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FOR SOCIAL POLICY
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Lurie Institute
for Disability Policy

Using the Disability Data Dashboards to Advance Policy and Advocacy



Community Living Equity Center
Centro para la Equidad en Vida Comunitaria

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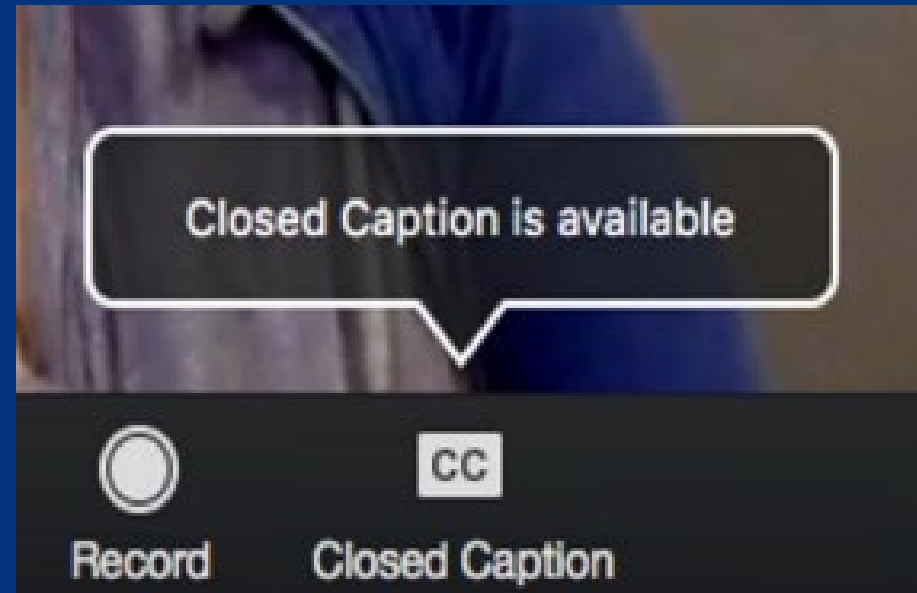
National Research Center for
Parents with Disabilities
Centro Nacional de Investigación para
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Accessibility

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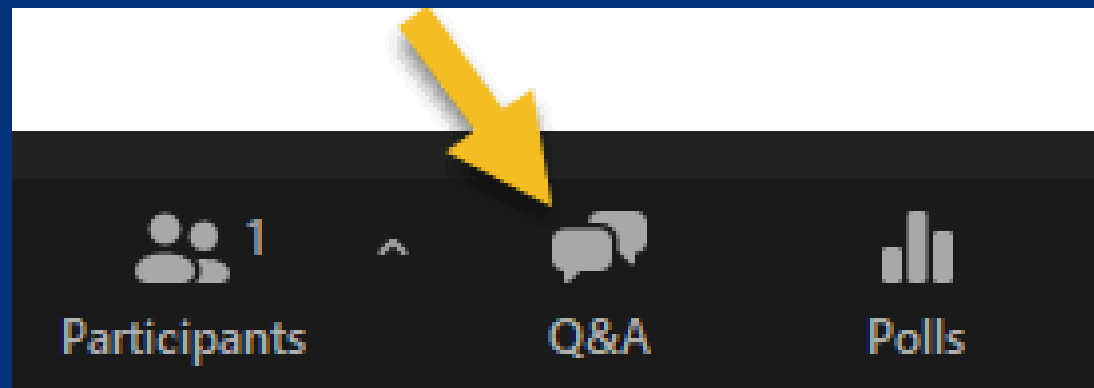
Zoom Closed Captions



Using the Q&A Function

Please use the Q&A function (not the Chat) to ask questions.

The Q&A function is usually located at the bottom of your Zoom webinar screen.



Funding Statement

The contents of this dashboard were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant numbers 90RTCP0006 & 90RTCP0009). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The content is solely the responsibility of the authors and does not necessarily represent the official views of NIDILRR, ACL, or HHS.

