
Housing Needs for Individuals with Intellectual and Developmental Disabilities

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The authors are solely responsible for any errors or omissions.

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Executive Summary

Introduction

Individuals with intellectual and developmental disabilities (IDD) desire more options to live independently or in a housing setting of their choice. Improved living skills¹ and better health outcomes² for individuals with IDD can be linked to different living arrangements. Housing with the right levels of independence, affordability, and support can be life-affirming and can maximize wellbeing in any household, not just those with IDD. Yet, a lack of data to quantify the number of individuals in the IDD community in Oregon and Southwest Washington, misperceptions about needs and desires for housing, and a lack of affordable and accessible housing options in the region leave many in housing situations that are not sustainable or limit independence.

Oregon, Southwest Washington, and our nation as a whole have a troubled history when it comes to housing for individuals with IDD. In the past, and to some extent today, individuals with disabilities have been stigmatized, confined to institutions, and isolated from society. The civil rights efforts of the 1960s spurred new thinking about individuals with disabilities, as structural barriers and systemic discrimination were questioned and slowly dismantled.

These societal shifts had a lot to do with where people with IDD lived. Previously relegated to residential institutions that were isolating and disenfranchising, calls for community integration and person-centered care grew with the movement.³ These efforts were encouraged by federal legislation, policy changes, and litigation that incentivized and eventually mandated public health systems to shift the locus of care to the community. The process of deinstitutionalization was undoubtedly a positive change for society, individuals with IDD, and their families, but goals around community integration have fallen short. Policies and litigation focused on transitioning individuals out of institutions failed to consider, fund, or plan for alternative housing options. This has left individuals with few options: live with family caregivers, navigate byzantine regulations to find supports in the

“We generally understand what we want to remove and avoid in disability housing and services, but we lack a consensus about what we want to add or create.”

- Harvard Joint Center for Housing Studies, 2015

¹ Charlie Lakin, Sheryl Larson, and Shannon Kim, “The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities?” *Evidence-Based Policy Brief*, March 2011: 1-4, https://www.aucd.org/docs/councils/core/Evidence-Based%20Policy%20Brief_1.pdf.

² The Association of University Centers on Disabilities and the American Association on Intellectual and Developmental Disabilities, “Community Living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us,” 2015, <https://tash.org/wp-content/uploads/2015/08/CommunityLivingPaper-Final-1.pdf>.

³ Micaela Connery, *Disability Housing: What’s happening? What’s challenging? What’s needed?* (Cambridge, MA: Harvard Joint Center for Housing Studies, April 2016).

private market, or live in group homes or foster care settings that potentially give up independence.

Today, individuals with IDD live in one of these three broad categories: in supervised residential settings such as group homes or foster care homes, independently (alone or with roommates), or with family caregivers. However, the region's housing affordability crisis and national demographic trends pose risks for individuals living in two of these three settings:

- **Independent housing options are limited by affordability and accessibility.** Housing unaffordability has two root causes: 1) the unusually high cost of housing because of market conditions, government regulatory policy, or both, and, 2) the low incomes of the people accessing the housing. In the Pacific Northwest, many adults with IDD face challenges on both fronts. The housing market is not producing enough supply at the right price points for low income individuals with IDD. And despite having lower incomes and needing more support than other communities, individuals with IDD are not specifically prioritized for regulated affordable housing, which is an important option to maximize independence.
- **Adults with IDD living with aging family caregivers may also be at risk.** Caregivers who are part of the baby boomer cohort (those who are over age 60) may struggle to continue to provide care as their own health deteriorates and they eventually pass on. The vast majority of individuals with IDD in the region live with caregivers. And the vast majority of individuals with IDD whose caregiver is over age 60, are themselves adults who will soon need alternative housing options. With few affordable housing options available, these individuals face housing insecurity. Further, many individuals with IDD living with caregivers are not currently connected to state service agencies and would face an emergency enrollment or lapse in care if a caregiver were suddenly unable to provide care.

These trends will threaten the housing security for many adults with IDD during this decade. For those who wish to live independently – some of whom may need rent assistance and or wraparound services – the affordability crisis and competing demand for regulated affordable housing limits choice. And those who live with aging family caregivers may struggle to find housing alternatives in a tight housing market when a caregiver passes or is no longer able to provide care. Without affordable and accessible options, many individuals with IDD who desire to live independently may be unable to find a suitable unit and may turn to housing settings that are less independent than they desire, more expensive than they can afford, or may face homelessness.

This report seeks to estimate the number of adults with IDD who are facing housing insecurity in Oregon and Southwest Washington and identifies key recommendations that can improve housing options and stability.

However, understanding the scale of this issue—necessary to inform potential solutions—is challenged by a lack of current, reliable data. Estimates of the total population of adults with IDD—regionally and nationally—rely on quarter-century-old survey data that researchers do not believe reflect conditions today. The absence of a reliable answer to a basic, fundamental question—*how many adults with IDD live in Oregon and SW Washington?*—limits the broader conversation about affordable, stable housing for the IDD community. This report draws on the best available research, highlights the gaps in industry knowledge, and begins to characterize the housing challenges faced by the region’s adults with IDD.

Fundamental data on this population - the number of people, basic demographics, and living arrangements - are some of the most outdated and assumption-laden this firm has experienced in 30+ years working on public policy solutions.

Key Findings

The region’s housing crisis—bad for everyone—is undoubtedly far more challenging for adults with IDD. Many in the community live with aging caregivers, rely on fixed incomes, and—like everyone in the region—encounter an increasingly unaffordable market. Imprecise estimates suggest that around 24,000 adults with IDD in the region face housing insecurity. A more precise understanding of housing needs requires better national and state data. And improving these conditions will require IDD-focused housing policies and better coordination of housing support and wrap-around services.

Data Limitations on IDD Prevalence

- **Research on the prevalence of IDD among adults is outdated and an inadequate foundation for assessing baseline conditions or making policy.** The top scholars in the IDD field rely on a study conducted in 2001⁴ that, in turn, used national survey data collected during 1994-1995.⁵ The study estimated that in the mid-1990s about 8 out of every 1,000 adults in the United States lived with an intellectual or developmental disability. The rate is accepted as the best available and is used in a number of federally funded reports.

This lack of quality data is not a new issue, as calls for better data have been made since the mid-1990s.⁶ However, progress has actually waned: instead of adding questions to national health surveillance surveys to better understand people with IDD in the U.S.,

⁴ See for example: *The State of the States in Intellectual and Developmental Disabilities, “Oregon and Washington State Profiles,”* (Broomfield, CO: University of Colorado, 2020), <https://stateofthestates.org>; Sheryl Larson, Heidi Eschenbacher, Lynda Anderson, Sandy Pettingell, and Amy Hewitt, “In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2016,” (Minneapolis, MN: The Residential Information Systems Project, 2018), <https://risp.umn.edu/>.

⁵ Sheryl Larson, Charlie Lakin, Lynda Lahti Anderson, Nohoon Kwak, Jeoung Hak Lee, and Deborah Anderson, “Prevalence of Mental Retardation and Developmental Disabilities: Estimates From the 1994/1995 National Health Interview Survey Disability Supplements,” *American Journal of Mental Retardation* 106, no.3 (June 2001): 231-252, DOI: 10.1352/0895-8017(2001)106<0231:POMRAD>2.0.CO;2.

⁶ Ibid.

two promising national surveys removed questions in 2019 that could help to identify individuals with IDD.^{7,8} As such, the best way to estimate the full number of adults with IDD remains by using prevalence rates that are based on 25-year old population survey data.

- **When applied to current population levels, the quarter-century-old prevalence rate implies more than 31,000 adults in the region live with IDD.** If IDD prevalence rates have not changed in the past 25 years and the region’s prevalence rates are the same as the nation’s—two important assumptions—then the seminal study implies that about 26,600 Oregon adults and 4,500 Southwest Washington adults lived with IDD in 2019.
- **Newer, related studies suggest IDD prevalence rates among adults are probably higher than found through the mid-1990s survey.** While the federal government has not replicated the depth of the 1994-1995 National Health Interview Survey (NHIS) disability supplement in the past 25 years, newer research suggests the widely accepted IDD prevalence rate is conservative.

In 2015, an Ohio-based study, focused on adult Medicaid recipients, estimated a 41 per 1,000 prevalence rate for people with *developmental disabilities* rather than the wider IDD population.⁹ If today’s true adult prevalence rate is closer to this estimated rate out of Ohio, the total population of adults with IDD would be five times higher: more than 138,000 in Oregon and 23,400 in Southwest Washington.

