



## Why the Census Matters for People with Disabilities: A Guide to the 2020 Census Operations & Challenges

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*Note that: The decennial census does not ask about disability and the Census Bureau cannot measure an undercount of people with disabilities. For example, the bureau is able to measure potential undercounts of young children, renters, racial and ethnic minorities since the decennial census does ask questions on age, race and homeownership. While the annual American Community Survey (ACS) does ask about disability, a potential undercount of people with disabilities has not been studied by staff working on the ACS.)*

### KEY TAKEAWAYS

- The decennial census is the constitutionally mandated count of all residents of the United States.
- Census data help direct more than \$800 billion a year in federal funding, including for key programs that support and protect the rights of people with disabilities.
- The Census Bureau considers people with disabilities hard to count. However, the bureau has taken steps to make participation more accessible.
- Stakeholders can help ensure a fair and accurate count of people with disabilities. Community organizations can, for example, play a vital role as trusted partners in conducting effective outreach.
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### THE IMPORTANCE OF AN ACCURATE COUNT

Once a decade, the Census Bureau fulfils a constitutionally mandated count of every person living in the United States. The decennial census is the largest peacetime mobilization undertaken by the federal government, culminating in a collection of data vital to U.S. social, political, and economic systems.

How congressional seats are reallocated to U.S. states, where the boundaries of legislative, school, and voting precincts are drawn, and whether more than \$800 billion annually in federal funds will be fairly distributed all depend on a fair and accurate decennial count. Communities and groups that are undercounted do not get their fair share of political representation or federal funding.

The Census Bureau has identified people with disabilities as a hard-to-count population, which means they are at a greater risk of being undercounted in the census. The reasons for this include accessibility challenges and wider system inequalities. People with disabilities are also overrepresented among other groups that are considered hard-to-count, such as people of color people with low incomes, and people experiencing homelessness. Currently, 61 million adults in the United States live with a disability.<sup>1</sup>

A fair and accurate decennial census is vital for people with disabilities—and, indeed, for every person in the United States. The Census Bureau, its partners, and other stakeholders can and must take steps to help ensure a fair and accurate count of people with disabilities in the 2020 Census.

## **PARTICIPATING IN THE 2020 CENSUS**

The Census Bureau will begin inviting people to participate in the 2020 Census in March of 2020. Most households will receive an invitation in the mail to self-respond online. Households will be able to complete their census forms online using either a desktop computer, a laptop, a tablet, or a smartphone.<sup>2</sup> These respondents will also have the option to respond by phone or by mail. Every household that does not self-respond either online, by mail, or by phone, will receive reminders from the Census Bureau. Census enumerators, also referred to as census takers, will visit all households that did not self-respond, to collect responses in person.<sup>3</sup> Those living in group living situations, such as skilled nursing homes or college dorms, will be counted in a separate operation called the Group Quarters (GQs) enumeration.<sup>4</sup>

The Census Bureau has indicated that every self-response mode in 2020 will be fully accessible.<sup>5</sup>

- Section 508 of the Rehabilitation Act of 1973 requires all federal agencies—including the Census Bureau—to make their electronic and information technology accessible to all people with disabilities.<sup>6</sup> The bureau has conducted checks to ensure system compliance with Section 508 standards.<sup>7</sup>
- Braille and large print guides will be available to respondents to assist with self-response.<sup>8</sup> The Census Bureau also plans to disseminate these print guides through their partnership programs.<sup>9</sup> Language guides will also be available in 59 non-English languages, including an American Sign Language video guide.<sup>10</sup>
- As a part of the Census Questionnaire Assistance (CQA) operation, the Census Bureau’s telephone call centers will answer questions and accept responses in English and in 12 other languages: Spanish, Chinese, Vietnamese, Korean, Russian, Arabic, Tagalog, Polish, French, Haitian Creole, Portuguese, and Japanese.<sup>11</sup> The call centers will utilize Telephone Device for the Deaf (TDD) technology and their telephone number will be included on the postcards mailed to every household.<sup>12</sup>

