

We create opportunities for independence for people with disabilities through research, education, and consultation







#### Disability, Diversity, and Intersectionality: Data Mining and Community Mapping to Address Diversity

January 16, 2019

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IL-NET is a project of Independent Living Research Utilization (ILRU) in partnership with the National Council on Independent Living (NCIL), the Association of Programs for Rural Independent Living (APRIL), and Utah State University Center for Persons with Disabilities (USU-CPD)



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Visit the ILRU Disability, Diversity, and Intersectionality in CILs website at CIL-diversity.org to find the nine CIL case studies and other information gathered from this project.



#### What You Will Learn Today



- The nature and value of disability statistics relevant to centers' goals and priorities around issues of diversity and inclusion.
- How to find and gauge the quality of data sources that can provide centers with relevant local data.
- Ways to analyze data when Centers cannot find the community-level information they are seeking.
- Strategies that broaden centers' scope and use of data through shared examples that include key areas such as education, employment, transportation, health care access, and housing.



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### **Presentation Outline**

- University of New Hampshire (UNH)
  - Describe data availability, measurement, examples.
- Center for Independence of the Disabled, New York (CIDNY)
  - Describe how they have used disability statistics to answer questions of local interest.
- Together
  - Think about how to identify your unique data needs.
  - Where to turn for answers.

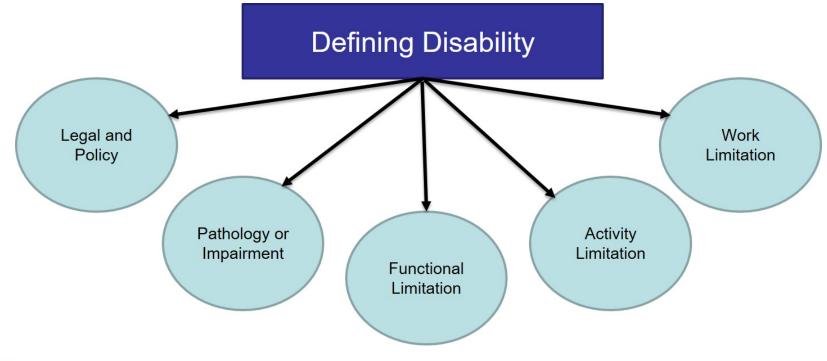


# What data exist on disability? How is disability measured?



• National datasets

We will discuss several major national datasets that capture disability status, how to access these, and what local-level data may be available from each.



## **Measuring disability: Policy definitions**



#### **Social Security**

"Inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months."

Prevalence Rate: 4% of those under age 65

#### Workers' Compensation:

"Incapacity because of injury to earn the wages which the employee was receiving at the time of injury in the same or any other employment; ...term shall mean permanent impairment, determined ...by the American Medical Association."

#### **VA** definition

"Disabled veteran" means an individual who has served on active duty in the armed forces, has been separated there from under honorable conditions, and has established the present existence of a service-connected disability or is receiving compensation, disability retirement benefits, or pension because of a public statute administered by the Department of Veterans Affairs or a military department

Prevalence rate: 16% of all veterans

Americans with Disabilities Act "A physical or mental impairment that substantially limits one or more of the major life activities, a record of such an impairment, or being regarded as having such an impairment." (same definition applies to Vocational Rehab Act)

Prevalence Rate: 20%



# Measuring Disability: Pathology and Impairment methods

• The presence of a condition or medical diagnosis

#### Pros

 An impairment-based definition is less likely influenced by changes in the environment and government policy.

#### Cons

- Relies on a medical model of defining disability; ignores presence of social & environmental barriers.
- Misses some we might want to count; includes some we might not.



# Measuring Disability: Activity Limitation (and work limitation)

"Does anyone in this household have a health problem or disability which prevents them from working or which limits the kind or amount of work they can do?" (Current Population Survey)

#### Pros

- Can inform you about disability benefits receipt (SSDI, DI, Workers Compensation).
- Useful if your interest is in access to work or certain activities.
- Data dating to 1981 on the CPS if trend data are useful to you.

