

**Intellectual and Developmental Disabilities**  
**Housing and Long-term Supports and Services for People with ID and DD from Diverse Communities**  
--Manuscript Draft--

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<b>Abstract:</b>	This article describes research on the places people with IDD live and disparities in housing and LTSS outcomes for people with IDD from diverse racial, ethnic, or cultural communities. It also summarizes the conclusions and recommendations of the Housing and Long-Term Services and Supports strand of the 2022 State of the Science Conference on the Intersection of Diversity, Equity and Inclusion and Supports and Services for People with IDD. It identifies limitations of the available research and recommends strategies to improve research, knowledge translation, and interventions.

**Housing and Long-term Services and Supports for People with Intellectual or Developmental**

**Disabilities from Racially and Culturally Minoritized Communities**

January 8, 2024

## Abstract

This article describes research on the places people with intellectual and developmental disabilities (IDD) live and disparities in housing and long-term services and supports (LTSS) outcomes for people with IDD from racially and culturally minoritized groups. It also summarizes the conclusions and recommendations of the Housing and Long-Term Services and Supports strand of the 2022 *State of the Science Conference on the Intersection of Diversity, Equity and Inclusion and Supports and Services for People with IDD*, identifies limitations of the available research and recommends strategies to improve research, knowledge translation, and practices.

## Introduction

Safe, accessible, and affordable housing is a basic human need. However, people with disabilities struggle to find and maintain housing (Friedman, 2023). Those with LTSS needs are more likely to live in homes with upkeep problems, to have inadequate housing or to live in low quality housing, to live in neighborhoods with serious crime, that are at risk of flooding or other natural disasters, and to struggle to afford their housing (National Council on Disability, 2010; Trivedi, et al., 2020). Amongst Medicaid recipients with disabilities, women, people who were not white, those with less than a high school education, and people with household incomes below \$25,000 were more likely to have one or more unmet support needs (Mitra, 2011).

People with intellectual or developmental disabilities (IDD) often need life-long supports to live the life of their choosing. For them housing and support are often intertwined. Most people with IDD live with family members throughout their lives whether they are supported informally by family members (Larson et al., 2005) or formally through publicly funded long-term supports or services (LTSS; Larson et al., 2022) or both. In 1995, when the last nationally representative household survey allowing researchers to identify both adults and children with IDD was conducted, an estimated 78% of people with IDD lived with a relative, 8% lived alone or with a roommate, 6% lived with a spouse, and 8% lived

in a group home, IDD institution or nursing home (Larson et al., 2005). Amongst people with IDD getting LTSS through state IDD agencies in 2019, an estimated 60 percent lived with a family member, 11 percent lived in their own home, 5 percent lived with a host or foster family, and 24 percent lived in a provider owned or operated residence (16 percent in settings of six or fewer people, and 8 percent in settings of 7 or more people; Larson et al., 2022). Of the estimated 2.13 million adults with IDD in the United States in 2019, 46% were known to state IDD agencies (Larson, et al., 2022).

This article summarizes the literature reviewed by participants in the housing and services strand of the State of the Science Conference on the topic: “To what extent do people with IDD from diverse racial, ethnic, and cultural backgrounds experience disparities in accessing housing and access to long-term supports and services?” We searched EBSCOhost, Web of Science, PubMed, and JSTOR using the search terms (housing OR residential OR “long-term supports and services”) AND (intellectual OR developmental disabilit\*) AND (disparities OR race) to locate research on the intersection between race, ethnicity, housing, and LTSS for people with IDD. We also requested articles on these topics from scholars who have published research in this area. We focused on original research, literature syntheses or meta-analyses; published by an academic institution, a federal or state governmental agency, or in a peer reviewed journal. We sought United States research written in English published between 2000 and 2023. We excluded case studies, pilot studies, conference abstracts, commentaries, and articles that did not describe housing or long-term service or supports. We were especially interested in studies of housing or LTSS that included people with IDD and reported on differences by race, ethnicity, linguistic, and cultural backgrounds. A summary of key findings and highlights from the identified studies follows.