Research on the prevalence of IDD among children is more up to date, in part because of the emphasis of service provision for students with special needs. A 2017 study estimated IDD prevalence among children at 70 per 1,000—or almost nine times the commonly used rate for adults.¹⁰

- **State caseloads for IDD-service recipients shed some light on characteristics of the adult population. But not all adults with IDD receive services, so the picture is incomplete.** The percent of adults with IDD receiving state services depends on the total population estimated from the prevalence rate. Using the Larson Study prevalence rate, Washington serves about 61 percent of the estimated adults with IDD while Oregon

⁷ Susan Havercamp, Gloria Krahn, Sheryl Larson, Glenn Fujiura, Tawara Goode, Barbara Kornblau, and the National Health Surveillance for IDD Workgroup, “Identifying People With Intellectual and Developmental Disabilities in National Population Surveys,” *Intellectual and Developmental Disabilities* 57, no. 5 (October 2019): 376–389. <https://doi.org/10.1352/1934-9556-57.5.376>.

⁸ Alexandra Bonardi, Gloria Krahn, Andrew Morris, and the National Workgroup on State and Local Health Data, *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities*, (Washington, DC: Administration on Intellectual and Developmental Disabilities, 2019).

⁹ RTI International, “2015 Ohio Medicaid Assessment Survey: Methodology Report.” (Research Triangle Park, NC: RTI International, 2015), <http://grc.osu.edu/sites/default/files/inline-files/12015OMASmethReptFinal121115psg.pdf>.

¹⁰ Benjamin Zablotzky, Lindsey I. Black, and Stephen J. Blumberg, “Estimated Prevalence of Children With Diagnosed Developmental Disabilities in the United States, 2014–2016,” *National Center for Health Statistics Data Brief*, No. 291 (November 2017): 1-8, <https://pubmed.ncbi.nlm.nih.gov/29235982/>.

serves about 73 percent.^{11 12} If an updated prevalence study were to show higher rates of IDD in the adult population, those estimated program participation rates would fall and the “invisible,” unserved population would grow.

Affordable Housing Needs

- **An extension of recently released research from the federally funded Coleman Institute suggests there may be upwards of 24,000 adults in the region with IDD who are at risk of losing their housing in the coming years.** Without a good estimate of the overall number of adults with IDD, it is even harder to identify the number of those adults who have insufficient housing options. However, a recently released *State of the States* report—issued by the University of Colorado’s Coleman Institute—addresses housing conditions and offers clues about the magnitude of the problem.¹³ The Institute estimates the number of adults with IDD who live independently as well as those who live with family caregivers.

Beginning with the Institute’s estimate of the number of adults living independently, this report measures housing instability via cost burdening – which occurs when a household spends more than 30 percent of its income on housing-related costs.

Using Census data proxies, this is estimated to be about 5,500

adults with IDD in Oregon and 1,100 adults with IDD in Southwest Washington.

Secondly, the Institute estimates the number of individuals with IDD who live with caregivers, and separates the data by caregiver age. This report considers those living with a caregiver over age 60 to be at risk of housing instability, given the chance of the caregiver developing an incapacitating illness or dying in the next 8-10 years. Again, using Census data to sharpen the calculation, this is estimated to be about 15,200 adults with IDD in Oregon and 2,700 adults with IDD in Southwest Washington.

These are rough estimates and sit at the lower end of plausible answers. The true number could be multiple times higher, depending on how severely the existing prevalence rates undercount the true population. Supervised residential settings, such as group homes, intermediate care facilities, or foster care homes are excluded from estimates of housing instability. The benefits, challenges, and risks associated with housing stability in these settings are worth future study.

There may be upwards of 24,000 adults in the region with IDD who are at risk of losing their housing in the coming years.

¹¹ Washington Developmental Disabilities Administration, “2019 Caseload and Cost Report,” <https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/2019%20Caseload%20and%20Cost%20Report.pdf>.

¹² Oregon Health Authority and Oregon Department of Human Services, “Spring 2019 OHA-DHS Caseload Forecast,” (Salem, OR: Office of Forecasting, Research & Analysis, 2019). <https://www.oregon.gov/DHS/business-services/OFRA/ofradocuments/Spring%202019%20Regional%20Caseload%20Forecast.pdf>.

¹³ The State of the States in Intellectual and Developmental Disabilities, “Oregon and Washington State Profiles,” (Broomfield, CO: University of Colorado, 2020), <https://stateofthestates.org>.

- The region’s current regulated affordable housing stock is in high demand and short supply and does not prioritize individuals with IDD.** In high-cost housing markets like the Pacific Northwest, regulated affordable housing is key to providing housing choice to low-income adults with IDD. But this housing is in short supply. Oregon’s housing finance agency estimates that there are 2,650 units in 66 apartment buildings with set-aside preferences for individuals with “developmental disabilities,” and does not offer competitive funding advantages for developers looking to use tax credits to build new units for this population.¹⁴ In Washington, the housing finance agency does not have a publicly available estimate for the number of units set-aside for individuals with IDD, and also does not provide an advantage for developers looking to use tax credits to build new properties.
- In most housing markets in Oregon and Southwest Washington, monthly rents exceed supplemental security income (SSI) benefits, which can be an important income source for people with IDD.**¹⁵ In Oregon, the 2019 median SSI payment was \$783 per month, which was less than the average monthly rent for a one-bedroom apartment in almost every major market. In Washington, the median monthly SSI payment of \$823 was slightly higher than the average one-bedroom monthly rent in Southwest Washington housing markets but would leave little remaining for other basic necessities. Individuals with IDD in the region who rely on SSI payments for all or a portion of their housing costs will struggle to find housing that costs less than the average monthly benefit.

Despite having lower incomes and needing more support than other communities, individuals with IDD are not specifically prioritized for regulated affordable housing, which is an important option to maximize independence.

Over the past two decades, average nominal monthly rents in the Portland metro area grew 83 percent, while nominal monthly SSI payments grew only 50 percent.¹⁶ SSI benefits typically grow at 2-3 percent per year, but housing costs in the Portland market have seen 8-10 percent growth in some years. For individuals with IDD living in unregulated housing, rent increases can create housing risk. And for individuals facing housing instability due to aging caregivers, finding affordable, accessible housing can be challenging in tight housing markets.

Lack of Coordination

- Research and interviews identified a severe lack of coordination between housing and service agencies in each state.** Community-based living settings have been shown

¹⁴ Oregon Housing and Community Services, “Housing Inventory Data,” <https://www.oregon.gov/ohcs/Pages/research-multifamily-housing-inventory-data.aspx>.

¹⁵ Technical Assistance Collaborative, “Priced Out Where You Live Tool,” <http://www.tacinc.org/knowledge-resources/priced-out-v2/>.

¹⁶ ECONorthwest analysis of 2020 CoStar data and 2019 Social Security and Supplemental Security Income Data. Social Security Administration Office of Retirement and Disability Policy, Office of Research, Evaluation, and Statistics, “Annual Statistical Supplement to the Social Security Bulletin, 2019,” (Washington, DC: Social Security Administration, 2019), <https://www.ssa.gov/policy/docs/statcomps/supplement/2019/supplement19.pdf>.

to improve living skills¹⁷ and offer better health outcomes¹⁸ for individuals with IDD compared to larger residential institutions. However, state agencies responsible for service provision and the well-being of individuals with IDD in Oregon and Washington do not meaningfully interact with the housing agencies to create more community-based options. The state agencies providing services for individuals with IDD do not provide housing while the state housing agencies do not have priorities or preferences for this population. Similar to national efforts, many advancements made in community integration, person-centered care, and funding improvements for individuals with IDD have been driven by advocates, often using litigation to encourage state and federal agencies into action.

- **Regulated affordable housing developers are unaware of subsidy options and underutilize funding opportunities for individuals with IDD.** In 2015, Oregon Housing and Community Services received \$2.3 million from the U.S. Department of Housing and Urban Development (HUD) for rental assistance for extremely low-income Oregonians (those earning 0-30 percent of the area median income) “with severe and persistent mental illness, intellectual disabilities, and/or developmental disabilities.”¹⁹ It committed to building 75 units of affordable housing for this population but has only built 23 units thus far.

This underuse of hard-to-find development subsidies illustrates the large disconnect between service providers and housing providers. Developers looking to build affordable housing at this income level often have difficulty securing funding for the resident services that help tenants thrive. But because of a general lack of awareness of the support needs, funding mechanisms, and policy environment surrounding the IDD population, these developers may not know how to effectively utilize the program and take advantage of the subsidy. This underuse of hard-to-find development subsidies illustrates the large disconnect between service providers and housing providers.