#### Cons

- Not all persons with a disability report a work limitation.
- Not relevant to children, older adults.



## Measuring Disability: Functional Limitations

## Six standardized questions to identify people with disabilities in national surveys

Vision: (all ages)

Are you blind or do you have serious difficulty seeing, even when wearing glasses?

Hearing: (all ages)

Are you deaf or do you have serious difficulty hearing?

Ambulatory: (ages 5+)

Do you have serious difficulty walking or climbing stairs?



## **Measuring Disability: Functional Limitations**, / cont'd.

## Six standardized questions to identify people with disabilities in national surveys

#### Cognitive: (ages 5+)

Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

Self-care: (ages 5+)

Do you have difficulty dressing or bathing?

Independent living: (ages 15+)

Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?





## Which definition to use?

- Considerations:
  - What definition informs your work?
  - Balance pros & cons mentioned.
  - More importantly... what data are available using these definitions? How easy (or difficult) are these data to access?



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#### **Overview of major disability data sources**

- American Community Survey (ACS)
- Behavioral Risk Factor Surveillance System (BRFSS)

These surveys use the 6-question sequence to measure disability. (Some have additional questions on disability.) Each one has:

- Different questions of substantive interest.
- Nationally-representative (and some locally-representative) data.
- Publications about disability from the collecting agency.
- A table generation or data extraction system for users to get data.



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#### **American Community Survey (ACS)**

- Conducted by the U.S. Census Bureau, it can be thought of as a regular, annual population estimate that fills in the gaps between decennial censuses.
- ACS data is useful because you can find current data for a variety of geographies.
- There are 1-year estimates for large geographies and 5-year pooled estimates for smaller geographies
  - Which should you use?



## American Community Survey (ACS) cont'd.

#### 1-year estimates

- 12 months of data (Jan-Dec 2017 data available since Oct. 2018)
- Data for large geographies (population of 65,000+)
- Least precise; most current
- Use if you have a large geographic area and want only the most recent data

#### 5-year estimates

- Pool 60 months of data
- Data for smaller geographies (Block groups, Census Tracts, Zip Code Areas, State Legislative Districts)
- Most precise; least current
- Use if you have a small geographic area

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## Using the Census Bureau's FactFinder (ACS) / ilr



#### **Popular Tables**

Population and Housing

- Annual Population Estimates (2017 PEP, PEPANNRES)
- Demographic and Housing Estimates (2016 ACS, DP05)
- General Housing Characteristics (2016 ACS, DP04)
- General Demographic Characteristics (2010 Census, DP-1)

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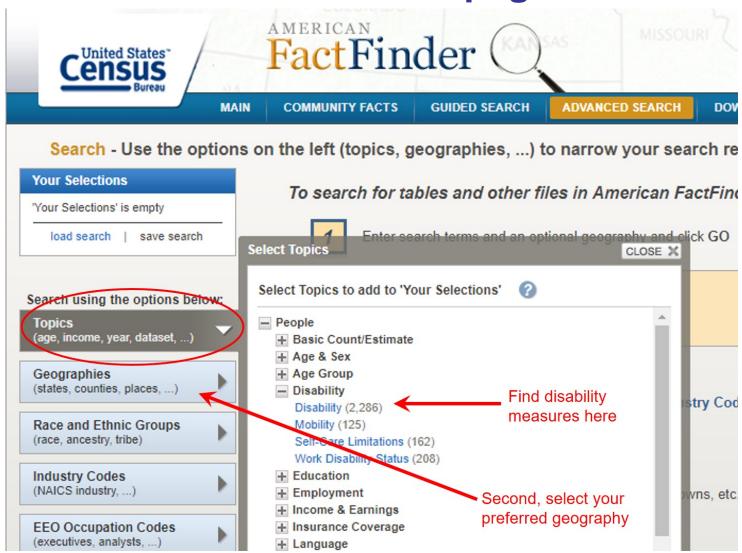
General Economic Characteristics (2016 ACS, DP03)