### **Housing and LTSS for People with IDD**

Until 1967, nearly all people with IDD getting publicly funded LTSS lived in large state-run institutions. Authorization of Medicaid’s Intermediate Care Facilities for People with Intellectual disabilities (ICF/IID) in 1971 spurred reforms to reduce overcrowding in state-run institutions by offering

federal matching funds to states for those state-funded facilities in exchange for improving conditions, reducing overcrowding, and providing active treatment for the people living there. Between 1967 and 2019, the number of people living in large state-run IDD institutions declined from 194,650 to 16,200 as almost all children and most adults returned to live with family members or moved to community homes (Larson, et al., 2022). By 2019, 17 states had closed all large state-run IDD institutions and only 67,498 people with IDD lived in any state or non-state ICF/IID.

Shortly after the introduction of the ICF/IID program, two other federal policies shifted the landscape again. In 1975, Public Law 94-142 (now the Individuals with Disabilities Education Act, IDEA) created an entitlement to a free public education for all children with disabilities. In 1981, Medicaid made funds available to support people needing LTSS living with family members, in their own homes, or in other community settings through the Medicaid Home and Community Based Services (HCBS) Waiver. Between 1982 and 2019, the number of people with IDD receiving Medicaid HCBS Waiver funded support grew from 1,381 to 930,356 (Larson et al, 2022; See Figure 1).

**Insert Figure 1 About Here**

The number of LTSS recipients with IDD living with a family member increased dramatically as use of Medicaid HCBS Waiver funding grew. Between 1998 and 2019 the number LTSS recipients with IDD living with family members getting state-funded services (not matched by Medicaid dollars) grew from 244,841 to 349,963 (an increase of 43 percent) while the number getting Medicaid HCBS funded supports increased from 80,799 to 499,139 (an increase of 518 percent; See Figure 2). Medicaid HCBS Waiver funds could also be used to support people living in their own homes or with a host or foster family. Between 1998 and 2019, the number of HCBS Waiver recipients with IDD receiving LTSS while living in homes they own or lease increased from 62,669 to 153,079, and the number living with a host or foster family increased from 28,122 to 64,869. The percentage of LTSS recipients with IDD living in group homes or institutional settings declined from 56% in 1998 to 28% in 2019.

**Insert Figure 2 About Here**

A robust body of research has shown that people moving from institutional to small community homes are more satisfied with their services, and are more likely to learn new skills (e.g., Larson et al., 2012), and that people with IDD living with fewer roommates with IDD are more likely to choose when to eat, what to do in their free time, and how to spend their money (e.g., Ticha' et al., 2013), and are more likely to participate in making big choices such as where they will live and with whom (e.g., Stancliffe, et al., 2011).

While access to publicly funded LTSS in home and community-based settings for people with IDD has improved, access varies by state. For example, in 2019, there were an average of 372 adult LTSS recipients with IDD per 100,000 of the population. However, in eight states there were fewer than two hundred adult LTSS recipients with IDD per 100,000 while in nine states there were more than 500 LTSS recipients with IDD per 100,000 (See Figure 3). Adults with IDD in some states were up to seven times more likely to receive publicly funded LTSS than in other states. States also differed in the extent to which they provided LTSS for people with IDD in people's own home, host or foster family homes, or in group settings of three or fewer people rather than in larger settings. For example, 54 percent of LTSS recipients with IDD lived in homes shared by three or fewer people with IDD, but the percentage ranged from 1 to 97 percent across states (Larson et al., 2022). Finally, waiting lists for HCBS funded support for people with IDD vary by state. In 2019, while 14 states reported no waiting lists, an estimated 194,983 people living with a family member or in their own home were waiting for and not getting any Medicaid HCBS waiver funded LTSS. The number of people waiting ranged from zero to more than 10,000 in Florida, Illinois, North Carolina, Ohio, South Carolina, Virginia, and Washington (Larson et al., 2022).

**Insert Figure 3 About Here****Disparities in Housing and LTSS**

Less research is available about the compounding effect of race, ethnicity, and other marginalizing characteristics on housing and LTSS for people with IDD. The research that is available uses large administrative data sets or national public health surveys. Administrative data to evaluate the nature or extent of disparities is inadequate. For example, the quality of race and ethnicity data in Medicaid administrative data is of high concern or is unusable in nineteen states (SHADAC Staff, 2023).

