



Disability Rights Education & Defense Fund

2020 Census Disability Community Toolkit!

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Introduction

While people with disabilities make up 22% of the American public according to figures released by the Center for Disease Control and Prevention (CDC) in August 2018, they remain largely a neglected, albeit sizeable minority in terms of recognition and participation in the decennial census according to our findings. Many factors contribute to this reality. In addition to logistical social and structural barriers, people with disabilities face widespread economic inequity, cultural isolation, and discrimination in education, employment and a broad range of societal activities in ways that are often specific to a person's disability, and are generally not a factor for non-disabled individuals.

Demographics suggest some groups are more likely to have a disability than others are, but disability is its own category as well as a unique subset found within every social, economic, and racial demographic in the United States. People with disabilities are rich, poor, and middle class. They are black, white, brown, gay, straight, bi, male, female, Trans, Christian, Muslim, Jewish, Buddhist, Agnostic, Atheist, and every demographic beyond and in between.

In developing this toolkit, we completed field research in the Los Angeles and Inland Empire area. Appendix A describes our methodology that lead to our findings and recommendations below.

Reasons People with Disabilities Do Not Participate in the Census

Number One

“I’ve never been asked.” Of the 68 people with disabilities we interviewed in our focus groups and listening sessions during the Fall 2018, only 11 had ever received the census—in their entire lives. Of those, only nine had returned it. There is no reason to suspect this is not also true beyond the scope of our inquiry, suggesting that the number of people with disabilities who have participated in the census is significantly lower than the number of people with disabilities who should, and could be counted.

Other Reasons

- “I don’t think the census has an impact on my life.”
- “I don’t feel comfortable sharing personal information.”

- “I have trouble completing forms.”
- “I’m worried information will be used against me.” Participants were concerned that personal information provided to the census could interfere with Social Security, Medi-Cal and other benefit procurement. This is of particular concern when people have waited years to get an eligibility determination to receive lifesaving supports or services.

Reasons People Will Participate

People are more willing to take part

- If surveys are conducted in partnership with a trusted community group, advocacy organization, or person they already know. When pressed to explain why, focus group participants said they felt strongly that community organizations, service providers or advocacy groups they already had a relationship with understood them better and were trustworthy because of the relationship.
- If they understand the census is bigger than they are, completing it not only helps them obtain supports and services to get medical care, go to work, get an education, etc., but it also helps their peers obtain those things.
- If they complete surveys in a place where they feel comfortable, such as an independent living center, a frequently visited community center, or church.
- In person or with the support of someone they trust when completing the survey on a computer or by using a smartphone app. This was not true for all focus group participants but mentioned often enough that it is important when assessing outreach approaches.
- Some people with sensory disabilities need web-based information in accessible formats, such as screen reader friendly or in American Sign Language (ASL). Other people with learning or intellectual disabilities need information in plain language.

Preferred Messages

Of the ten messages we tested, these were the preferred messages.

1. The 2020 Census: The Disability Community is Counting on YOU
2. The 2020 Census and Disability: Everyone Deserves to Be Counted
3. Why the Disability Community Matters When Counting the 2020 Census

Recommended Hashtag for Promotional Materials and Social Media

#DisabilityCounts2020

Factors to Consider When Reaching Out to People with Disabilities

Significant barriers remain in identifying hard to count populations of people with disabilities. They include, sometimes in combination, a number of cultural, socio-economic, generational, or other dominant factors, including stigma.

As a result, we suspect a large number—if not the majority—of people who meet the Americans with Disabilities Act definition of “disabled” (limits one or more ‘major’ life activities) may not identify as disabled culturally, medically or otherwise. It is important to remember people have lives and identities of significance and meaning beyond one classification. This makes finding, identifying, and counting a large number of people who technically meet the criteria/classification difficult in ways not faced by other populations.

- According to the Pew Charitable Trust, the racial makeup of people with disabilities varies greatly when it comes to who chooses to disclose. According to the report, American Indians or Alaskan Natives were most likely to report having a disability at 17.7 percent. Black and white Americans were about equally as likely to report having a disability, at 14.1 percent and 13.9 percent respectively. Of the tracked groups, Asian Americans were the least likely to report having a disability at 6.9 percent.
- Age is a significant factor in determining the likelihood of having a disability. Almost half of people ages 75 and older have a disability. The same is true of more than a quarter of Americans aged 65 to 74. However, in 2015 people ages 35 to 64 made up the largest age demographic of people with disabilities, or roughly 16 million Americans. The Pew Charitable Trust report did not report on disclosure rates based on age.