Age, Race, Sex and Education

- Selected Social Characteristics (2016 ACS, DP02)
- Educational Attainment (2046 ACC \$4504)

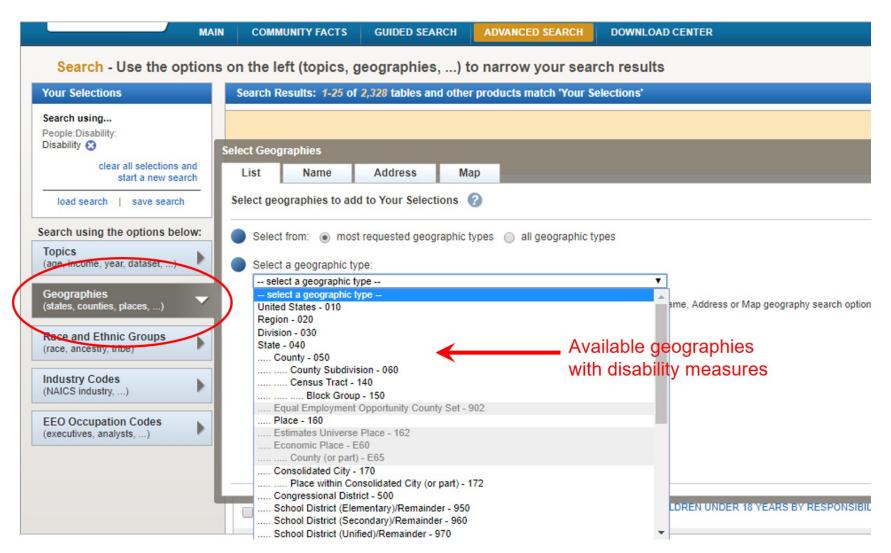
### **Screenshot FactFinder Webpage**





#### **Screenshot Search**





#### **Screenshot Search Results**



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	DP02	* SELECTED SOCIAL CHARACTERISTICS IN	THE UNITED STATES		2017 ACS 5-y estimates	year	0
	B18120	* EMPLOYMENT STATUS BY DISABILITY STA	TUS AND TYPE		2013 ACS 3-y estimates	/ear	0
	S1810	DISABILITY CHARACTERISTICS			2017 ACS 1-) estimates	/ear	0
	S1811	SELECTED ECONOMIC CHARACTERISTICS FOR	R THE CIVILIAN NONINSTITUTIONAL		2017 ACS 5-y estimates	/ear	0
	B10052	DISABILITY STATUS OF GRANDPARENTS LIVIN GRANDCHILDREN AND AGE OF GRANDPARENT		7	2017 ACS 1-y estimates	/ear	0
	B18101	SEX BY AGE BY DISABILITY STATUS			2017 ACS 5-y estimates	/ear	0
	B18101A	AGE BY DISABILITY STATUS (WHITE ALONE)			2017 ACS 1-) estimates	year	0
	B18101B	AGE BY DISABILITY STATUS (BLACK OR AFRICA	AN AMERICAN ALONE)		2017 ACS 1-y estimates	/ear	0
	B18101C	AGE BY DISABILITY STATUS (AMERICAN INDIA)			20 TACS 5	ear	6

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#### **Screenshot Disability Characteristics**



DISABILITY CHARACTERISTICS

2013-2017 American Community Survey 5-Year Estimates

 Table View
 Image: Create a Map

 Actions:
 Image: Modify Table
 Image: Add/Remove Geographies
 Image: Bookmark/Save
 Image: Print
 Image: Download
 Image: Create a Map

 This table is displayed with default geographies.
 Image: Operation of the second seco

Click Back to Search to select other geographies using the search options on the left.

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Although the American Community Survey (ACS) produces population, demographic and housing unit estimates, it is the Census Bureau's Population Estimates Program that produces an states, counties, cities, and towns and estimates of housing units for states and counties.