#### *Access to LTSS*

A few studies using administrative data sets examined variations in access to services. Two California studies found that, after controlling for need, compared to people with IDD who were white, people with IDD from other racial groups were less likely to receive LTSS and when they did, had lower per person expenditures (Harrington & Kang, 2008, 2016). Service expenditures varied by geography and were less for females, children, and those from racial and ethnic minority groups. In an Illinois study, amongst people waiting for IDD services, individuals from racial and ethnic minority backgrounds had greater unmet needs than individuals who were white (Burke & Heller, 2017).

A study using the 2012 Medicare-Medicaid Linked Enrollee analytic data evaluated differences in eligibility for Medicaid, or both Medicaid and Medicare and spending on services by race and ethnicity for 172,071 adults with autism (Benevides et al., 2021). Controlling for gender, intellectual disability, presence of chronic conditions, rural status, county median income and US Census region, Black beneficiaries with ASD were significantly less likely than white beneficiaries to be eligible for both Medicaid and Medicare. In addition, median 2012 expenditures were higher for white beneficiaries with ASD than for Black beneficiaries with ASD. Medicaid HCBS Waiver participation varied by race. Amongst Medicaid only beneficiaries, the proportion who received HCBS Waiver funded supports was significantly higher for recipients who were Asian/Pacific Islanders (55%) or Hispanic (43%), than for recipients who were white (37%), Black (36%), or Other/more than one race (19%).

A 2012 national study of racial disparities amongst 117,848 children aged 4 to 17 years with autism enrolled in Medicaid reported that Medicaid-enrolled children who were white were significantly more likely to receive case management services than Medicaid-enrolled children who Black, Latinx, Asian or Native American or Pacific Islander. Children who were Black were significantly less likely to receive respite services than children who were white while children who were Asian were more likely than children who were white to get respite services (Bilaver et al., 2020).

A study using 1994/1995 National Health Interview Survey Disability Supplement (NHIS-D) data to examine differences in access to services for adults with IDD versus adults with other disabilities, or no disabilities found that the likelihood of needing but waiting to receive mental health services was higher for adults with IDD in households with below poverty level incomes but lower for adults who were Black (Larson et al., 2003). The likelihood of needing but waiting to receive case management services was higher for adults with IDD who were non-white who were living in households with below poverty level incomes. The likelihood of needing but waiting for employment or day program supports was higher for adults with IDD in households with below poverty level incomes but was not different by race.

#### *Living Arrangements*

One NHIS-D study found that adults with IDD who were Black or another race other than white, female, ages 18 to 34 years, or had household incomes above poverty level income were more likely to live with a family member (rather than alone or with a spouse) than adults with other disabilities, those who were white, were male, were 35 years or older, or who had household incomes below the poverty level (Doljanac et al., 2004). In another NHIS-D study, the likelihood of having lived in a facility for people with mental illness was higher for adults with IDD living in households with below poverty level income, but not different by race (Larson et al., 2003). The likelihood of having lived in an IDD facility was higher for adults with IDD, but not different by race or poverty level. The likelihood of having lived in a nursing

home was lower for adults who were Black but did not differ by type of disability or household poverty. Finally, the likelihood of having previously lived in any type of long-term care facility was higher for adults with IDD, in households with below poverty income levels, but not different by race.

*Transportation and Community Participation*

An NHIS-D study reported that controlling for gender, age, and health status, work status, and living arrangement, the odds of having difficulty accessing public transportation did not differ by race or poverty status but were higher for people with IDD than for adults with other disabilities (Doljanac et al., 2005). This study also reported differences in participation in social activities controlling for disability type (IDD or other), gender, age (18 to 34 versus 35 years or older), health status (Excellent or very good versus good, fair or poor), race (Black, white or other), work status, living arrangement (own home, with family member, with a spouse), household poverty, and difficulties accessing transportation. Controlling for the other variables, adults with IDD who were Black were more likely to have met with friends or neighbors in the last two weeks but there were no differences by household poverty status. People with IDD living in households with below poverty rate incomes were less likely to have talked on the phone with friends or neighbors but there were no differences by race. People with IDD in households with higher than poverty level incomes who were Black were more likely to have attended religious services. People of other races were less likely to attend religious services. Finally, people who were white in households with above poverty level incomes were more likely to report attending events like going to a movie. Participation did not differ by type of disability.