When talking about health care, women's rights, civil rights, and human rights, we need to make sure disability rights are part of the conversation. Because of the frequently unique—and very often disability specific—experiences, insights and

perspectives of people with disabilities, they should, whenever possible, lead those conversations, in addition to taking part in them.

Communication Considerations

Most people with disabilities communicate the same way people without disabilities communicate. Those who have disabilities that affect hearing, seeing, speaking, reading, writing, remembering, or understanding may use different methods to communicate. Often referred to as “auxiliary aids and services,” these devices or services enable effective communication. Generally, the requirement to provide an auxiliary aid or service is triggered when a person requests it, but providing accessible communication services such as Computer Aided Real-Time Transcription (CART) at public events signals that disabled people are welcome. Similarly, ensuring websites are accessible to people who are blind ensures their participation.

Imagery

Despite the high percentage of people with disabilities in the general population, Getty Images reported in 2018 that only 2 percent of stock photos contain representations of disability. When reaching out to disability communities, it is important to use images that represent the reality of living with a disability rather than unwittingly reinforcing negative stereotypes. What may seem like a minor detail on the surface can have greater significance to people with disabilities. If the imagery does not reflect a person’s lived-experience, the credibility and, quite likely, the sincerity of the organization, agency, or campaign coordinators may be in doubt. Avoid red flags, including images that use standard, un-customized, hospital-issued wheelchairs, for example, or scenes that depict people with disabilities in insolation. Strive instead to use actual disabled people, in real life situations, doing a variety of things alongside friends, family members or colleagues. This is likely to resonate better with the target audience and, as such, assist rather than work against outreach goals.

Communicating with People Who are Deaf and Hard of Hearing

The Deaf and hard of hearing communities are diverse—there are people who became deaf later in life and may think of themselves as having lost their hearing. There are people born deaf who do not think in terms of having lost their hearing.

They consider themselves culturally and linguistically Deaf (with a capital D) whose primary language is likely ASL.

Sign Language Interpreters

Most Deaf individuals consider the Deaf community a distinct cultural and linguistic group. In order for a hearing person to communicate effectively with someone who is Deaf and whose primary language is ASL, an interpreter is necessary. Sign language interpreters are highly skilled, typically certified professionals who facilitate communication between hearing individuals and people who are Deaf or hard of hearing. Outreach organizations should identify independent sign language interpreters or companies to contract with sign language interpreters to accommodate people who request interpreters. (See Disability Organizations and Resources, below.)

Communicating with People who are Blind and Low Vision

People who are blind or low vision have varying degrees of sight. Some blind people may rely on Braille, or accessible digital text that can be read to them by screen reader software (text to audio), or audio recordings, while others need large print or use magnifying devices.

Outreach and information materials, as well as digital announcements should include statements that print materials are available in accessible formats such as Braille. Outreach organizations can build their capacity to produce documents in Braille by developing relationships with community groups that produce accessible formats. (See Disability Organizations and Resources, below.)

Provide, too, web based information in accessible formats, so people who use screen readers can access the information. (See Disability Organizations and Resources, below.)

Communicating with People with Cognitive and Intellectual Disabilities

Some people with cognitive, intellectual, or other related disabilities may require additional time and repetition to understand the information presented at events, and have adequate opportunity to ask questions. Information delivered at a literacy level that meets individual needs will help to ensure they understand.

Advertise Accommodations

Outreach organizations should indicate on print and digital announcements that accommodations are available, such as sign language interpreters, assistive listening devices, CART, large-print, and Braille. When outreach involves face-to-face communication organizations must hire sign language interpreters, when requested, and ensure locations meet access requirements.

Outreach to People with Disabilities

Where to Go

Nonprofit organizations and social service agencies, including social justice organizations, service providers operated by and for people with disabilities, and similar groups that among other functions provide referrals on obtaining supports and services, including employment and educational disability related assistance.