Versions of this table are available for the following years: 2017 2016 2015 2014 2013 2012

S1810

	United States						
	Total		With a disability		Percent with a disability		
Subject	Estimate	Margin of Error	Estimate	Margin of Error	Estimate	Margin of Error	
Total civilian noninstitutionalized population	316,027,641	+/-10,148	39,792,082	+/-62,060	12.6%	+/-0.1	
SEX							
Male	154,419,680	+/-11,041	19,232,246	+/-37,555	12.5%	+/-0.1	
Female	161,607,961	+/-9,022	20,559,836	+/-33,896	12.7%	+/-0.1	
RACE AND HISPANIC OR LATINO ORIGIN							
White alone	231,161,656	+/-56,265	30,257,521	+/-72,726	13.1%	+/-0.1	
Black or African American alone	39,358,184	+/-29,886	5,501,213	+/-18,465	14.0%	+/-0.1	
American Indian and Alaska Native alone	2,567,883	+/-14,413	432,020	+/-3,846	16.8%	+/-0.2	
Asian alone	17,102,024	+/-20,054	1,196,067	+/-7,320	7.0%	+/-0.1	
Native Hawaiian and Other Pacific Islander alone	556,875	+/-4,889	59,209	+/-1,859	10.6%	+/-0.3	
Some other race alone	15,364,254	+/-90,299	1,254,798	+/-9,460	8.2%	+/-0.1	
Two or more races	9,916,765	+/-88,367	1,091,254	+/-10,896	11.0%	+/-0.1	
White alone, not Hispanic or Latino	194,531,839	+/-11,442	26,973,726	+/-78,265	13.9%	+/-0.1	
Hispanic or Latino (of any race)	55,779,365	+/-4,862	4,951,747	+/-18,812	8.9%	+/-0.1	
AGE							
Under 5 years	19,852,138	+/-3,862	150,682	+/-3,272	0.8%	+/-0.1	
5 to 17 years	53 611 721	+/-5 789	2 903 877	+/-14 437	5 4%	+/-0 1	



# Behavioral Risk Factor Surveillance System (Ird) (BRFSS)

- Centers for Disease Control (CDC) survey
- Each state has a data coordinator and may have reports relevant to your agency's work: <u>https://www.cdc.gov/brfss/state\_info/brfss\_use\_example</u> s.htm

### **BRFSS – Table Generation**



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C https://www.cdc.gov/brfss/data\_tools.htm

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Centers for Disease Control and Prevention CDC 24/7: Saving Lives, Protecting People™

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#### Behavioral Risk Factor Surveillance System

BRFSS					
About BRFSS	+				
Prevalence Data and Data Analysis Tools					
Survey Data and Documentation	+				
Questionnaires					
Publications and Resources	+				
State Information	+				
Fact Sheets					

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about this page, enter your



CDC > BRFSS > Prevalence Data and Data Analysis Tools

Prevalence Data & Data Analysis Tools

Find city and county data collected through the Selected Metropolitan/Micropolitan Are (SMART) project, the Web Enabled Analysis Tool (WEAT), interactive maps, and other re through BRFSS.

PREVALENCE AND TRENDS DATA

Using the Prevalence and Trends Data Tools, users may produce charts for individual states or the nation by health topic. Users may select specific years or request multiple year data. The Prevalence and Trend

#### SMART: CITY AND COUNTY DATA

Selected Metropolitan/Micropolitan Area Risk (SMART) is an ongoing project that uses BRFSS produce some local area estimates. Counties ar

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#### **BRFSS: Table Generation**



#### https://www.cdc.gov/brfss/data\_tools.htm

#### PREVALENCE AND TRENDS DATA

Using the Prevalence and Trends Data Tools, users may produce charts for individual states or the nation by health topic. Users may select specific years or request multiple year data. The Prevalence and Trend Data Tools will produce line graphs for multiple years and bar charts for single years for each selected indicator.