Recommendations

The following recommendations start with the decades-old call for better data on the population. Public policy is lost without it. But action cannot wait for better data. The needs are too urgent. The twin trends of aging caregivers and rising housing costs will make the conditions outlined in this report even more challenging over the next decade.

The good news is the region is embarking on nation-leading efforts to increase housing production, improve affordability, and prevent homelessness. Improving housing conditions for adults with IDD should be among the top priorities of those efforts. Further work on data

¹⁷ Lakin, Larson, and Kim, 2011.

¹⁸ The Association of University Centers on Disabilities and the American Association on Intellectual and Developmental Disabilities, 2015.

¹⁹ Oregon Housing and Community Services, “HUD 811 Project Rental Assistance (PRA),” <https://www.oregon.gov/ohcs/Pages/hud-811-project-rental-assistance.aspx>.

collection, increased housing options, and better coordination can help Oregon and Washington leaders continue to advance community integration, individual choice, and person-centered care for this community.

Improve Data Collection Efforts

While most recommendations relate to housing choices and stability, it is critical to have better data on the needs, desires, and current living arrangements of adults with IDD in the region, in addition to the size of the population itself. Without a fundamental understanding of the scale of the population and existing housing conditions – how many people live in what type of setting, and whether those are stable, desirable, life-affirming options – it is difficult to implement policies and move toward person-centered care ensuring that all individuals are living in housing that maximizes well-being. The following recommendations could help Oregon and Washington better understand the population of adults with IDD in each state along with current housing choices and future needs.

- **Align with national efforts to update the prevalence rate of adults with IDD.** Advancing public policy requires three steps: defining a problem, designing solutions to address the problem, and finding the political ways and means to implement a solution. Clearly there is a great need for better, more accurate, and more recent data on the population of adults with IDD. Oregon and Washington stakeholders lack the needed funding to carry out census-style surveys but should put their weight behind national efforts and calls for better data.
- **Enhance state data collection efforts.** Oregon and Washington should not wait for federal efforts to improve national health surveillance survey data but can work toward improving their own state data collection and analysis efforts. The best place to start is expanding the data collected and analyzed at Washington’s Developmental Disabilities Agency (DDA) and Oregon’s Office of Developmental Disabilities Services (ODDS) since they already have the means to contact and work with individuals known to have IDD. These agencies should collect more information on the individuals and families they serve, including preferences and satisfaction with living arrangements, employment, and social activities, as well as measures of autonomy and life direction. The questions used in the National Core Indicators annual surveys can serve as an example of what types of information should be collected and analyzed. A parallel effort should be undertaken to collect information on individuals and families who are not known to or served by the state agencies.
- **Align intra-agency capacity and ability to link and analyze data.** The Oregon ODDS and Washington DDA should work with other state agencies interacting with and serving individuals with IDD – such as the education department or agencies responsible for Medicaid and SSI benefits. Efforts should be made to link data from different department databases to leverage collection efforts and provide enhanced understanding of the health and service needs of this population. In addition, harmonizing the different definitions of IDD and differing eligibility criteria across these

agencies can help to improve each agency's ability to use and analyze data and conduct outreach. Streamlining these different definitions can also greatly improve clients' ability to access and receive services.

- **Conduct additional outreach to find and serve individuals unknown to state agencies.** DDA and ODDS should work with other state agencies serving adults and children with IDD and should also expand into the community, including faith based organizations, community service organizations or homeless shelters, to conduct outreach to families and individuals in an effort to help identify people with IDD previously unknown to the agencies.

Increase Housing Options

The housing markets along the West Coast are some of the most expensive in the nation because of a decade of underproduction and continued growth in the number of households. People who have fewer housing options – those with low incomes or large families, those who need accessible units, or those who need in-home supports – are often neglected by the majority of private market housing developers, who focus on building new housing for the general population and mass market needs. This can leave households of all types in precarious situations – living in undesirable locations or settings, living doubled up with friends or family, or paying too much for housing.

This report's finding that 24,500 adults with IDD in the region – and potentially many more – may face housing instability warrants policy action to increase housing options and reduce risk. These individuals may be at risk of homelessness, curtailed independence, or a rapid, traumatic transition in care if a caregiver is suddenly unable to provide care or if housing costs increase. The following recommendations are a starting point to help increase housing choices, accessibility, and affordability for individuals with IDD in Oregon and Southwest Washington.

- **Elevate the needs of adults with IDD when allocating scarce housing resources.** Agencies charged with allocating scarce housing resources could do more to prioritize support for adults with IDD. For example, Qualified Action Plans (QAPs) govern the distribution of the Low-Income Housing Tax Credit (LIHTC), the largest source of funding for newly constructed affordable housing in the nation.²⁰ Neither Oregon's nor Washington's QAP calls out specific prioritization or funding boosts for projects that include set-asides for people with IDD. Oregon's QAP offers additional points to preservation projects that house tenants who are at risk of displacement – but this wide definition includes all disabled households, along with frail elderly households and large family households. It does not appear to offer additional points for including any

²⁰ Corianne Payton Scally, Amanda Gold, and Nicole DuBois, *The Low-Income Housing Tax Credit: How It Works and Who It Serves*, (Washington, DC: The Urban Institute, July 2018), https://www.urban.org/sites/default/files/publication/98758/lithc_how_it_works_and_who_it_serves_final_2.pdf.

disabled populations in new construction projects.²¹ Washington’s QAP offers additional points to new construction project applications if the development includes at least 20 percent of its units for people with disabilities²² but does not specify between disability types.

- **Use the newly approved Metro resources to end homelessness for adults with IDD in tri-county Portland.** In May, Portland-area voters passed a tax initiative to address the region’s homeless crisis.²³ Local governments will use the resources to provide supportive housing for people experiencing, or at risk of, chronic homeless and for people with disabilities at risk of homelessness. Thus, the initiative provides an opportunity for targeted attention on building new housing for low-income individuals with IDD.

Data on the counts and characteristics of people experiencing homelessness are notoriously unreliable and decidedly low. As discussed, the data used to estimate adult IDD prevalence are 25 years old. Thus, identifying the number of people with IDD who are experiencing homelessness lies at the intersection of challenging, faulty data. However, larger counties with substantial homeless populations do make an effort. In 2019, Multnomah County’s Point-In-Time count estimated that 198 people with a “developmental disability” experienced homelessness on a given night in January.²⁴

The size of the Metro services measure should be sufficient to end chronic homelessness for all adults with IDD in the tri-county area, as well as lower the rents of low-income adults with IDD who face cost-burdening and may be at risk of homelessness.

- **Get behind calls to preserve existing affordable housing.** It is clear that more housing units and more housing options are needed to serve the adult population with IDD. However, it is equally important to ensure that current housing options are maintained and preserved for continued use. Interviewees noted that much of the housing stock that serves adults with IDD – such as group homes or regulated affordable housing – was built in the 1990s in the wake of lawsuits and deinstitutionalization efforts. These properties are now aging, and many have insufficient operating budget and reserves to pay for deferred maintenance and necessary capital improvements. Without a robust

²¹ Oregon Housing and Community Services, *State of Oregon Qualified Allocation Plan For Low Income Housing Tax Credits*, (Salem, OR: Oregon Housing and Community Services, November 2019), <https://www.oregon.gov/ohcs/HD/MFH/LIHTC/QAP/2019-QAP-Final.pdf>.

²² Washington State Housing Finance Commission, *9% Competitive Housing Tax Credit Policies 2020*, (Seattle, WA: Washington State Housing Finance Commission, June 2019), <http://www.wshfc.org/mhcf/9percent/2020application/c.policies.pdf>.

²³ Oregon Metro, “Supportive housing services: Addressing homelessness in greater Portland,” <https://www.oregonmetro.gov/public-projects/supportive-housing-services>.

²⁴ City of Portland Oregon, Home Forward, A Home for Everyone, Multnomah County, and City of Gresham, “2019 Point-In-Time Count of Homelessness in Portland/Gresham/Multnomah County, Oregon,” <https://multco.us/file/82568/download>.

preservation strategy, these looming capital obligations put this existing housing stock at risk.

Regulated affordable housing is an important housing option for people with IDD to live as independently as possible: without sufficient accessible and affordable housing options, many individuals with IDD live in housing that has less independence than might be preferred (such as a supervised residential setting or remaining with family). Advocates, researchers, and policy makers should support efforts to fund and preserve this important component of housing stock to increase independent housing options for people with IDD.