Researchers used the National Core Indicators for IDD (NCI-IDD) 2018/19 In-Person Survey to compare 22,009 adults served by state IDD agencies across thirty-nine states (Bradley et al., 2021). Compared to white LTSS recipients those who were Black were more likely to live with family members; attend religious services in the past month; want to go shopping, out for entertainment, out to eat, attend religious services; live in settings with rules about having friends or visitors at their house; need

more help to keep in contact with friends or to make new friends; and to have helped choose the services received. Adults who were Black were less likely to have provided input on where they live or who their roommates are, to be able to be alone with guests in their home, or to have input on their daily schedule. However, this study did not use logistic regression or other statistical techniques to evaluate how differences in age, living arrangement, health and support needs and other factors affected these outcomes.

*Employment*

One NHIS study found that adults with IDD who were non-white who lived in households with below poverty level incomes were less likely to be employed (Larson et al., 2003).

**State of the Science Housing and Services Strand Findings**

Stakeholders in the Housing and LTSS strand of the 2022 State of the Science Conference reviewed the research on the intersection of race and ethnicity, disability, housing and LTSS summarized above. They concluded that these studies paint an incomplete but clearly complex picture of the intersectionality between disability, race, household poverty and LTSS need, housing, and outcomes. None of the studies examined the root causes of differences or disparities identified. Nearly all the studies used quantitative methodologies and examined data from large administrative or public health surveys. Qualitative or mixed methods studies centering on the lived experiences of people with IDD from racially or culturally minoritized groups were absent. While multivariate analyses based on large samples examined combinations of the individual factors affecting people from multiply marginalized communities, jointly constructed research led by people from those communities was missing.

Other limitations were also noted. For example, while several studies used administrative data sets to examine factors associated with outcomes and included people from multiply marginalized communities, administrative datasets are themselves limited in that records maintained for administrative purposes may not include variables of most interest; amount and specificity of

information vary across diagnostic categories or service types; decentralized administration and data collection resulting in data that varies in level of detail, definitions and quality across jurisdictions, and not all data are stored in retrievable electronic formats. Also importantly, administrative data sets do not include people who are not current service recipients (Bonardi et al., 2019). Only an estimated 46% of adults with IDD who might be eligible for services through or under the auspices of state IDD agencies are on the caseloads of those agencies (Larson et al., 2022). The living arrangements and LTSS support needs of the other 54% of adults cannot be known by conducting research using administrative datasets.

Nationally household surveys such as the NHIS provide a wealth of information about the needs and experiences of representative samples of Americans regardless of whether they are known to service delivery systems. Unfortunately, the most recent studies of adults with IDD based on nationally representative health surveillance studies are decades out of date. Ongoing surveys such as the American Community Survey (ACS) which are primary data sources for population level research do not collect disability information that is specific enough to robustly identify adult sample members with IDD (Havercamp, et al., 2019; Anderson et al, 2019). Including even three questions asking surveyed adults whether they had an intellectual disability, autism, or developmental disabilities would vastly increase the usefulness of the ACS and a host of other national public health surveys for examining housing and LTSS outcomes for people with IDD from various racial, ethnic and other cultural identities and comparing those outcomes to people with other disabilities or no disabilities.

The Residential Information Systems Project offers annual summaries of the living arrangements of LTSS recipients with IDD who are known to state IDD agencies. However, the project did not add data on race and ethnicity of LTSS recipients until its 2022 survey and has not yet released the 2022 results. Those data will offer state level information about racial and ethnic differences amongst people with IDD served by state IDD agencies. However, researchers will also need to examine individual level data

using qualitative, quantitative, and mixed methods research to understand the intersection of race, ethnicity, and cultural differences in housing and LTSS for people with IDD and the implications of those differences.

### **Research and Practice Recommendations**

The workgroup concluded that because the body of research is so limited and much of the data heretofore used is old and may no longer be valid, updated research is needed. The group offered recommendations about research topics, research methods, and practices to improve housing and LTSS outcomes for people from racially or culturally minoritized populations.