#### WEB ENABLED ANALYSIS TOOL (WEAT)

The Web Enables Analysis Tool (WEAT) permits users to create custom crosstabulation tables for health indicators within selected states. Up to two control variables may be included to create crosstab tables within each category of control variables. WEAT also may be used to create logistic equations using BRFSS data. Users are prompted to make selections of year, state and variables to be included in the analyses.

#### MMWR SURVEILLANCE BY YEAR

Each year the BRFSS publishes prevalence estimates in the Morbidity



#### SMART: CITY AND COUNTY DATA

Selected Metropolitan/Micropolitan Area Risk Trends (SMART) is an ongoing project that uses BRFSS data to produce some local area estimates. Counties and Metropolitan/Micropolitan Areas (MMSAs) were selected for SMART if there were 500 or more respondents BRFSS combined landline and cell phone data for any year.

#### CHRONIC DISEASE INDICATORS (CDI)

The Chronic Disease Indicators Tool allows users to select two or more geographic areas such as states,

Metropolitan/Micropolitan Areas (MMSAs), or regions within states. The tool then creates a table illustrating differences on user selected health indicators by geographic area. Chronic conditions and health risk behaviors may be selected for inclusion in customized tables.

#### WORKER HEALTH CHARTS



#### **Other Data Sources**

- Other data sources contain state- and local-level estimates of disability but may not have a user-friendly table generation system
  - Examples: Current Population Survey (CPS) and Survey of Income and Program Participation (SIPP)



## **Current Population Survey (CPS)**



- Conducted by the Census Bureau on behalf of the Bureau of Labor Statistics.
- Claim to fame: Provides us with the monthly unemployment rate.
- A monthly survey of approximately 100,000 households.
- The March Supplement, known as the Annual Social and Economic Supplement (ASEC) includes disability data.
- March CPS is the primary source of poverty and health insurance information.
- CPS data are used extensively by government agencies, researchers, policy makers, and journalists to evaluate employment, government programs, and the economic well-being of the population in the U.S.



# Survey of Income and Program Participation (SIPP)



- U.S. Census Bureau survey
- Longitudinal (re-interviews same people for 3 to 5 years)
- Focus is on estimating
  - 1) annual and sub-annual income dynamics;
  - 2) movements into and out of government transfer programs;
  - 3) family and social context of individuals and households; and
  - 4) interactions among these items.
- Disability is measured using the six disability questions from the ACS as well as three additional questions related to child disability, and three additional questions related to work disability.

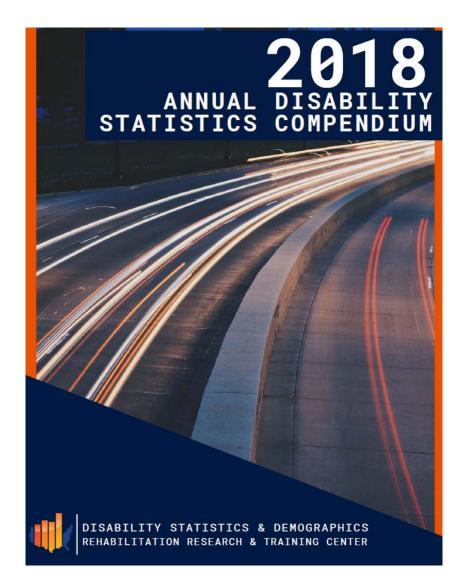
Source: https://www.census.gov/topics/health/disability/guidance/data-collection-sipp.html





### Where to find this data? Options

- Annual Disability Statistics Compendium (report and event) is a good guide to existing data in summary form
- State-level reports will also be available (newly updated each year)
- <u>disabilitycompendium.org</u>
  February 12-13, 2019 online or in-person in Washington, DC