Improve Housing and Service Coordination

Data and housing solutions are needed to understand the scale of the issue and reduce housing instability for individuals with IDD in the region. But without improved coordination and communication between housing and service providers, the system will remain difficult and complex for families and individuals to navigate as they piece together funding, prove eligibility, and find suitable housing options. The following recommendations can help streamline these complexities and encourage families and individuals to plan ahead for housing options in an environment of aging caregivers and declining affordability.

- **Provide family caregivers—especially aging caregivers—resources and education to prepare for care transitions.** Surveys conducted by the National Core Indicators (NCI) program can shed some light on what caregivers of individuals with IDD need. In 2018-2019, 55 percent of Oregon survey respondents²⁵ and 56 percent of Washington survey respondents²⁶ (caregivers of individuals with IDD of all ages who receive state supports) suggested they needed help planning for housing, above the 48 percent national average.

Importantly, housing options need to be available for family caregivers to plan for. Just as the deinstitutionalization process was not paired with a plan for housing alternatives, caregivers cannot plan for transitions without meaningful housing options that will maximize well-being for their family members.

- **Bridge the gap between housing supports and services.** To live independently, some adults with IDD require a combination of rent subsidies and wraparound support services. But the provision of subsidies and services is disconnected. Research, anecdotal evidence, and interviews suggests that agencies providing services for people with IDD are “not in the business of providing housing,” and the state housing agencies do not prioritize adults with IDD in their eligibility criteria. Better integration of housing with

²⁵ National Core Indicators, *Child Family Survey (CFS) State Report: Oregon (OR) Report*, (Cambridge, MA: National Core Indicators, 2019), <https://www.nationalcoreindicators.org/states/OR/>.

²⁶ National Core Indicators, *Child Family Survey (CFS) State Report: Washington (WA) Report*, (Cambridge, MA: National Core Indicators, 2019), <https://www.nationalcoreindicators.org/states/WA/>.

services and coordination amongst these agencies are needed to provide more housing options and better housing security for individuals with IDD.

- **Help developers understand the in-home support funding for individuals with IDD to incentivize more affordable housing units affordable at 0-30 percent of area median income.** Developers looking to build affordable housing at this income level often have difficulty securing funding for the resident services that help tenants thrive. Due to the lack of coordination between housing developers and service providers, many developers are unaware that individuals with IDD have supportive services funded through the state IDD agency. Better awareness of the synergies between housing development opportunities and already-funded support services could help encourage the development of more affordable housing units for this population.

This recommendation would be particularly helpful paired with the “universal design” concept, where units are architecturally designed to be universally accessible to a wide range of people and abilities. With universal design, individuals with disabilities who can and want to live independently are able to live in any unit at a property, rather than just a few that are set aside in compliance with the Americans with Disabilities Act (ADA) standards. If the cost of building to universal design standards is not prohibitively higher than baseline costs (perhaps an area of future study), this can provide the developer with flexibility in the funding subsidy and provide tenants with more unit availability rather than needing to wait for a select few units to become available.

Conclusion

The request for this study was exceptionally well-timed. In recent years, academics, policymakers, and advocates have amplified calls for a better understanding of the number, characteristics, and living conditions of adults with IDD. Those calls take on a greater urgency in a year that opened with a global pandemic and recession. The public health and economic crises will likely exacerbate two longer standing trends that have weakened housing stability of adults with IDD: the increasing mortality rate of aging caregivers and the unrelenting increase in the cost of housing. In short, a population that has always encountered extraordinary, housing-related challenges is entering an even more challenging era.

Policymakers who seek to improve housing conditions for adults with IDD need much better information about the population and service programs. This report provides the beginning of a problem statement: a sizable population of adults with IDD face housing instability, and demographic and market trends suggest the population at risk will grow in coming years. But, the most important findings are less about what this report could say and more about what it could not: *there is far too little known about adults with IDD in Oregon and Southwest Washington.*

The good news is that the Kuni Foundation is not alone in its efforts. Advocacy for an updated U.S. prevalence rate is underway by a well-coordinated group of national experts. State analysts —if asked— are capable of providing a much richer understanding of the profile of individuals

who access IDD-related services. And, in the Portland area, the unprecedented effort to end homelessness provides an opportunity to learn more about housing challenges for this community.

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1. Introduction

As part of its advocacy efforts to improve the lives of adults with intellectual and developmental disabilities (IDD) in Oregon and Southwest Washington, the Kuni Foundation contracted with ECONorthwest to study housing insecurity for people with IDD. The Foundation sees twin challenges limiting housing options and increasing housing risk for individuals with IDD: a housing affordability crisis along the West Coast which severely limits options for adults with IDD who have low-incomes and desire to live independently, and the national demographic trend of the aging baby boomer cohort which creates risk for adults with IDD who live with an older caregiver.

The combination of both of these challenges—a growing need for housing options as caregivers age, and already too few affordable options for independent living arrangements—points to a larger problem looming ahead. Crafting solutions to this growing problem will require policy actions that need to begin now. But without a solid understanding of the scale of the issue, awareness and action toward those solutions will be limited. Understanding the urgency of these trends, the Kuni Foundation commissioned this report to quantify how many adults (over age 18) with IDD might be at risk of housing insecurity in the coming years and offer recommendations to advance policy solutions across the IDD and affordable housing communities.

Historical Context

Beginning in the 1960s and continuing today, communities have been working to dismantle the structural barriers that have kept individuals with IDD isolated from society. One of the major efforts of this movement has been reintegrating people with IDD into the community by closing large, isolating, government-run residential institutions and funding community-based settings focused on individual needs. This process of deinstitutionalization was spurred in the late 1960s due to a volume of media exposés that revealed many overcrowded institutions with sub-standard levels of medical care and poor living conditions.²⁷

Federal and state governments created programs and funding streams to aid these transitions, while policy changes and litigation also helped encourage the shift. The signing of the Americans with Disabilities Act (ADA) in 1990 was a crucial piece of civil rights legislation that prohibited discrimination against persons with disabilities.²⁸ Furthermore, the landmark Olmstead Supreme Court ruling of 1999, which used the ADA as a basis for its decision,

²⁷ Gretchen Engquist, Cindy Johnson, and William Courtland Johnson, *Trends and Challenges in Publicly-Financed Care for Individuals with Intellectual and Developmental Disabilities* (Hamilton, NJ: Center for Health Care Strategies, Inc, September 2012), http://www.chcs.org/media/IDD_Service_Delivery_Systems_082812.pdf.

²⁸ United State Department of Justice, Civil Rights Division, “Information and Technical Assistance on the Americans with Disabilities Act,” https://www.ada.gov/ada_intro.htm.

summarily declared “that people with disabilities have a qualified right to receive state funded supports and services in the community rather than institutions.”²⁹

The ADA coupled with the Olmstead decision further propelled the nation-wide effort of deinstitutionalization forward. Some states fully deinstitutionalized before 1999, such as New Hampshire, Vermont, and Rhode Island. While some states still have institutions open today, a majority of states (including Oregon) closed their institutions between 1960 and 2008, decreasing the total count by 186 establishments (354 down to 168).³⁰

The process of deinstitutionalization was undoubtedly a positive change for society, individuals with IDD, and their families, but goals around community integration have fallen short. Policies and litigation focused on transitioning individuals out of institutions failed to consider, fund, or plan for alternative housing options. This has left individuals who want to live as independently as possible with few options: live with family caregivers, navigate byzantine regulations to find supports in the private market, or live in IDD group homes or foster care settings and potentially give up independence.

“Even as expectations for people with IDD have changed to include better health and greater participation in their communities, eligibility for services that support these outcomes is rooted in expectations of dependence and poverty.”

- Gloria Krahn, 2019

This lack of housing options with varying levels of independence is not necessarily a new issue. However, new problems are emerging that increase the urgency of needing to create more housing options: rising home costs in many housing markets around the region are limiting the supply of affordable, accessible units for individuals with IDD who desire to live independently, and the baby boomer generation is aging and caregivers in this cohort may soon be unable to provide for their family members with IDD.

Scope of This Work

Recognizing the urgency of this problem, this report sought to investigate housing insecurity for adults (over age 18) with IDD. Answering this question, however, requires taking a step back to understand an even more basic question – *how many adults with IDD are living in Oregon and Southwest Washington?* Unfortunately, this was not a simple question to answer. Fundamental data on this population – the number of people, basic demographics, and living arrangements – are some of the most outdated and assumption-laden we have experienced in 30+ years working on public policy solutions.

Thus, in addition to evaluating housing insecurity and offering recommendations to improve housing choice and stability, this report summarizes the relevant research on adults with IDD,

²⁹ OlmsteadRights.org, “Olmstead V. LC: History and Current Status,” <https://www.olmsteadrights.org/about-olmstead/>.

