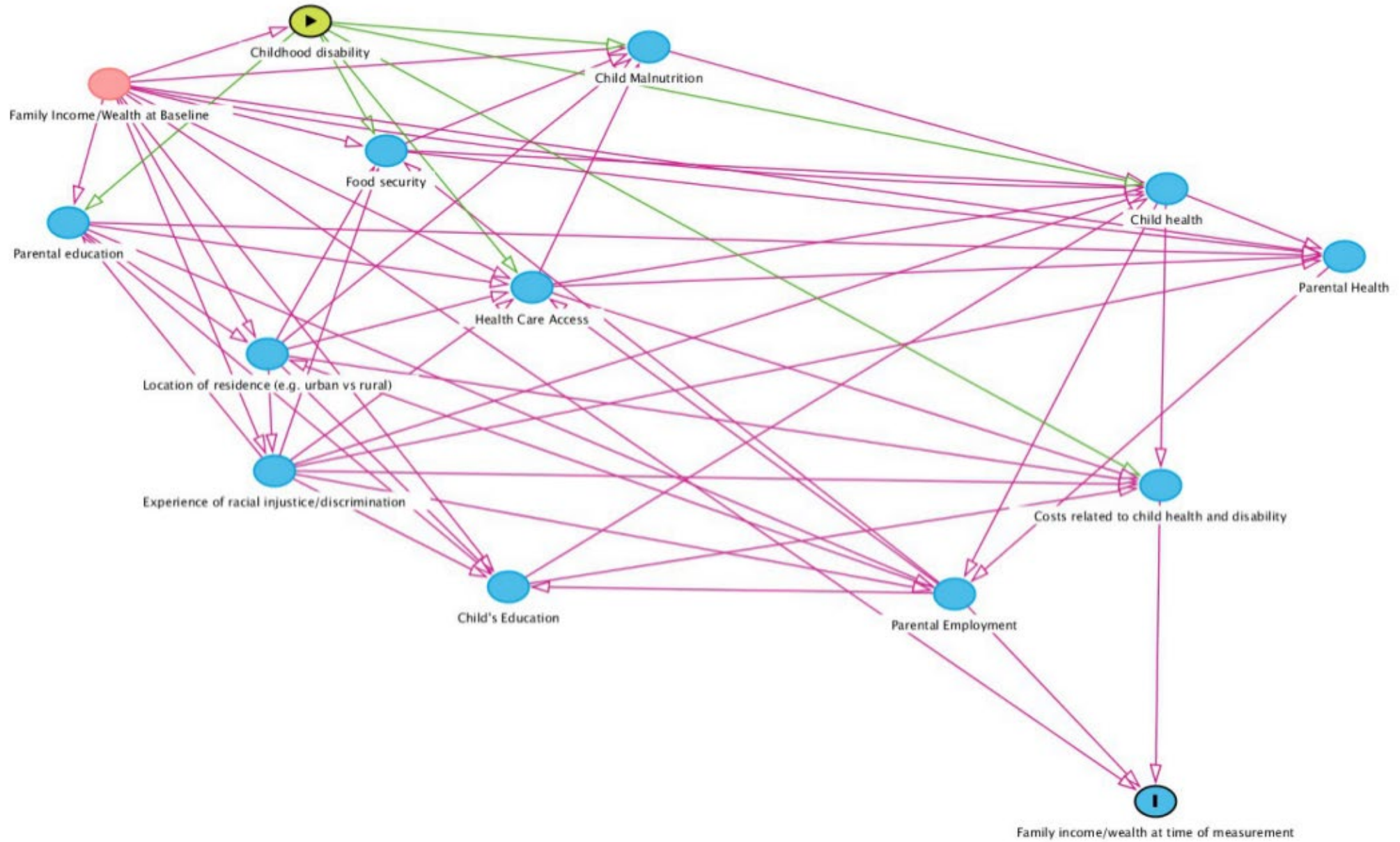
- Racial discrimination in housing persisted, for example through landlords being less likely to show units to Black applicants compared to White (Ondrich, et al, 1999), and mortgage applications from minority applicants being rejected at more than twice the rate as White applicants, even after net wealth and credit score are controlled (Munnell, et al, 1996).
- These practices reduced Black home ownership rates and house values, and increased racial segregation (Mitchell & Franco, 2018).

Rochester Home Owners' Loan Corporation  
"Residential Security Map"

- The effects on Black wealth have spanned generations such that by 2017, Black families' median and mean net worth was less than 15 percent that of White families (Board of Governors of the Federal Reserve System (U.S.) *et al.*, 2017).
- We found this experience with racial injustice to be either barely mentioned, or ignored altogether, in the existing literature on the economic outcome of families with children with disabilities.