### Where to find this data? Options, cont'd.

- Published reports
  - UNH Institute on Disability Annual Disability Statistics Compendium <u>disabilitycompendium.org</u>
  - Data collection agency reports on disability:
  - ACS: <u>https://www.census.gov/topics/health/disability/library/publications/acs-disability-publications.html</u>
  - CPS: <u>https://www.census.gov/topics/health/disability/library/publications/cps-</u> <u>disability-publications.html</u>
  - SIPP:<u>https://www.census.gov/topics/health/disability/library/publications/sipp-disability-publications.html</u>

BRFSS State-level fact sheets <u>https://www.cdc.gov/brfss/factsheets/index.htm</u>

- Look it up yourself using the tools mentioned
- Request technical assistance



#### Which dataset to use?



When locating data yourself, here are some things to keep in mind:

- <u>Who is reporting</u>: All national data sets rely on self-reports of representative samples.
- <u>Who is included</u>: Some samples include only non-institutionalized residents; some include group quarters.
- <u>What definition of disability</u>: The surveys presented here all use the 6question sequence on functional limitations, but some have additional measures.
- <u>Information you want</u>: What do you want to know about people with disabilities? Employment, health, poverty, benefits receipt?
- <u>Geographic availability</u>: Some data permit local-level (state/county/metro area) analyses, but not all.
- <u>Examining trends</u>: Some of the disability and/or outcome measures may change over time in each survey this needs to be understood.



#### **Questions & Discussion**

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## Disability, Diversity and Intersectionality Data Mining **ilru** and Community Mapping to Address Diversity

We believe our mission includes a mandate to remove barriers that are embedded in law, policy, structure, and practice; and it is these barriers that result in disparities for people with disabilities, which are much more extreme depending on your race and ethnicity.

~ Susan Dooha, Executive Director Center for Independence of the Disabled, New York (Manhattan & Queens)





### Center for Independence of the Disabled, New York (CIDNY)

- CIDNY is celebrating its 40th Anniversary!
- New York and Queens counties—serve people citywide;
- 75% of staff are Black, Latinx/Hispanic, Asian American.
- 58% are bilingual/bicultural and speak 26 languages.
- Speak 10 of the top 12 languages in the City.



# Why are disability statistics so important to **ilru** our work?

- Help to identify and serve *all* people with disabilities in an *equally effective* way.
- Improve our own understanding and reflect the needs and concerns of the whole community in our work.
- Better identify issues related to education, employment, poverty, health, housing, transportation, and food...



## Why are disability statistics so important to / our work? cont'd.

- Remove barriers that cause worse outcomes for people due to a "double burden" of discrimination based on disability and race/ethnicity.
- Help identify and eliminate disparities like graduation rate gaps, income gaps, health outcome gaps, for example.
- Communicate with the public, policy makers and funders in a more effective way.



#### How did we get started with data mining and community mapping? (We'd never done research before)

- 2001 report showed that Asian Americans were being underserved by VR or ILCs.
- We conducted focus groups, case reviews, and key informant interviews with community members.
- We asked about key barriers to getting help:
  - Need for language competent staff
  - Materials in translation
  - Knowledgeable counselors placed at familiar organizations
  - Help knowing about programs and navigating them

Percentage of Asian Americans working with CIDNY has grown from 3% in 2002 to 16% in 2018 (prevalence rate in NYC is 14%).



# What did we do since then that made a difference?



- Talked with community groups in the areas targeted.
- With their go-ahead, put our bilingual ILC staff at their agencies to help.
- Created a language access policy, got a translator and language line.
- Translated materials.







# What did we do since then that made a difference? cont'd.

- Advertised in local papers targeting Asian American populations.
- Invited reporters from community to talk to our bilingual staff at an event focused on community needs and access (curb cuts).
- Visited local elected officials and shared our resources with constituent office workers.
- Came to coalition meetings, listened and joined in.