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Panelists



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Webinar Objectives

- Advance understanding of the data dashboard and its relevance to diverse stakeholders
- Develop skills to utilize the dashboard data within your organization and/or advocacy efforts
- Identify how the data dashboard can support the disability community, policymakers, advocates, and other stakeholders to advocate for data-driven responses for equity in policy making

Community Living Data Dashboard

- Provides advocates and policymakers with an understanding of who needs Long-Term Services and Supports (LTSS) and who receives Medicaid LTSS at state and national levels
- People with disabilities advised the development of the accessible and interactive dashboard at all phases of the design process
- Can apply filters to look at disparities (examples: by age and race)

Why is this dashboard important?

People with disabilities deserve to live independently and in the community

Aids advocacy for HCBS services

Assess unmet need and utilization

Anticipate expenditures / Aid in Equity Analysis



Why does this data matter?

- Prior research on racial disparities in LTSS has primarily focused on nursing homes or Medicare home health rather than HCBS, due in part to substantial variation in HCBS across states and limited data.
- Lack of data hinders the development of policies and interventions to address the institutional bias and improve access to HCBS.
- Data is essential for “rebalancing” efforts that allocate Medicaid LTSS funds and services away from institutionalized care and towards community-based settings.

Who is this data relevant to?

- Advocates/Families (disability and aging communities)
- Policymakers
- Researchers
- HCBS/LTSS Providers
- Public Health Workers
- Direct Care Workers
- Other stakeholders interested in LTSS need and utilization

How can the Community Living Data Dashboard be useful for advocacy?

- Identify specific populations for targeted policy interventions
- Understand how current policies or litigation may disproportionately affect certain populations by race/ethnicity, sex, or age
- Defend Medicaid by providing estimates of who receives LTSS
- Use the demographic information in the dashboard to tailor messaging to specific audiences
- Protect Medicaid Expansion by showing who needs LTSS, including highlighting the percentage of people above the federal poverty level

Where does the data on who needs LTSS come from?

Who Needs LTSS?

- American Community Survey ([ACS](#)), 2021 5-year sample
- Collected by U.S. Census Bureau
- Nationally representative sample of U.S. adults

How do we define LTSS Need using the American Community Survey data?

Someone is considered to have an LTSS need if they self-report one (or both) of the following types of disabilities:

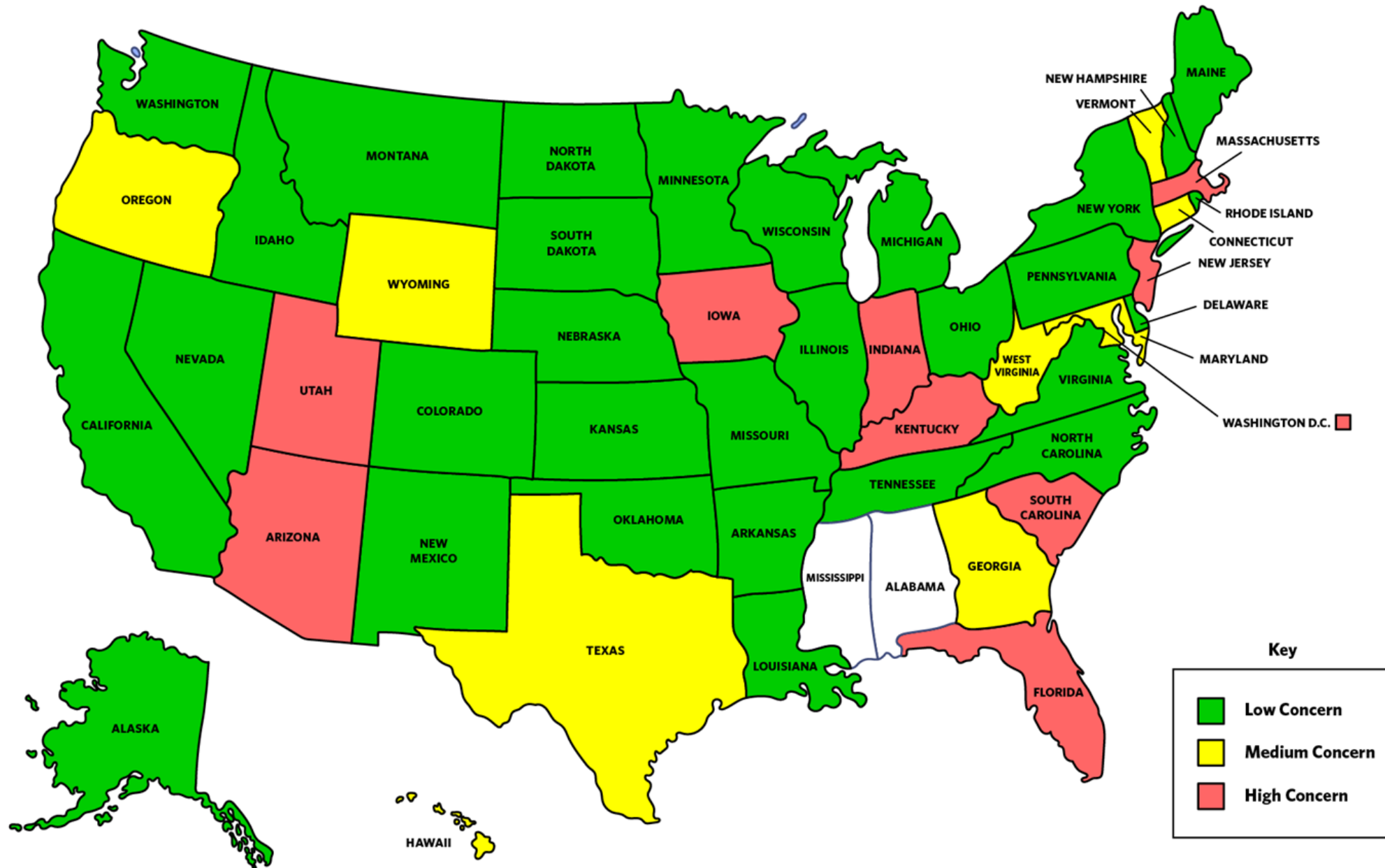
- **Self-care Disability**: Because of a physical, mental, or emotional condition lasting at least six months, the person has serious difficulty dressing or bathing.
- **Independent Living Disability**: Because of a physical, mental, or emotional condition lasting at least six months, the person has difficulty doing errands alone such as visiting a doctor's office or shopping.

Where does the data on who receives Medicaid LTSS come from?

Who Receives Medicaid LTSS?

- Transformed Medicaid Statistical Information System ([T-MSIS](#)), 2021
- State-reported Medicaid claims data
- Population of adult Medicaid beneficiaries

Race and Ethnicity Data Quality Assessment among Adults Receiving Medicaid HCBS



How do we define who receives Medicaid LTSS using the T-MSIS data? [CMS method]

Home and Community-Based Services (HCBS):

- Section 1915(c) Waiver, Section 1915(i) HCBS State Plan Option, Section 1915(j) Self-Directed Personal Assistance Services, Section 1915(k) Community First Choice, PACE, Personal Care Services, Home Health, Rehabilitation Services, Case Management, & Private Duty Nursing Services

Institutional LTSS:

- Nursing Facilities, Mental Health Facilities, & Intermediate Care Facilities for Individuals with Intellectual Disabilities

How many adults need LTSS versus how many adults receive Medicaid LTSS?

Who Needs LTSS?

- 17.6 million adults (6.8% of adult U.S. population)

Who Receives Medicaid LTSS?

- 6.4 million adults (10.7% of adult Medicaid beneficiaries)*

*Alabama and Mississippi are excluded due to data quality concerns.

Why is there a difference between who needs LTSS and who receives Medicaid LTSS?