## **GROUP QUARTERS (GQS)**

The Census Bureau counts individuals living in group facilities through the Group Quarters operation. GQs include skilled nursing facilities, residential treatment centers, college/university student dormitories, prisons, military barracks, shelters for people experiencing homelessness, and vocational training facilities.<sup>13</sup> People living in GQs do not self-respond online, by phone, or by returning a paper questionnaire by mail.<sup>14</sup> Instead, the census field staff will collect data using special GQ enumeration methods. These methods include the following:

- **Electronic Data Transfer:** The Electronic Response Data Transfer (eResponse) enumeration is available to specific GQ types. The method allows administrators of GQs to electronically transfer requested respondent-level data to the Census Bureau in a standardized template.<sup>15</sup>

- **In-Person Interviews:** Depending on the type of GQ, Census workers or a sworn-in GQ administrator may conduct in-person interviews with individuals residing there.
- **Paper Questionnaires & Listings:** Census workers may also drop off and pick up modified paper questionnaires, called Individual Census Reports, to be completed by each person staying at the GQ. Alternatively, census workers may collect paper listings with respondent-level data from the GQ administrator.<sup>16</sup>
- **Service-Based Enumeration:** People experiencing homelessness will be counted at the places where they receive services, including shelters and meal centers, and at targeted outdoor locations, over a three-day period starting on March 30 and ending on April 1, 2020.<sup>17</sup> Census staff will contact GQ administrators ahead of time to set an agreed-upon date, time, and preferred method for the enumeration.<sup>18</sup>

## ACHIEVING A FAIR & ACCURATE CENSUS COUNT

### THE DIGITAL DIVIDE

The Census Bureau’s online response option represents both an opportunity and challenge to the disability community. For many, the option will be more convenient than responding by mail. This is, in part, due to the greater availability and increased effectiveness of screen readers, electronic magnifiers, and other assistive technology tools. However, a significant digital divide exists between people with and without disabilities: people with disabilities are about 20 percentage points less likely to own a computer, tablet, or smartphone or subscribe to home broadband.<sup>19</sup> Without reliable internet access, people with disabilities may encounter difficulties completing the online form.

Respondents may also choose to answer the census over the phone and households that do not self-respond by mid-April will receive a paper questionnaire if their initial census package did not include one. For households that do not self-respond, census staff will follow up in person. The American Library Association reminds households that they can also self-respond using the internet at their local libraries.<sup>20</sup>

### HARD-TO-COUNT POPULATIONS

Hard-to-count populations are groups and communities that are at a higher risk of being missed in the decennial census. The Census Bureau had identified people with disabilities as a hard-to-count population. Other hard-to-count populations include young children, people of color, people experiencing homelessness, LGBTQ persons, and people with disabilities.<sup>21</sup>

People with physical and developmental disabilities may be undercounted due to distinct yet often overlapping causes. When poorly designed and tested, inaccessible surveys restrict the participation of people with disabilities. Similarly, insufficient or ineffective outreach efforts may also mean that people with disabilities are not informed of the necessary resources available to support completing the survey.

People with disabilities may also feel reluctant to participate in the census. Anecdotal evidence suggests that people with disabilities may be suspicious of the government or concerned that personal information will be used to determine their eligibility for government programs.<sup>22</sup> Individuals with a

mental health history, for example, may strongly mistrust federal authorities due to past experiences of involuntary treatment or the criminalization of behavior and circumstances associated with their mental health condition.<sup>23</sup>

Moreover, people with disabilities are disproportionately likely to be part of other hard-to-count populations. Disability is prevalent among racial and ethnic minorities who have been undercounted historically: a quarter or more of American Indians/Alaska Natives, and Black adults have a disability.<sup>24</sup> An equivalent share of individuals experiencing homelessness have one or more disabilities.<sup>25</sup> LGBTQ people and people with low-incomes are also more likely to be living with disabilities.<sup>26</sup> Analysis shows that 19 percent of people with disabilities live in areas that are considered hard-to-count.<sup>27</sup> In at least six US states, such as New Mexico and Alaska, a third or more of people with disabilities live in areas considered hard-to-count.<sup>28</sup>

**Maine specific data about people with disabilities in hard to count census tracts** (Inserted here from, <https://www.ndrn.org/wp-content/uploads/2019/07/States-Ranked-by-Percent-of-People-with-Disabilities.pdf> )