Lunar New Year Celebration at CIDNY Queens office with Local Asian-American Advocates





# What happened next to increase our data literacy?



- 2005-2007 data desert—no access to comprehensive data on our local communities.
- 2008 disability employment expert joined our Board.
- 2009 Wanted to educate electeds re: intersection of race/ethnicity and disability and critical issues.
- 2010 our Board member introduced us to UNH.

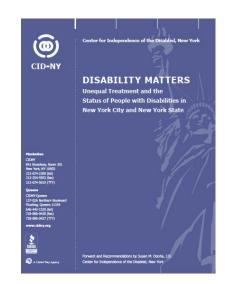
### – THEY HELPED US FOR FREE!

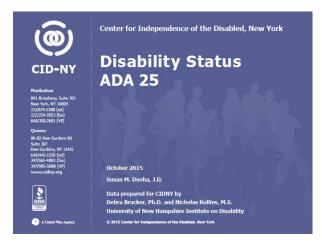


# What happened next to increase our data literacy? cont'd.



- Used data collected to create and publish reports on disability status in New York
  - 2011 "Disability Matters..."
  - 2014-2015 "The ADA at 25"
  - 2016-2018 "Untitled report..."







# How do we look at our community now? On a map!

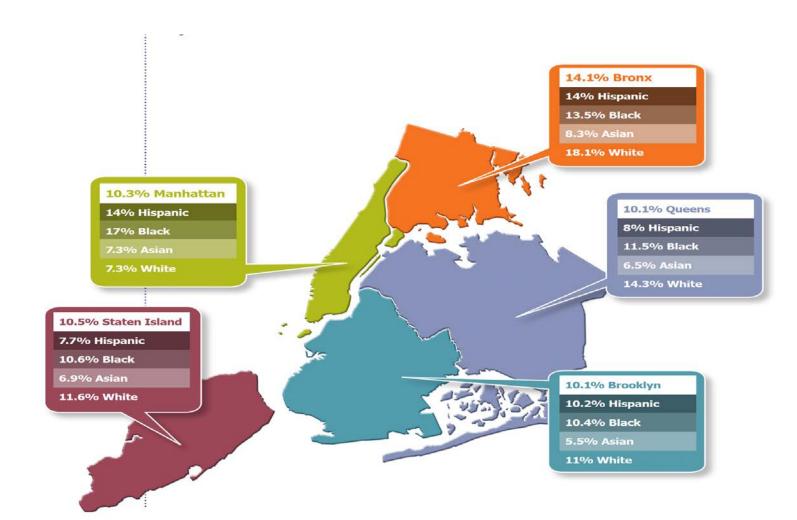
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We ask for federal, state, city, county, and zip code data:

- Disabilities, age, gender, race/ethnicity
- "Key indicators of well-being" including education, employment, poverty, health, housing, transportation, family status, and food.
- Use Google Maps to show where the people we serve are living in comparison to data we receive.
- Find "Geographic Information Mapping System" assistance with mapping the data to *show* the data.
- Provide information to staff for outreach, etc.



### How do we look at our community now? On a map! cont'd.



# How do we use data to help target resources? Ird Hurricane Sandy and "disaster food stamps!"

After Hurricane Sandy hit NYC data helped:

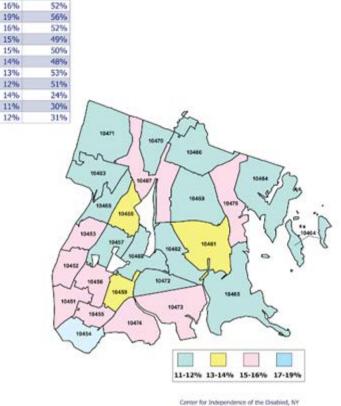
- We wanted to direct disaster food resources to people with disabilities in hurricane zones in Queens.
- People with SSI/SSDI were eligible.
- We used zip codes, names of neighborhoods, SSA population in those neighborhoods, and languages spoken.
- We took information to disaster response planners and asked them to target the neighborhoods with translated materials and resources.
- We partnered with other groups to get translated information about disaster food stamps to people that needed it.