³⁰ Engquist, Johnson, and Courtland Johnson, 2012.

examines the data used to estimate the size of the population in the region and the ways the data sources fall short, and also provides recommendations to improve data collection.

The Kuni Foundation’s geographic scope for funding, advocacy, and philanthropic work extends throughout Oregon and the Southwest portion of Washington. Southwest Washington includes Clark, Cowlitz, Skamania, Klickitat, Lewis, Wahkiakum, and Pacific counties. These geographies are the focus areas of this report.

Key Definitions

Intellectual Disability & Developmental Disability

Definitions of intellectual disabilities (ID) and developmental disabilities (DD) can vary according to the use of the definition. Often, these types of disabilities are grouped and referred to as *intellectual and developmental disabilities* (IDD) and capture people who have either or both disabilities. Grouped together, IDD includes several separate diagnoses and conditions under one larger umbrella. This report refers to people with IDD unless otherwise stated.

The research literature commonly defines ID as “significant limitations in both intellectual functioning and adaptive behavior that are evident before the age of 18,” and DD as:³¹

- “A severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments,
- Manifested before age 22,
- Likely to continue indefinitely,
- Results in substantial functional limitations in three or more of the following areas of major life activity:
 - (1) self-care,
 - (2) receptive and expressive language,
 - (3) learning,
 - (4) mobility,
 - (5) self-direction,
 - (6) capacity for independent living,
 - (7) economic self-sufficiency,
- And, reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of

³¹ Gloria Krahn, “A Call for Better Data,” *Intellectual and Developmental Disabilities* 57, no. 5 (October 2019): 357-375, <https://doi.org/10.1352/1934-9556-57.5.357>.

assistance that are of lifelong or extended duration and are individually planned and coordinated.”

Generally, these definitions include individuals with cerebral palsy, epilepsy, autism, and other neurologically disabling conditions. The Oregon Office of Developmental Disabilities Services (ODDS) and the Washington Developmental Disability Administration (DDA) use similar definitions.^{32 33}

Housing Definitions

To assess housing insecurity, this report describes the housing settings available to individuals with IDD. Like other households, an individual with IDD’s living arrangement will depend on many factors, including his or her age, preferences, desire and ability to live independently, and the availability and affordability of housing options. However, unlike many other households, individuals with IDD may have fewer options due to affordability and accessibility limitations, discrimination, or pressure in decision making from family or caregivers. Typically, individuals with IDD live in one of three broad housing settings:³⁴

- Supervised residential settings include group homes, foster care, or residential institutions;
- With family caregivers, or
- Independently, alone or with roommates.

In each of these settings, individuals with IDD may receive supportive services commensurate with their needs, ranging from 24-hour care to occasional visits from case managers. Adults have more housing options than do children, but the vast majority of both adults and children with IDD live with family caregivers.

This report also discusses regulated affordable housing, which provides important housing options for individuals who need supported living and or those earning low incomes. Often developed with public funding, this type of housing is deed-restricted to be affordable to certain income levels for long periods of time. Regulated affordable housing differs from unregulated properties that are affordable by virtue of their location, age, condition, or lack of amenities, and provides stability and affordability that can be hard to find in the private market. Often, regulated affordable housing properties have units “set aside” to serve certain incomes or certain populations (such as individuals with IDD).

³² Washington State Department of Social and Health Services Developmental Disabilities Administration, “Eligibility: What is a developmental disability in Washington State?” <https://www.dshs.wa.gov/dda/consumers-and-families/eligibility>.

³³ Oregon Department of Human Services Seniors & People with Disabilities Office of Developmental Disability Services, “What Are Intellectual and Developmental Disabilities?” <https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/Pages/definitions.aspx>.

³⁴ The State of the States in Intellectual and Developmental Disabilities, 2020.

Note on COVID-19

The COVID-19 pandemic has had a large impact on people with IDD.^{35 36} The pandemic and the uncertainty around healthcare provision, equal access to services and testing, and the fear of potential negative health impacts has struck the IDD community hard. Although the situation is still unfolding, preliminary analyses on COVID-19 are showing that it has had an acute impact on this population.³⁷

One potential reason for this directly relates to housing options: people with IDD are more likely to live with roommates or housemates than the general population and many interact with care staff in their residence on a regular basis, due to supportive living needs.³⁸ In addition, people with IDD may have preexisting health conditions – such as heart disease, diabetes, hypertension, or respiratory diseases – that increase overall risk for worse outcomes and death from COVID-19.^{39 40} A May 2020 study found that younger patients with IDD had higher COVID-19 case-fatality rates than the general population.⁴¹

In addition to immediate concerns over contracting the disease and worse health outcomes, many in the IDD community are also concerned about the economic and fiscal fallout resulting from the COVID-19 pandemic, including lost jobs and or housing. State agencies overseeing service provision and case management for people with IDD – underfunded before this crisis – are being asked to cut budgets and may need to reduce service levels or furlough staff as a result.^{42 43} The pandemic underscores the urgent need for more housing options for individuals with IDD.

³⁵ Joseph Shapiro, “COVID-19 Infections And Deaths Are Higher Among Those With Intellectual Disabilities,” *NPR*, June 9, 2020, www.npr.org/2020/06/09/872401607/covid-19-infections-and-deaths-are-higher-among-those-with-intellectual-disabili.

³⁶ Margaret A. Turk, Scott D. Landes, Margaret K. Formica, and Katherine D. Goss, “Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis.” *Disability and Health Journal*, 2020, <https://doi.org/10.1016/j.dhjo.2020.100942>.

³⁷ Shapiro, 2020.

³⁸ Ibid.

³⁹ Turk, Landes, Formica, and Goss, 2020.

⁴⁰ Shapiro, 2020.

⁴¹ Turk, Landes, Formica, and Goss, 2020.

⁴² Washington State Department of Social and Health Services Developmental Disabilities Administration, “DDA Coronavirus Information,” <https://www.dshs.wa.gov/dda/consumers-and-families/dda-coronavirus-information>.

⁴³ Oregon Department of Human Services Seniors & People with Disabilities Office of Developmental Disability Services, “DD Director Budget Exercise Message,” www.oregon.gov/dhs/SENIORS-DISABILITIES/DD/DirectorMessages/DD-Director-Budget-Exercise-Message.pdf.

How This Report is Organized

This report is organized into five sections, beginning with this introduction. Section 2 steps through the estimates of the number of people with IDD in Oregon and Southwest Washington. This section also includes a discussion of the antiquated data used to calculate the prevalence rates, and the variation in prevalence rates by age (children versus adults) and over time.

Section 3 assesses the current housing options for people with IDD in Oregon and Southwest Washington and Section 4 evaluates the housing instability risk for adults with IDD. Section 5 offers recommendations for policymakers, advocates, researchers, and others to implement to enhance data on the population of individuals with IDD and improve housing options for adults with IDD at risk of housing insecurity. It also includes recommendations for future studies.

2. Number and Characteristics of People with Intellectual and Developmental Disabilities

Assessing the housing conditions of people with IDD necessarily starts with a basic question: *how many people in the region live with IDD?* Unfortunately, that is a difficult question to answer.

Research and anecdotal evidence point to a large population of individuals with IDD who are unknown to state agencies, living with family and receiving no support for housing, medical costs, or daily living services.⁴⁴ These individuals, and their family caregivers, are often invisible to the state agencies who administer funding and provide services. As such, relying on state agency caseload information to estimate the IDD population is inadequate.

Census-style national surveys are also insufficient to provide a reliable estimate of the population with IDD in the U.S. In general, survey questions are not specific enough to identify this population, and there is “no national effort to collect such surveillance information” by including relevant questions or categories on existing national surveys.⁴⁵ While this is not a new issue – the U.S. Surgeon General called for better data in 2001⁴⁶ – progress has actually waned: in 2019, the Survey of Income and Program Participation (SIPP) and the National Health Interview Survey (NHIS) both removed questions that could identify an

“Surveillance data allow policy analysts and population health researchers to track the size and nature of target populations, to identify health disparities, and to determine characteristics that contribute to health.

However, for the population of people with intellectual and developmental disabilities (IDD), there is no national effort to collect such surveillance information.”