Rank	State	Total Population of People with Disabilities**	Total Number of People with Disabilities Living in HTC Tracts	Percent of People with Disabilities Living in HTC Tracts
	United States	39,792,082	7,476,133	18.8%
48	Maine	208,646	9,489	4.5%

**FEDERALLY-FUNDED PROGRAMS GUIDED BY THE CENSUS**

Federal programs play a crucial role in protecting the political, socio-cultural, and economic rights of all people living in the United States, including people with disabilities. A fair and accurate census count is essential for the appropriate allocation of funding and strategic decision-making regarding these programs. Programs that rely on census data include the following (all dollar figures are for FY 2019):<sup>29</sup>

Civil Rights and Advocacy:

- **Protection and Advocacy Systems (\$155 million):**<sup>30</sup> The Protection and Advocacy (P&A) program provides legal, administrative, and other services to people with disabilities. The program’s purpose is to protect the civil and political rights of people with disabilities. P&As work in all 50 US states, the District of Columbia, Puerto Rico, and the US territories. There is a P&A affiliated with the Native American Consortium which includes the Hopi, Navajo and San Juan Southern Paiute Nations in the Four Corners region of the Southwest.
- **State Councils on Developmental Disabilities (\$75 million):**<sup>31</sup> State Councils on Developmental Disabilities (SSDD) identify and address the needs of people with developmental disabilities in all 50 US states, the District of Columbia, Puerto Rico, and US territories.<sup>32</sup>
- **Statewide Independent Living Council (\$24.5 million):**<sup>33</sup> Statewide Independent Living Councils (SILCs) are community-based organizations that provide independent living services for people with disabilities. SILC work in all 50 US states and US territory.

#### Education:

- **Title I Grants to Local Educational Agencies (\$15.9 billion):**<sup>34</sup> The largest federal program supporting elementary and secondary education, Title I grants are used to fund a variety of supplementary educational and related services, including services for students with disabilities. The purpose of the program is to narrow achievement gaps through access to “a fair, equitable, and high-quality education.”<sup>35</sup>
- **Education Grants to States for Students with Disabilities (\$13.3 billion):**<sup>36</sup> The Individuals with Disabilities Education Act (IDEA) requires states to provide free, appropriate public education to students with disabilities. The largest component of the IDEA, Part B, specifically covers children and youth with disabilities between the ages of 3 and 21. This program ensures that over 7 million children receive education and early intervention services.<sup>37</sup>

#### Food and Nutrition:

- **Supplemental Nutrition Assistance Program (\$73.4 billion):**<sup>38</sup> Supplemental Nutrition Assistance Program (SNAP, formerly known as food stamps) provides food and nutrition assistance to families with low-incomes, helping families maintain a healthier food diet.<sup>39</sup> A fifth of all SNAP households include a person with a disability.<sup>40</sup>

#### Healthcare:

- **Medicaid (\$418.7 billion):**<sup>41</sup> More than 11 million people with disabilities are enrolled in Medicaid.<sup>42</sup> As the main health insurer for adults and children with disabilities, Medicaid covers services that other insurers typically do not such as attendant care and supportive housing services.<sup>43</sup> Nearly half of all nonelderly adults with disabilities are covered under Medicaid.<sup>44</sup>

#### Housing:

- **Section 811 Supportive Housing for Persons with Disabilities (\$230 million):**<sup>45</sup> As the Department of Housing and Urban Development’s only program for non-elderly people with disabilities, Section 811 Supportive Housing for Persons with Disabilities program funds the development of affordable, accessible rental housing.<sup>46</sup>

#### Employment:

- **Vocational Rehabilitation State Grants Program (\$3.5 billion):**<sup>47</sup> Vocational Rehabilitation (VR) programs provide services for people with disabilities pursuing employment opportunities. Provided services include vocational training, counseling, supported employment, and post-employment assistance.<sup>48</sup> In 2019, 170,000 people with disabilities were employed with the support of VR programs.<sup>49</sup>

#### WHAT CAN YOU DO TO ENSURE A MORE ACCURATE COUNT OF PEOPLE WITH DISABILITIES?

- **Become a 2020 Census “partner” and help ensure that the Census Bureau’s Partnership Program gets the funding it needs.** Budget shortfalls are putting this important program at risk. Partners get timely updates about 2020 Census operations, as well as promotional and

educational materials ([census.gov/partners](https://www.census.gov/partners)). Organizations, associations, state and local governments can all become 2020 Census partners.