#### **Research Topics**

The workgroup identified discussed a host of possible research questions to better understand access to and experience with housing and LTSS outcomes for people with IDD from racially or culturally minoritized populations and prioritized these.

1. What disparities and systematic barriers exist in housing and LTSS access, accessibility, acceptability, quality, and utilization for this population?
2. To what extent do traditional (family home, group homes, and host or foster family homes) and nontraditional housing models (e.g., shared living, intentional communities, or farmsteads) increase or reduce disparities in access, acceptability, quality, and availability of housing and LTSS this population?
3. What are the impacts of social determinants of health such as household (e.g., poverty, income, household composition, living with a family member, alone or with others) and neighborhood characteristics (e.g., safety, transportation, crime, food deserts, availability of affordable housing) on housing and LTSS needs and outcomes for this population?
4. What are the impacts of evolving Medicaid funding models (e.g., ICF/IID, State plan HCBS, 1915(c) and other HCBS waiver authorities) and administrative arrangements (Fee-for-Service

versus Managed LTSS) on access, outcomes, and disparities for people with IDD from racially minoritized groups?

5. What are the lived experiences of people from diverse, race, ethnic, and cultural groups in access and receipt of IDD services? What systemic barriers do they face in access to housing and LTSS and what are potential policy and practice recommendations to improve access and delivery of culturally and linguistically competent services and supports?

These questions cover policy relevant topics, explore the impact of social determinants of health and examine the lived experiences of people with IDD from diverse communities. However, while these were the top priority research topics, a host of other topics were discussed. Ongoing programs of research cocreated with people with IDD from racially or culturally minoritized populations will need to be flexible to add or change the topics for research and the associated research questions as they move forward.

### **Research Methods**

Future research will need to be informed by full participation from people with IDD from racially or culturally minoritized populations. Quantitative research using both administrative and population based survey research will continue to be best suited to answer some research questions, but qualitative and mixed research methods will also be needed to begin centering the lived experience of people with IDD from racially minoritized groups and their families. The IDD Counts initiative of the Administration on Community Living (ACL) continues to focus on improving the quality and usefulness of identifiers for people with IDD in population and administrative data sets so that people with IDD, including those from racially or culturally minoritized populations, will not be left out of national policy and public health research (USHHS, 2023). The ACL funded I/DD Longitudinal Data Projects will need to continue to expand their data collection and reporting to provide system level information on the full

range of diversity of people with IDD served by state IDD agencies (c.f., <https://acl.gov/programs/idd-longitudinal-data-collection-projects>).

Improving data on housing and LTSS for all people with IDD will require attending to the recommendations made by Dr. Tawara Goode at the State of the Science Conference (see Goode, et al. in this issue). Of particular relevance are the recommendations to use methodological approaches that recognize, respect, and address the multiple cultural identities of persons who experience IDD, employ methodological designs that foster meaningful partnerships with persons with IDD across cultural groups, and consider how the experiences of persons with disabilities vary based on socio-cultural contents (Goode, 2022). The quantitative research activities will be enhanced by qualitative and mixed methods research focusing on housing and LTSS needs and outcomes.

Community-Based Participatory Research (CBPR) is one way researchers might incorporate and share power with people from targeted communities into research conceptualization, design, and administration process at all stages to address racism and discrimination in systems of power (e.g., government systems or academic institutions; Fleming et al., 2023). To foster meaningful partnerships, this requires including people with people with IDD from diverse racial, ethnic, and cultural communities in informing and conducting research and mentoring and building the capacity of future researchers with IDD from marginalized communities (Johnson, Bogenschutz & Peak, 2021). Approaching this research using an intersectionality-based policy analysis framework (Hankivsky et al., 2014) may also be helpful.