-Havercamp, et al. 2019 (emphasis added)

⁴⁴ See for example: The State of the States in Intellectual and Developmental Disabilities, “Oregon and Washington State Profiles,” (Broomfield, CO: University of Colorado, 2020), <https://stateofthestates.org>; Sheryl Larson, Heidi Eschenbacher, Lynda Anderson, Sandy Pettingell, and Amy Hewitt, “In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2016,” (Minneapolis, MN: The Residential Information Systems Project, 2018), <https://risp.umn.edu/>; Lynda Lahti Anderson, Sheryl A. Larson, Sarah MapellLentz, Jennifer Hall-Lande, “A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000,” *Intellectual and Developmental Disabilities* 57, no. 5 (October 2019): 421-438, <https://doi.org/10.1352/1934-9556-57.5.421>; Susan Havercamp, Gloria Krahn, Sheryl Larson, Julie Weeks, and the National Health Surveillance for IDD Workgroup, *Working Through the IDD Data Conundrum: Identifying People with Intellectual Disability and Developmental Disabilities in National Population Surveys* (Washington, DC: Administration on Intellectual and Developmental Disabilities, 2019); Alexandra Bonardi, Gloria Krahn, Andrew Morris, and the National Workgroup on State and Local Health Data, *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities*, (Washington, DC: Administration on Intellectual and Developmental Disabilities, 2019); Gloria Krahn, “A Call for Better Data,” *Intellectual and Developmental Disabilities* 57, no. 5 (October 2019): 357-375, <https://doi.org/10.1352/1934-9556-57.5.357>

⁴⁵ Havercamp, Krahn, Larson, Fujiura, Goode, Kornblau, and the National Health Surveillance for IDD Workgroup, 2019.

⁴⁶ Office of the Surgeon General (US), National Institute of Child Health and Human Development (US) and Centers for Disease Control and Prevention (US), “Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation,” (Washington, DC: US Department of Health and Human Services, 2002), www.ncbi.nlm.nih.gov/books/NBK44346/.

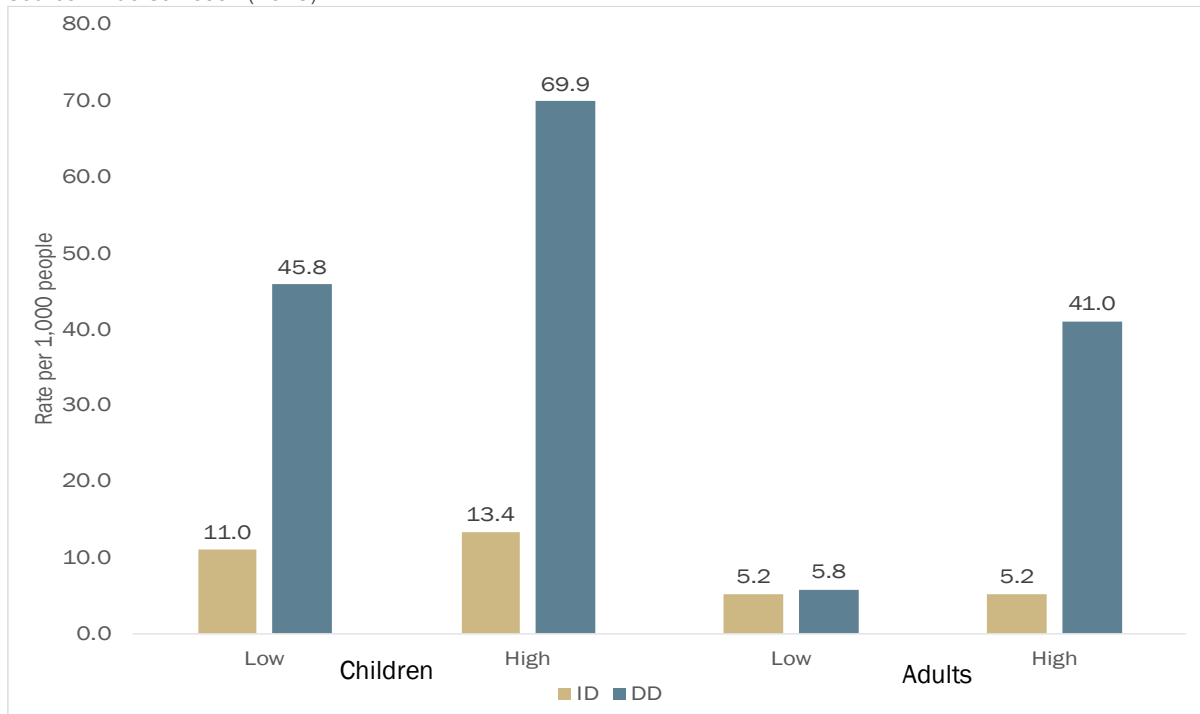
individual with IDD from their annual surveys.^{47 48} Therefore, the best way to estimate the full population of individuals with IDD is through prevalence rates applied to an entire population. Unfortunately, however, sufficiently detailed data upon which to estimate prevalence rates has not been collected in national surveys since the mid-1990s.

This report focuses primarily on the conditions—specifically, housing conditions—of adults with IDD in Oregon and Southwest Washington. The prevalence rate of IDD among children, while not directly useful in this research study, is included as a way to illustrate the poor quality of data available to estimate the adult IDD prevalence rate. The data available to researchers of IDD in children and IDD in adults are discussed in the following sections.

Wide Variation in IDD Prevalence Rates Estimated Since 2000

A 2019 meta-analysis of 14 U.S. studies on IDD published since 2000 demonstrates the variation across studies in estimated prevalence rates by age and diagnosis (see Figure 1). Differences in classifications, terminology, study scopes, study years, and the underlying data upon which these prevalence rates rely make it incredibly challenging to summarize and align the findings. The large variations shown below demonstrate the lack of consensus in the research.

Figure 1. High and Low Variation in Prevalence Rates for ID and DD from U.S. Studies Since 2000
Source: Anderson et al. (2019).



The 69.9 children’s DD prevalence comes from a 2017 study by Zablotsky, Black, and Blumberg (see page 10). This rate is for “any developmental disability” including “intellectual disabilities.” The 2019 meta-analysis shows this as the DD rate in its abstract, which is how it is reported here. However, other researchers use this as the children’s IDD prevalence rate.

⁴⁷ Havercamp, Krahn, Larson, Fujiura, Goode, Kornblau, and the National Health Surveillance IDD Workgroup, 2019.

⁴⁸ Bonardi, Krahn, Morris, and the National Workgroup on State and Local Health Data, 2019.

These 14 studies illustrate the range in perspectives on the prevalence of both ID and DD. Of these, two studies stand above the rest and are widely used in top IDD research centers: a 2001 study by Larson et al. (“Larson Study”)⁴⁹ that is considered to be the most reliable IDD prevalence rate for adults and for “all ages,” and a 2017 study by Zablotsky, Black, and Blumberg (“Zablotsky Study”)⁵⁰ that is considered to be the best estimate of IDD in children.

The 2001 Larson Study: Estimating Adult IDD Prevalence Rates

In 2001, a study by Larson et al. used 1994-1995 NHIS survey data to estimate a prevalence rate for IDD in across numerous age ranges, finding an IDD prevalence rate of 38.4 for children under age five, a rate of 31.7 for children ages 6-17, a rate of 7.9 for adults over age 18, and a blended rate of 15.8 for all ages.^{51 52}

In 1994-1995, the NHIS conducted a two-year disability supplemental survey along with the regular NHIS annual survey. It occurred in two phases after the core NHIS interview, with in-person visits and follow-up interviews conducted with the individuals who had disabilities (20 percent used proxies) to narrow in on key abilities, skills, and self-direction topics (see Figure 2).

Figure 2. Larson et al. Table showing NHIS and NHIS-D Question Topics

Source: Larson et al. 2001. Table 1

NHIS Core Survey Topics	Disability Supplement Phase 1 Topics	Disability Supplement Phase 2 Topics
<ul style="list-style-type: none"> • Housing arrangements and household composition • Demographics • Health and medical information • Abilities and limitations in activities of daily living • Limitations or specific conditions among household members, service needs and access, and related information 	<ul style="list-style-type: none"> • Type of disability: sensory, communication or mobility limitations, specific conditions, activities of daily living, functional limitations, mental health, services and benefits, early child development, education, perceived disabilities, etc. • Immunizations • Family resources • Year 2000 objectives: environmental health, tobacco, occupational health and safety, clinical preventative services, family, firearm safety • AIDS knowledge and attitudes 	<ul style="list-style-type: none"> • Work, school experiences, or vocational rehabilitation • Services used: home care services, transportation, work childcare, medical services, assistive devices, educational services, other, coordination • Assistance with key activities • Participation in social activities • Mental health services and needs • Physical activity limitations • Personal adjustment skills • Family structure and relationships • Impact on the family • Health insurance • Housing and long-term care services • Transportation • Self-direction

⁴⁹ Larson, Lakin, Lahti Anderson, Kwak, Lee, and Anderson, 2001.