- **Directly engage people with disabilities** to share the importance of an accurate census and encourage participation. In particular, trusted community members can play an important role in reassuring people with disabilities, including those who are undocumented or who distrust or fear government employees. Organization may, for example, encourage and support the hiring of people with disabilities as enumerators ([census.gov/about/census-careers](https://www.census.gov/about/census-careers)).
- **Form or participate in a Complete Count Committee (CCC)**. CCCs ([census.gov/programs-surveys/decennial-census/2020-census/complete-count](https://www.census.gov/programs-surveys/decennial-census/2020-census/complete-count)) are voluntary groups that promote census participation by leveraging knowledge of the local community. CCCs can be an effective tool for organizing outreach to people with disabilities. Successful CCCs include a broad range of civic and community leaders.
- **Reach out to clients, customers, family, friends and community members**. Make sure they know to look out for the census materials in 2020, understand the importance of being counted, and have the support they need to respond. For example, service providers such as Independent Living Centers, Protection and Advocacy Systems, and parent associations can play a vital role as trusted partners to conduct effective outreach.
- **Stay informed about key census policy and operational developments**. The Census Counts campaign publishes many helpful resources at [censuscounts.org](https://www.censuscounts.org). Resources from the Georgetown Center on Poverty and Inequality and the National Disability Rights Network (NDRN) can be found at [georgetownpoverty.org/issues/democracy/census/](https://www.georgetownpoverty.org/issues/democracy/census/) and [ndrn.org/issues/census-2020](https://www.ndrn.org/issues/census-2020) respectively. The Census Project also provides regular updates on census-related activities in Congress and the administration at [thecensusproject.org](https://www.thecensusproject.org).

## CONTACTS

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## REFERENCES

The following references are listed as URLs for brevity

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<sup>1</sup> Statistic draws from CDC data on the civilian, noninstitutionalized population of people with disabilities.

<https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>

<sup>2</sup> <https://www2.census.gov/programs-surveys>

<sup>3</sup> <https://www.census.gov/content/dam/Census/library/factsheets/2019/dec/how-census-invites-everyone.pdf>

<sup>4</sup> <https://www2.census.gov/programs-surveys/decennial/2020/program-management/planning-docs/2020-oper-plan4.pdf>

<sup>5</sup> Email exchange with Census Bureau staff.

<sup>6</sup> <https://www.section508.gov/manage/laws-and-policies>

<sup>7</sup> <https://www2.census.gov/programs-surveys/decennial/2020/program-management/planning-docs/2020-oper-plan4.pdf>

<sup>8</sup> Ibid.

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> Ibid.

<sup>12</sup> Email exchange with Census Bureau staff.

<sup>13</sup> <https://www.census.gov/2018censustest/gg>

<sup>14</sup> <https://www2.census.gov/programs-surveys/decennial/2020/program-management/planning-docs/2020-oper-plan4.pdf>

<sup>15</sup> <https://www.census.gov/programs-surveys/decennial-census/2018-census-test/test/providence/group-quarters/erdt.html>

<sup>16</sup> <https://www2.census.gov/programs-surveys/decennial/2020/program-management/planning-docs/2020-oper-plan4.pdf>

<sup>17</sup> <http://www.georgetownpoverty.org/wp-content/uploads/2018/09/GCPI-ESOI-Counting-People-Experiencing-Homelessness-20180904.pdf>

<sup>18</sup> <https://www2.census.gov/programs-surveys/decennial/2020/program-management/planning-docs/2020-oper-plan4.pdf>

<sup>19</sup> <https://www.pewresearch.org/fact-tank/2017/04/07/disabled-americans-are-less-likely-to-use-technology/>

<sup>20</sup> <https://www.census.gov/library/stories/2019/03/one-year-out>

<sup>21</sup> <https://www2.census.gov/programs-surveys/decennial/2020/program-management/planning-docs/2020-oper-plan4.pdf>

<sup>22</sup> <https://www.disabilityrightsca.org/post/census-2020-webinar-inclusion-of-people-with-disabilities>

<sup>23</sup> Ibid.