### **Practices**

While it is beyond the scope of this paper to fully explore interventions to address disparities and other needs identified by the Housing and LTSS Workgroup, the workgroup wanted to call attention to the need to use person-centered practices in LTSS settings and services. Person-centered practices (PCP) are practices that increase choice, advocate for difference, honor the voices of the individual with

a disability and those who know the person best, build relationships, design supports on a case-by-case basis, and advocate for change at the organizational level (O'Brien & O'Brien, 2000). PCP allows us to meet individual needs in a culturally responsive way. Providers using a PCP approach while assisting individuals with IDD create plans for housing or LTSS include the person throughout the process and assist the person to achieve the goals they identify. The 2014 Medicaid Home and Community Based Services Rule requires all Medicaid HCBS services to use PCP. It will be important to evaluate the extent to which these requirements are being implemented within and across states.

Finally, the workgroup emphasized the importance of ensuring that research findings are available and accessible to all relevant stakeholders. Research findings should be translated into formats that are easy to find and understand. People with IDD from racially and ethnically minoritized groups should participate in developing, designing, and sharing research findings. Researchers should support people with IDD to use the findings to advocate for improvements in their services. Findings should be communicated in the language of the target population using mediums suited for them. Resources should be budgeted for translating key findings into plain language and for non-English speaking audiences. Researchers should consult with or employ journalists to share findings with the public, hold community forums to listen to people affected by the research to identify unmet needs, and use strategies such as community data walks (as described by the Urban Institute; Murray et al., 2015) to share research findings.

### **Discussion and Conclusions**

This article describes the status of research on housing and LTSS for people with IDD from racially and culturally minoritized groups, reviews studies describing disparities, and shares findings and recommendations from the housing and services strand of 2022 *State of the Science Conference on the Intersection of Diversity, Equity and Inclusion and Supports and Services for People with IDD*.

The available research on housing and LTSS experiences and needs for people with IDD from racially and culturally minoritized groups is limited. More, and more diverse research is needed on the extent to which housing and LTSS are available in the array, type and intensity needed, whether those services are accessible, acceptable, and of high quality, and whether services meet the needs of individuals and families. This research must be developed through thoughtful and authentic collaboration with people with IDD from those groups. High quality qualitative, quantitative, and mixed research methods are needed to fully understand the disparities and to generate culturally competent strategies to improve outcomes. The Housing and LTSS Workgroup identified a few priority research topics, but that list should be edited and expanded as research is cocreated with people from this population.