- Not everyone who needs LTSS qualifies for Medicaid LTSS
- Some people receive LTSS through alternative sources:
 - Medicare (acute/post-acute care)
 - Private insurance
 - Out-of-pocket
 - Informal/unpaid
- Unmet LTSS needs

Community Living Data Dashboard Demonstration

[Link to the dashboard homepage](#)

Let's Connect!



Community Living Equity Center
Centro para la Equidad en Vida Comunitaria

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Disabled Parents Data Dashboard

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July 10, 2025

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National Research Center for
Parents with Disabilities

Centro Nacional de Investigación para
Padres con Discapacidades

National Research Center for Parents with Disabilities: About Us

The National Research Center for Parents with Disabilities is a cross-disability initiative guided by the ethos of the disability community, “**nothing about us without us.**” Through trainings, research, and advocacy, the Center provides information and support for parents with disabilities and their families. The Center is part of the Lurie Institute for Disability Policy at Brandeis University, and is supported by the National Institute for Disability, Independent Living and Rehabilitation Research.

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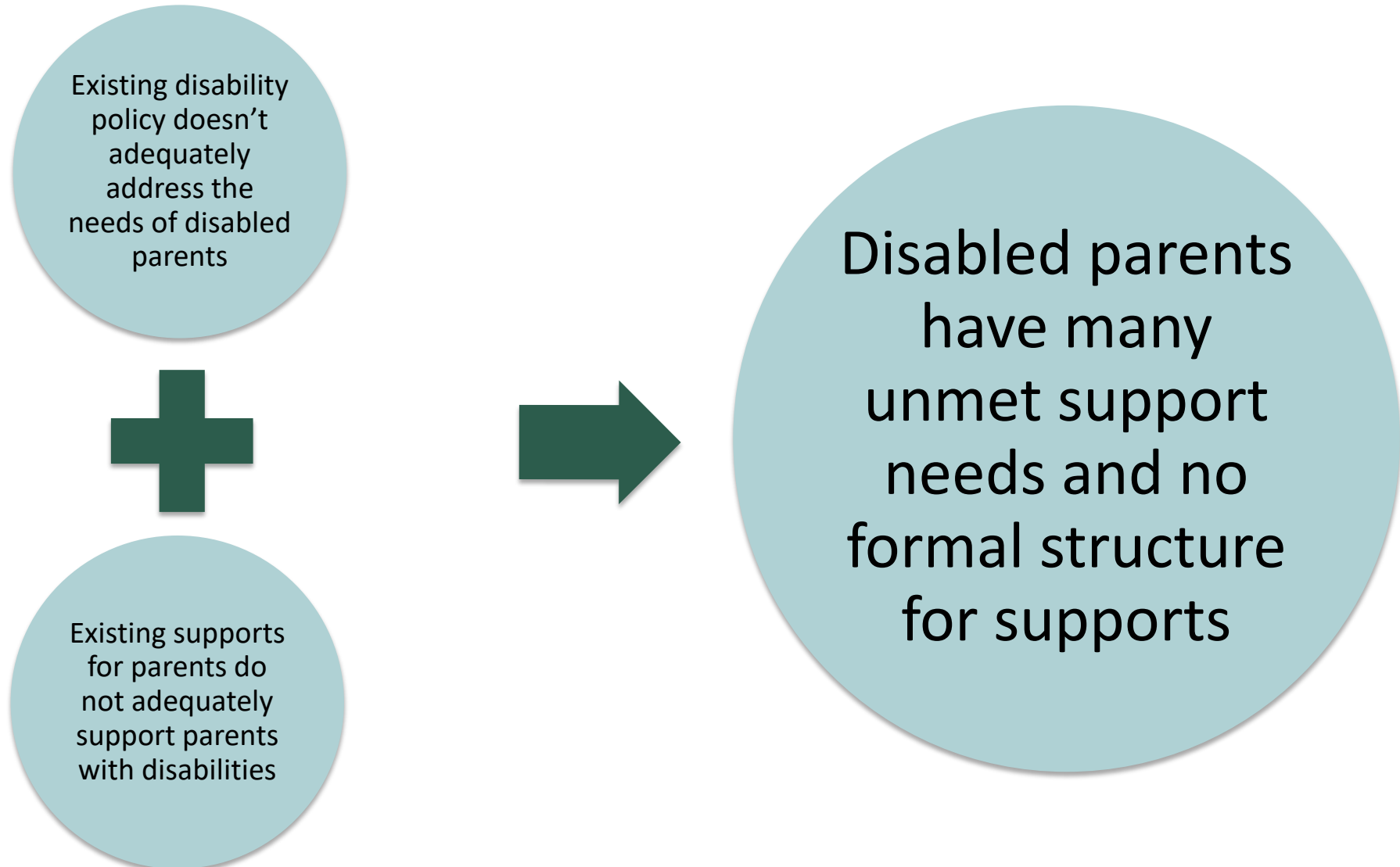
Who are Disabled Parents?