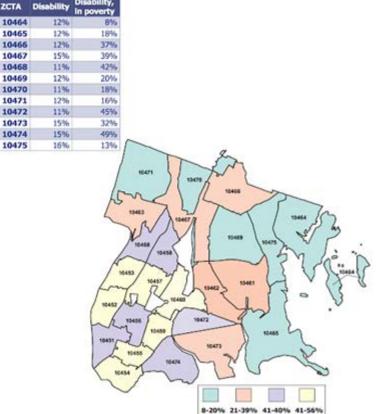


How do we use data to help target resources to Black, Hispanic/Latinx, and Asian American communities? Helping NYC relief agencies understand where we were during and after Hurricane Sandy.









Center for Independence of the Disabled, NY

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#### How do we use data to help target resources? New York Connects program outreach campaign.



- NY Connects outreach specialist used zip code lists and maps to show areas with the highest number of people with disabilities.
- Used Google Maps to search for community organizations using the "nearby" function.
- Targeted smaller groups that serve poor areas with higher rates of PWD who are Black, Hispanic/Latinx, Asian American.
- Organizations contact information popped up on Google maps.
- Example: Local AME Church with a soup kitchen and food pantry.
- Presented at the organization which now refers to our program.
- Numbers of referrals obtained through this method has shown us the effectiveness of the approach.



# Using data to affect policy



CIDNY uses research data in litigation, settlement talks and monitoring on issues that affect all people with disabilities, but particularly people with disabilities who are Black, Hispanic/Latinx, Asian American Communities.

Examples:

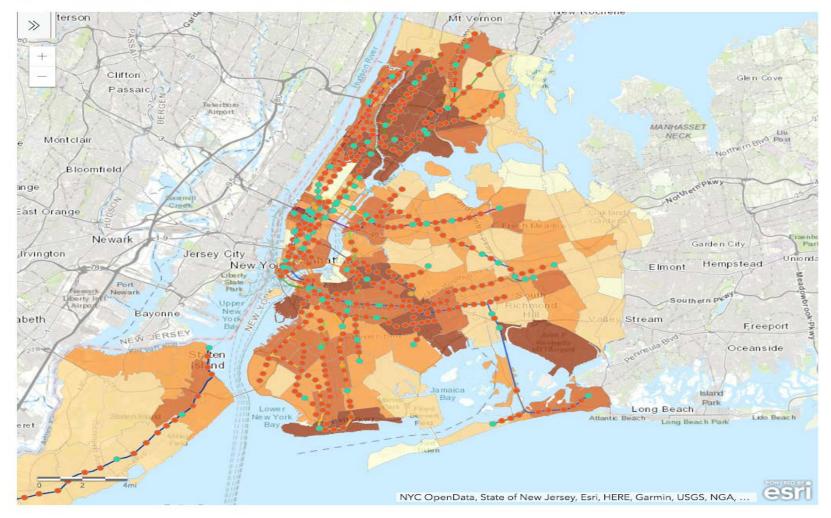
- Subway accessibility
- Homeless shelter accessibility
- Housing discrimination



### Using data to affect policy



#### NY Subway Accessibility and Disabled Population in Poverty





# Disability Data has transformed our work, our relationship with policy makers, the media, funders...



- Better able to meet our mission and ensure that we affirmatively seek to remove barriers that result in discrimination.
- Better method for planning outreach and engagement with local groups—better focusing of resources—we're growing and better mirror the communities we serve.
- Data studies used to supplement individual experiences for education of elected officials; testimony; comments on legislation; litigation.
- Developed a "go-to" relationship with reporters who want to know anything about disability, race, ethnicity.
- Funders seek our involvement and advice as an expert on the community.







Any final questions?

Directly following the webinar, you will see a short evaluation survey to complete on your screen. We appreciate your feedback!

https://usu.co1.qualtrics.com/jfe/form/SV\_8xfOKOB3niVU gmV



# **CIL-NET** Attribution



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