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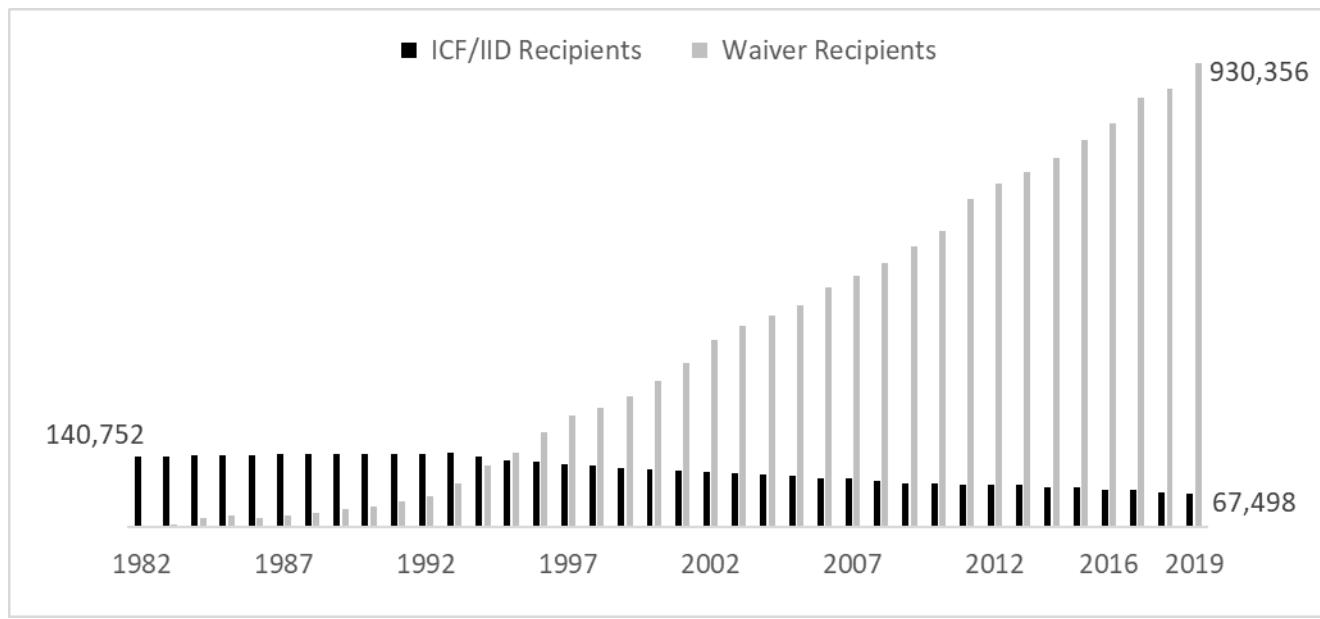
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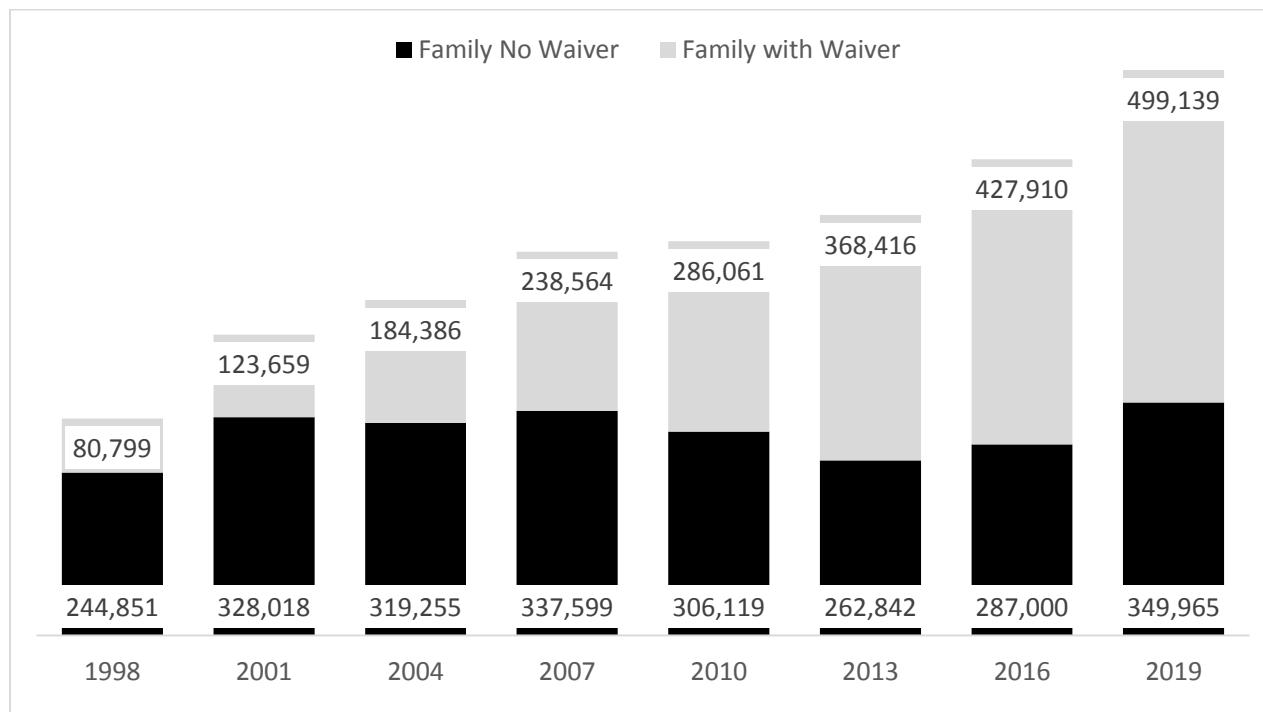
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**Figure 1** Medicaid ICF/IID and Medicaid Home and Community Based Waiver Recipients with IDD 1982 to 2019