Private resources, which may include professional organizations, consulting services, and companies with expertise in disability.

Educational institutions, among them community colleges, universities and other institutions of learning and training, including those that offer programs for people with specific disabilities. Most college campuses have designated offices for students with disabilities; contact those during outreach and communications efforts.

Frequently Asked Questions by People with Disabilities

1. What is the Census?

The United States Constitution requires the census. It is an accounting of the United States population conducted every decade, in years ending in "0" since 1790. There have been 22 federal censuses since then. The United States conducted the last census in 2010. The next census is in 2020 and, for the first time, the United States will use the internet to encourage participation.

A detailed census—and the collection of data about who lives in the United States and where—is important for electoral representation, health care, housing, and education.

2. Why is an Accurate Census Important?

An accurate census count directly affects our nation's ability to provide equal representation and equal access to more than \$600 billion a year in important governmental resources for all Americans, including people with disabilities.

An accurate census helps federal agencies monitor discrimination and implement civil rights laws that protect voting rights, equal employment opportunity, and more.

An accurate census assists state and local leaders in identifying and addressing emerging needs for health care, education, housing, food and income security, rural access to broadband, and other community needs.

Perhaps the most important role of the census is population apportionment, or an accounting of how many people live where. Apportionment determines how the 435 members of the House of Representatives is divided among individual states. Unlike the number of senators, of which every state has two, the number of representatives per state are determined solely on population.

Why the Census Is Important to the Disability Community

The United States Constitution requires the census to ensure fair political representation. Community leaders and elected officials rely on accurate census data to make funding decisions about education, senior citizen and veteran supports, and other community allocations. It is important to get the numbers right, everyone—including people with disabilities—must be counted.

While the United States census only comes around once every 10 years, census data play a vital role in the lives of people with disabilities every day.

As we stated at the beginning, according to the CDC, people with disabilities make up 22% of the US population, nearly 1 in 4 (<https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>).

The decennial census, not CDC estimates, determines allocations for real-life necessities, like health care, Supplemental Nutrition Assistance Program (SNAP), special education grants and Medicaid.

Medicaid, State Children's Health Insurance Program (S-CHIP), Head Start and Early Head Start, highway planning and construction, and our nation's foster care programs are among the top 16 largest federal programs whose funding—totaling nearly \$600 billion a year—depend on census data.

Special education grants provide resources to disabled students, tailored to their individual needs. If the U.S. Census Bureau does not conduct a full and accurate count, administrators of special education programs will have no way of knowing how many children they must teach, which school districts need more educators, or what communities need more schools.

Census figures help advocates, community leaders, and elected officials address disparities in housing, health care, employment, and education. Fair proportionate voting representation depends on valid census data, as does the enforcement of voting rights laws. The health and wellbeing, and the political power of all communities, rests on a fair and accurate census count. Elected officials cannot make informed decisions about how to allocate federal tax dollars fairly and effectively without an accurate accounting of the population.

As such, an accurate census count is essential in ensuring people with disabilities who need these necessary supports and services participate in the census.

Supporting Facts

Special Education Grants – \$11.2 billion. To help schools meet the requirements of the Individuals with Disabilities Education Act, special education grants provide resources to students with disabilities, tailored to their individual needs. At present, fifteen percent of the funds allocated are based on the states' relative populations of children who live in poverty. In the 2015-2016 school year, these grants served nearly 7 million children and youth with disabilities.

Medicaid – \$312 billion. Medicaid is a federal-state insurance program that provides health coverage to households and individuals with low incomes, children, parents, seniors, and people with disabilities. In 2015, Medicaid had about 70 million enrollees.

State Children’s Health Insurance Program (S-CHIP) – \$11.1 billion. S-CHIP provides funds so states can maintain and expand child health assistance to uninsured, low-income children. In 2015, S-CHIP served more than 8 million children.

Sources

“OSEP Grant Opportunities and Funding.” U.S. Department of Education Retrieved 13 December 2017. Available at <https://www2.ed.gov/fund/grant/apply/osep/index.html?exp=1>.

“Programs: Special Education – Technical Assistance on State Data Collection – IDEA General Supervision Enhancement Grant. United States Department of Education, June 2017.” Available at <https://www2.ed.gov/programs/osepidea/618-data/statictables/index.html>.