- About 1 in 10 children in the US have a parent with a disability.
- Disabled women have children at about the same rate as non-disabled women.
- Disabled parents are more likely to report health disparities and socioeconomic disparity such as housing, food, and economic insecurity.¹
- Disabled parents are more likely to have child welfare involvement, and more likely to experience TPR than non-disabled people.



1. Sonik, R., Parish, S., Mitra, M., and Nicholson, J. (2018). Parents with and without disabilities: Demographics, material hardship, and program participation. *Review of Disability Studies*, 14(9), 1–20.

The Problem



Disabled Parents Data Dashboard: Purpose

- To address this gap, and to learn more about parents with disabilities we need data
- Data can be difficult to access and interpret
- The dashboard provides information about disabled parents and can be sorted by:
 - » State
 - » Disability type
 - » Sex
 - » Poverty status

Disabled Parents Data Dashboard: Data Source

- The American Community Survey (ACS) collected by the United States Census Bureau
 - Largest and most comprehensive survey in the US
 - ACS typically samples ~ 3 million people every year
 - 2018–2022 5-year sample, which pools and weights data from 15 million people sampled to represent a five-year average, to improve the reliability of data and allow drilling down by state

Disabled Parents Data Dashboard: Disability Measure

- The ACS measures disability using a set of 6 yes/no questions.
- Respondents answering yes to more than one category are classified as having multiple disabilities by the ACS.

Disabled Parents Data Dashboard: Disability Measure Questions

The questions:

1. Are you deaf, or do you have serious difficulty hearing? (hearing)
2. Are you blind, or do you have serious difficulty seeing, even when wearing glasses? (vision)
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (cognitive)
4. Do you have serious difficulty walking or climbing stairs? (physical)
5. Do you have difficulty dressing or bathing? (self-care)
6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (independent living)

Disabled Parents Data Dashboard: Parental Status Measure

- Parental status:
 - Any person aged 18 years or older co-residing with a child(ren) under 18 years in the household.
 - We assigned minor children under 18 to parents/caretakers by the following order of priority:
 - » mothers or fathers
 - » grandparents
 - » the oldest adult in the family unit
 - » the oldest adult in the household

Disabled Parents Data Dashboard: Parental Status Measure (cont'd)

- Individuals aged 18+ were classified as a parent (or caregiver) if they were assigned a minor child(ren) under 18 based on our order of priority.
- Spouses or partners of any identified parents/caregivers were also assigned the same status and are presumed to jointly share responsibility for the minor(s) assigned to either adult.
- **Limitation: This methodology does not capture parents not co-residing with children under 18.**

Data Dashboard Use Cases

- Disability organizations planning outreach/programming implementation for disabled parents
- MCH program tailoring for parents with disabilities
- HCBS advocacy for disabled parents

Disabled Parents Data Dashboard Demonstration

Learn More/Contact Us



[@disabilityparentscenter](#)
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