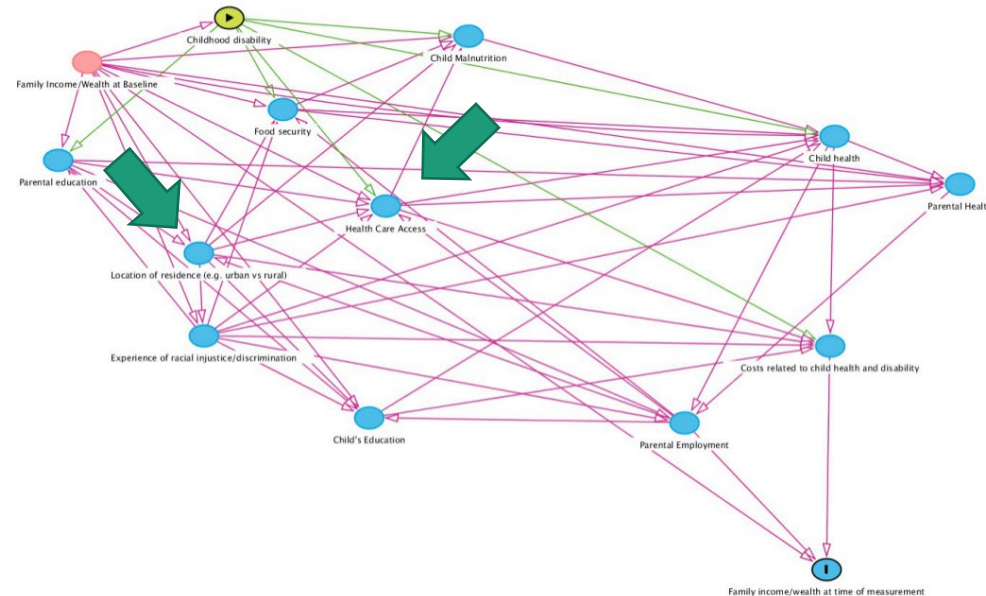
- The single long-running case-control study of the economic trajectory of families with children with disabilities noted, "approximately 79% of the *persistent poverty group* was non-white while 78% of the *persistent non-poverty group* was white", yet this factor was not mentioned further in their discussion (Rothwell, et al, 2019).



# Where do we go from here?

- Longitudinal data collection in upstate NY
- Families with and without children with IDD
- Goal of developing a predictive model: *which families raising children with IDD are at most risk of poverty?*

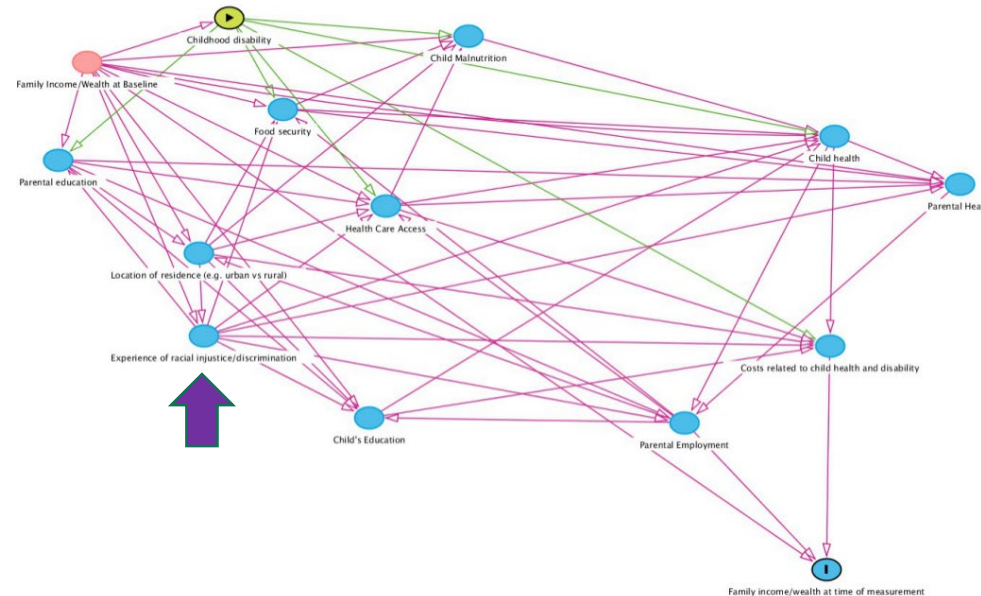
- What are the most highly connected nodes in this network?



# Where do we go from here?

- What effect do experiences of racial injustice have on the predictive model of risk?

- Is it possible to quantify the effects of racism?



# Conclusions

- Families raising a child with an IDD experienced:
  - Decreased parental employment
  - Decreased family income; total combined family income more likely to be <\$35,000 (33% vs 21%) and less likely to be >\$100,000 (27% vs 40%)
  - More likely to have started, but not completed college (22% vs 15%)
  - More likely to have food insecurity
- Black American families raising a child with an IDD experienced amplification of many of these challenges



Thank  
you!