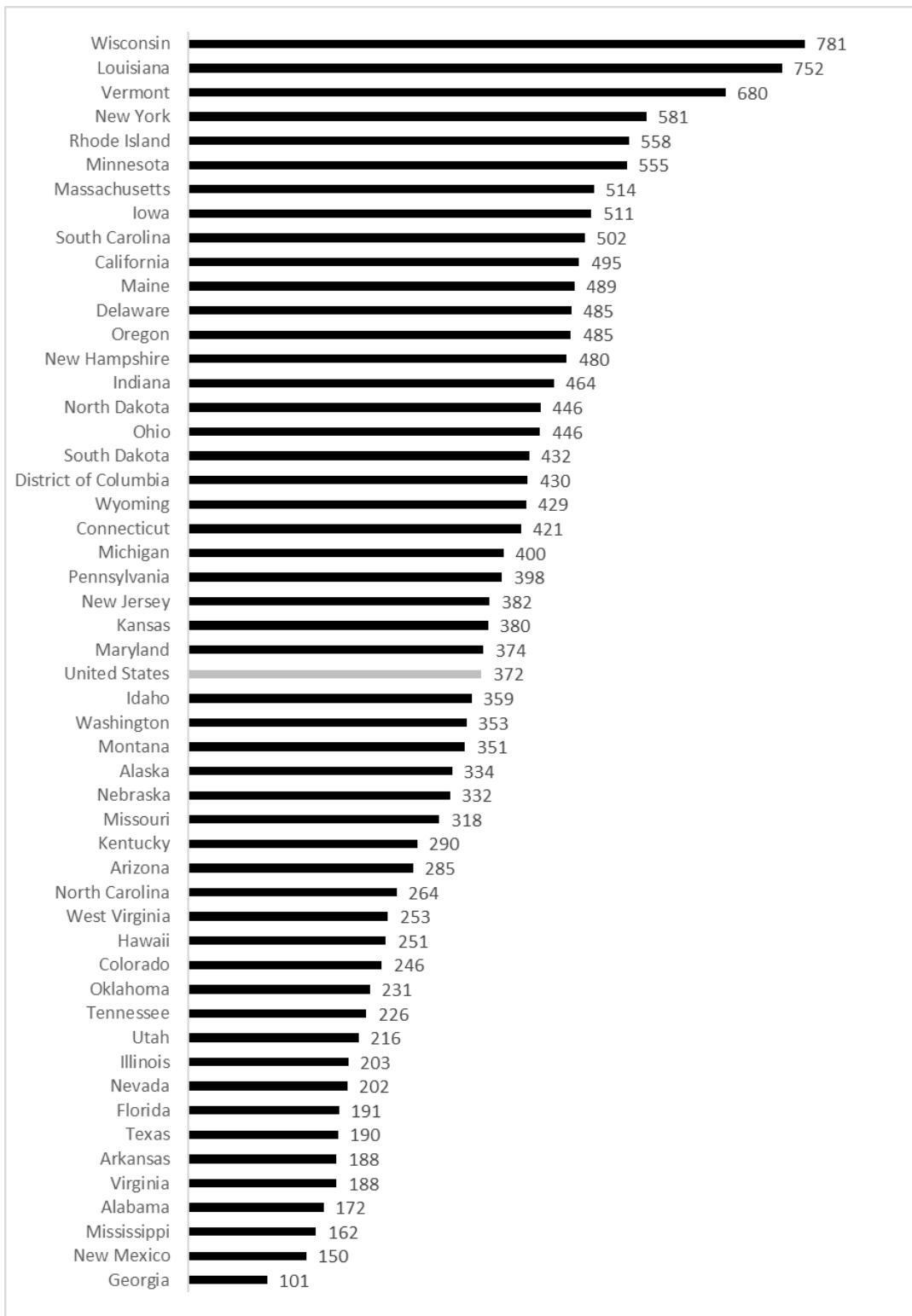
Data Source Larson et al. (2022).

**Figure 2** Number of LTSS Recipients with IDD Living with a Family Member Whose Supports Are or are not Funded by a Medicaid HCBS Waiver Selected Years from 1998 to 2019.



Data Source Larson et al. (2022).

## Housing Disparities for People with IDD

**Figure 3** Number of LTSS Recipients Ages 22 years or Older Served by State IDD Agencies per 100,000 of the Population

Data Source Larson et al. (2022).