Disability Organizations and Resources

California Council of the Blind (CCB)

<http://ccbnet.org/drupal7/>

California Disability Services Organization

<http://www.cal-dsa.org/>

California Foundation for Independent Living Centers (CFILC)

<http://cfilc.org/>

Computer Aided Real Time Transcription (CART)

<https://nationaldisabilitynavigator.org/ndnrc-materials/disability-guide/computer-aided-real-time-transcription-cart/>

Department of Developmental Services Regional Centers

<https://www.dds.ca.gov/RC/RCList.cfm>

Center on Deafness – Inland Empire

<http://codie.org/>

Disabled Students Program and Services

Located in California Universities and Community Colleges

Greater Los Angeles Agency on Deafness, Inc. (GLAAD)

<https://gladinc.org/>

NAMI California

<https://namica.org/>

State Council on Developmental Disabilities (SCDD)

<https://scdd.ca.gov/>

Website Accessibility

- Web Accessibility Initiative of the World Wide Web Consortium
<https://www.w3.org/WAI/>
- Introduction to Web Accessibility
<https://webaim.org/intro/>

Additional Census Resources

The 2020 Census at a Glance

<https://www.census.gov/library/visualizations/2018/comm/2020-at-a-glance.html>

California 2020 Census

<https://census.ca.gov/resources/>

California Complete Count

<https://census.ca.gov/wp-content/uploads/sites/4/2018/10/One-Pager-Fact-Sheet.pdf>

2020 Census Community Outreach Toolkit

<https://www.census.gov/partners/toolkit.pdf>

Appendix A – Methodology

Here we describe our methodology, including where we held groups and sessions and questions asked. The toolkit above provides summaries of the information gathered.

Focus Groups

Focus groups solicit public feedback in small group settings. We conducted four focus groups – each with six participants for 24 people – over two consecutive days in Southern California:

1. Pacific Clinics Rialto Clubhouse, Rialto, CA
2. Communities Actively Living Independent & Free (Independent Living Center), Los Angeles, CA
3. TASK Parent Training & Information Center, Alhambra, CA
4. United Cerebral Palsy (UCP) of Los Angeles, Culver City, CA

The participants included people with:

- Psychosocial disabilities
- Intellectual and developmental (I/DD) disabilities
- Physical disabilities
- Blind
- Hearing impairments

and

- Parents of children with disabilities.

Participants were ethnically and socio-economically diverse, and included people living on the streets and people previously institutionalized.

Questions posed to the focus group participants included:

- Are you familiar with the Census?
- Have you ever completed the Census?
- Do you know what the purpose of the Census is?
- Does the Census have an impact on your life?

- How do you feel about sharing personal information with strangers?
- How do you feel about sharing information with the government?
- Would you have trouble filling answering the questions on the Census?
- Who do you as a person with a disability listen to?
- Are there barriers to your participation? What are those barriers?
- Who do you trust to give you accurate information?
- Who would you trust to give you accurate information about the Census?
- Do you have access to a computer?
- Would you be comfortable using a computer to take the Census?
- Would you complete the Census using an App on a phone?
- Would you prefer to complete the Census using a computer or filling it out on paper?
- Where would you be most comfortable completing the Census?
- What would make it easier for you to participate in the Census?
- Do you use social media?

We asked the groups to consider ten outreach messages and select their two favorite messages.

Listening Sessions

Listening sessions build on existing trust between organizers, facilitators, and members of the larger disability community. At listening sessions, we talked with disability community organization staff who shared their opinions about the best ways to reach disabled people in their communities. Two listening sessions totaling 44 people were held in person in November 2018 in Culver City, CA with UCP Los Angeles and two sessions were conducted by conference call in January 2019, with staff at California parent centers.

Listening session participants selected their two favorite outreach messages, and were asked these questions:

- Why do you think disabled people might not participate in the Census?
- What do you think would increase participation by people with disabilities?
- Has your organization ever conducted outreach about the Census?
- Would your organization be interested in being a Census 2020 community partner focused on increasing participation by disabled people?
- Do you think that the Census has considered how or whether disabled people participate in the Census?