<sup>24</sup> Statistic draws from CDC data on the civilian, noninstitutionalized population of people with disabilities.

<https://www.cdc.gov/ncbddd/disabilityandhealth/materials/infographic-disabilities-ethnicity-race.html>

<sup>25</sup> [https://www.usich.gov/resources/uploads/asset\\_library/Homelessness-in-America-Focus-on-chronic.pdf](https://www.usich.gov/resources/uploads/asset_library/Homelessness-in-America-Focus-on-chronic.pdf)

<sup>26</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3490559/>

<sup>27</sup> This figure only refers to the civilian, noninstitutionalized population of people with disabilities. The decennial census does not ask about disability and the Census Bureau cannot measure an undercount of people with disabilities. For example, the bureau is able to measure potential undercounts of young children, renters, racial and ethnic minorities since the decennial census does ask questions on age, race and homeownership. While the ACS does ask about disability, a potential undercount of people with disabilities has not been studied by staff working on the ACS. Information based on email exchanges with Census Bureau staff. Figures based on authors calculations using U.S. Census Bureau, American Community Survey 5-year Estimates, 2017, and the CUNY

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Center for Urban Research, Hard-to-Count map data, 2019.

<sup>28</sup> Ibid.

<sup>29</sup> The programs noted below are all impacted by census data, as identified by the Census Bureau.

<https://www.census.gov/library/working-papers/2017/decennial/census-data-federal-funds.html>

<sup>30</sup> Authors' calculations. P&As are funded via nine federal funding streams.

<https://www.ndrn.org/issues/funding/>

<sup>31</sup> <https://acl.gov/sites/default/files/about-acl/2019-01/SCDD-2019.pdf>

<sup>32</sup> <https://acl.gov/programs/aging-and-disability-networks/state-councils-developmental-disabilities>

<sup>33</sup> <https://acl.gov/sites/default/files/about-acl/2019-01/ILSG-2019.pdf>

<sup>34</sup> <https://www.appropriations.senate.gov/news/fy2019>

<sup>35</sup> <https://www.law.cornell.edu/uscode/text/20/6301>

<sup>36</sup> <https://www.appropriations.senate.gov/news/fy2019-labor-hhs-and-education-appropriations-bill-gains-subcommittee-approval>

<sup>37</sup> <https://www2.ed.gov/about/overview/budget/budget20/summary/20summary.pdf>

<sup>38</sup> <https://www.obpa.usda.gov/budsum/fy2020budsum.pdf>

<sup>39</sup> <https://www.fns.usda.gov/snap/supplemental-nutrition-assistance-program>

<sup>40</sup> <http://frac.org/blog/snap-matters-people-disabilities>

<sup>41</sup> <https://www.hhs.gov/sites/default/files/fy-2020-budget-in-brief.pdf>

<sup>42</sup> <https://www.kff.org/medicaid/state-indicator/distribution-of-medicaid-enrollees-by-enrollment-group/?dataView=0&currentTimeframe=0&selectedDistributions=disabled&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22asc%22%7D>

<sup>43</sup> <https://www.cbpp.org/research/health/medicaid-works-for-people-with-disabilities;>

<https://www.kff.org/medicaid/issue-brief/10-things-to-know-about-medicaid-setting-the-facts-straight/>

<sup>44</sup> Ibid.

<sup>45</sup> <https://www.hud.gov/sites/dfiles/CFO/documents/HUD2020BudgetinBrief03072019Final.pdf>

<sup>46</sup> [https://www.hud.gov/program\\_offices/housing/mfh/progdesc/disab811](https://www.hud.gov/program_offices/housing/mfh/progdesc/disab811)

<sup>47</sup> <https://www2.ed.gov/about/overview/budget/budget20/summary/20summary.pdf>

<sup>48</sup> Ibid.

<sup>49</sup> Ibid.