⁵⁰ Zablotsky, Black, and Blumberg, 2017.

⁵¹ Havercamp, Krahn, Larson, Fujiura, Goode, Kornblau, and the National Health Surveillance for IDD Workgroup, 2019.

⁵² Bonardi, Krahn, Morris, and the National Workgroup on State and Local Health Data, 2019.

The supplemental survey asked detailed questions on individuals' health conditions and abilities and generated nationally representative data on the "characteristics, service use, needs, circumstances, and experiences of non-institutionalized people with disabilities in the United States."⁵³ The depth and breadth of the data gathered through the supplemental survey allowed researchers to estimate a prevalence rate for non-institutionalized individuals with IDD.

Unfortunately, whether due to funding limitations, political will, or other reasons, the supplemental disability survey has not been repeated as part of the annual NHIS and data do not exist to update these estimates.

Despite the fact that the underlying data is now 25-years old, leading research projects – including the University of Minnesota's Residential Information Systems Project (RISP) and the Coleman Institute's *State of the States in Intellectual and Development Disabilities Project* – continue to consider the 2001 Larson Study to have the best estimates available for adult IDD prevalence rates and for "all ages" prevalence rates.

The 2017 Zablotsky Study: Estimating Child (Age 3-17) IDD Prevalence Rates

In 2017, a study by Zablotsky, Black, and Blumberg used 2014-2016 NHIS survey data to estimate an updated prevalence rate for IDD in children ages 3-17, finding that as many as 69.9 children in 1,000 had "any developmental disability" (which includes intellectual disabilities, autism spectrum disorders, or other developmental delays) in 2016.⁵⁴ This was a statistically significant increase from the study's 2014 rate of 57.6 per 1,000 children. The overall increase comes from increases in diagnoses of "developmental delays other than autism spectrum disorder or intellectual disabilities" as those prevalence rates were constant over the years studied.

⁵³ Larson, Lakin, Lahti Anderson, Kwak, Lee, and Anderson, 2001.

⁵⁴ Zablotsky, Black, and Blumberg, 2017.

Calls for Better Data on the Prevalence of IDD

For now, leading researchers in the IDD field have settled on using Zablotsky's 69.9 per 1,000 rate for children and Larson's 7.9 per 1,000 rate for adults. But the sizable gap begs a question about the estimates' reliability. While not attempting to fully explain the discrepancy, various ideas about the sharp drop-off in prevalence rates between child- and adulthood include the following:⁵⁵

- Differing definitions of developmental disabilities, with a broader definition applied to children under age 9;
- A reluctance for adults to report their disability;
- Differences in reporting rates for adults self-identifying compared to parents identifying a child;
- A more robust research literature on children compared to adults and on autism spectrum disorder compared to other disabilities;
- Increased rates of DD and autism spectrum disorder in children;
- Ongoing health surveillance programs that monitor children but not adults;
- Diagnostic criteria, service eligibility criteria, and definitions used to identify disabilities changing over time.

In 2019, researchers, experts, and program staff from national disability agencies gathered for a symposium to evaluate data challenges and opportunities at both the federal and state levels, releasing two papers outlining their findings and recommendations and publishing a focused edition of the journal *Intellectual and Developmental Disabilities* (Volume 57, Issue 5 in October 2019) with numerous papers outlining data challenges and how to improve.⁵⁶

The symposium's report on state level improvements identified Washington State, along with California, Ohio, and South Carolina, as a leader in implementing enhanced data collection efforts focused on identifying people with IDD in their datasets, collecting expanded race and ethnicity data, and identifying people beyond service-eligibility criteria.

⁵⁵ See for example: Gloria Krahn, "A Call for Better Data," *Intellectual and Developmental Disabilities* 57, no. 5 (October 2019): 357-375, <https://doi.org/10.1352/1934-9556-57.5.357>; Gina A. Livermore, Maura Bardos, and Karen Katz, "Supplemental Security Income and Social Security Disability Insurance Beneficiaries with Intellectual Disability," *Social Security Bulletin* 77, no. 1 (2017), <https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html>; Lynda Lahti Anderson, Sheryl A. Larson, Sarah MapelLentz, Jennifer Hall-Lande, "A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000," *Intellectual and Developmental Disabilities* 57, no. 5 (October 2019): 421-438, <https://doi.org/10.1352/1934-9556-57.5.421>; Office of the Surgeon General (US), National Institute of Child Health and Human Development (US) and Centers for Disease Control and Prevention (US), "Closing the Gap: A National Blueprint to Improve the Health of Persons with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation," (Washington, DC: US Department of Health and Human Services, 2002), www.ncbi.nlm.nih.gov/books/NBK44346/.

⁵⁶ Susan Havercamp, Gloria Krahn, Sheryl Larson, Julie Weeks, and the National Health Surveillance for IDD Workgroup, *Working Through the IDD Data Conundrum: Identifying People with Intellectual Disability and Developmental Disabilities in National Population Surveys*, (Washington, DC: Administration on Intellectual and Developmental Disabilities, 2019), and Alexandra Bonardi, Gloria Krahn, Andrew Morris, and the National Workgroup on State and Local Health Data, *Enriching our Knowledge: State and Local Data to Inform Health Surveillance of the Population with Intellectual and Developmental Disabilities*, (Washington, DC: Administration on Intellectual and Developmental Disabilities, 2019).

Suggested Federal Improvements	Suggested State Improvements
<ul style="list-style-type: none"> ▪ Building a national research agenda to fill gaps in knowledge and improve data collection; ▪ Investing in research to study prevalence rates, the characteristics, and varying service needs of the IDD population; ▪ Disseminating research findings more widely; ▪ Creating new data collection methods focusing on longitudinal studies and program evaluation; ▪ Careful drafting of eligibility criteria and population definitions to ensure alignment with operational definitions and use in program evaluation studies; ▪ Improving existing, repeated, national health surveillance efforts such as the inclusion of questions that can identify people with IDD, questions to identify race, ethnicity, and other characteristics, questions to better understand unmet service needs, and the inclusion of U.S. territories; and ▪ Collaborating across federal agencies to support improved data collection, identification, and service implementation as well as to link and analyze data between sources. 	<ul style="list-style-type: none"> ▪ Expanding administrative data collected to include information on demographics beyond age and gender, such as race, ethnicity, or languages spoken; ▪ Expanding administrative data to include information on living arrangements, preferences, autonomy, and satisfaction, among other factors; ▪ Evaluating performance, monitoring outcomes, and client satisfaction, such as the questions asked in the NCI surveys; ▪ Linking data from different department databases to leverage collection efforts and provide enhanced understanding of the health and service needs of this population; ▪ Harmonizing definitions and eligibility criteria across different state departments so that data can be more flexibly used and analyzed; ▪ Creating databases that can offer real-time analytics and reporting; and ▪ Conducting outreach beyond service-eligible populations and working with community-based organizations or faith institutions to reach families and individuals who are unknown to the state agencies.

Estimating the Regional Population with IDD

Despite the limitations of the data, leading research centers including the University of Minnesota’s RISP study and the Coleman Institute’s *State of the States* study offer a precedent for estimating the total population with IDD:

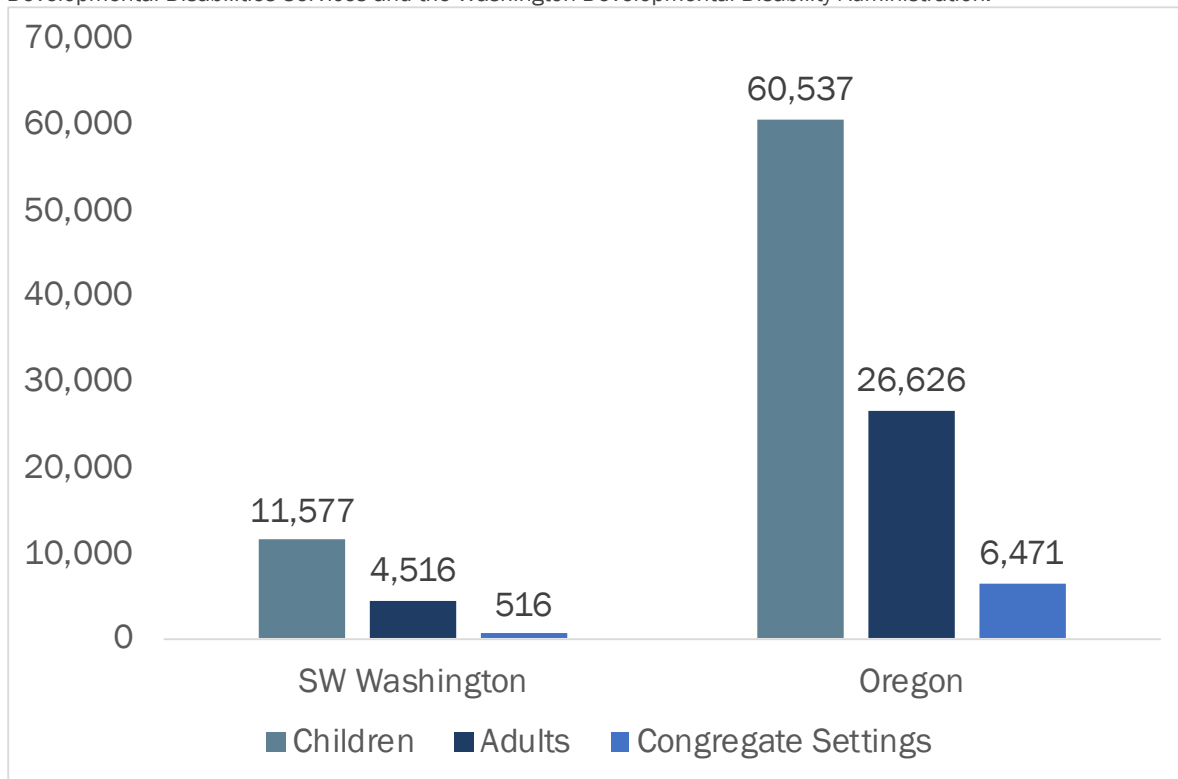
$$\begin{array}{l}
 \text{Child Prevalence Rate} * \text{Child Population} \\
 + \text{Adult Prevalence Rate} * \text{Adult Population} \\
 + \text{People with IDD Living in Congregate Settings} \\
 \hline
 \text{Estimated Total Population with IDD}
 \end{array}$$

The RISP study uses the 69.9 per 1,000 prevalence rate for children from the 2017 study by Zablotsky, Black, and Blumberg, and the 7.9 per 1,000 prevalence rate for adults from the 2001 study by Larson et al. Since these prevalence rates are calculated on survey data for the non-institutionalized population, they add in people with IDD who live in congregate settings.

To estimate the full population of individuals with IDD in Oregon and Southwest Washington, Figure 3 applies these prevalence rates to the 2019 population estimates from the Washington Office of Financial Management and the Portland State University Population Research Center, and includes estimates of the number of individuals with IDD living in congregate settings.

Figure 3. Estimates of the 2019 Population with IDD in Southwest Washington and Oregon

Source: ECONorthwest analysis of data from the Washington Office of Financial Management and Portland State University Population Research Center, using adult prevalence rates from Larson et al., 2001, and child prevalence rates from Zablotzky, Black, and Blumberg, 2017; 2019 Congregate Settings Caseload Information from the Oregon Office of Developmental Disabilities Services and the Washington Developmental Disability Administration.



Notes: Southwest Washington includes Clark, Cowlitz, Skamania, Klickitat, Lewis, Wahkiakum, and Pacific counties. The estimated number of individuals in congregate settings in Southwest Washington comes from Southwest Washington's share of the state population applied to an estimate of the total number of individuals with IDD in congregate settings in the state. This estimate of total people with IDD living in congregate settings includes individuals living in: Adult Family Homes, Child Foster Home / Group Care, Residential Rehabilitation Centers, Nursing Facilities, Group Homes, State Operated Community Residential Settings, Adult Residential Care and Assisted Living Facilities, Licensed Staffed Residential Settings, Correctional Facility/Jails (City or County), Psychiatric Hospitals, Medical Hospitals, Community ICF/IID settings, and Enhanced Services Facilities; also people experiencing homelessness and people with IDD living in "Other" settings. In Oregon, people living in congregate settings include: Adult and Child IDD Foster Care Settings, 24-hour Residential Care Settings, Stabilization & Crisis Unit Settings, and Children's Residential Care Settings.

Given that the data informing the Larson Study adult prevalence rate is 25 years old and that demographics, diagnostic criteria, and medical practices have all changed in that time, the Larson adult prevalence rate is very likely an undercount of the true population. A 2015 study conducted in Ohio using state Medicaid data found an adult prevalence rate for DD (not IDD) of 41.0 people per 1,000 – more than five times higher than the Larson Study.⁵⁷ If the true adult IDD prevalence rate is closer to 41.0, then the estimates would increase more than five-fold to about 23,400 adults with IDD in Southwest Washington and almost 138,200 adults with IDD in Oregon.

⁵⁷ RTI International, 2015.

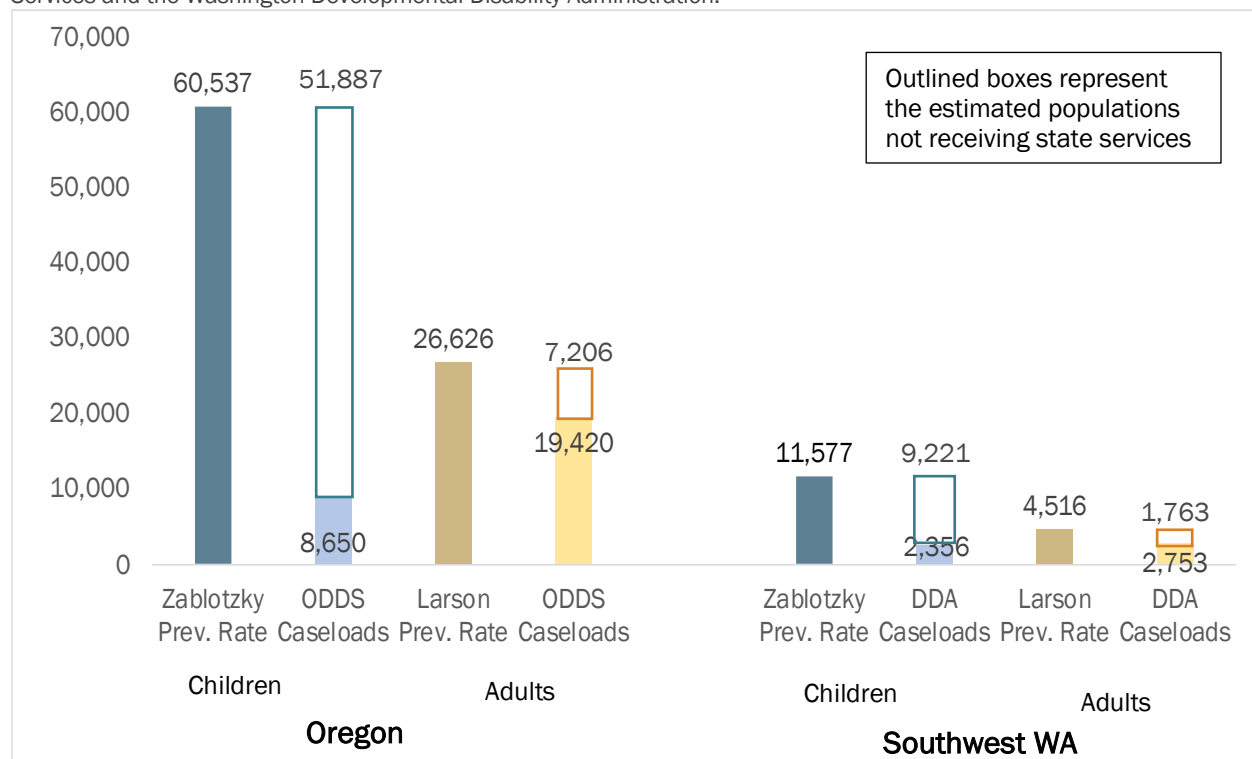
IDD Service Caseloads in Oregon and Southwest Washington

A review of caseloads for state services provides another—albeit incomplete—window into the number of adults with IDD as well as their characteristics and service needs. State-level agencies provide services to people with IDD in Oregon and Washington.⁵⁸ States fund a range of services including transportation, employment programs (for adults), case management and service coordination, day activity support programs, in-home supports for individuals living independently or with family (e.g., for help with daily activities such as eating, dressing, bathing, or housekeeping), foster care, and 24-hour comprehensive services, among others.

A review of state caseload information in Oregon and Southwest Washington indicates that not all individuals with IDD are receiving services. Compared to the total populations in Oregon and Southwest Washington estimated via prevalence rates, there may be upwards of 51,800 children with IDD in Oregon who are not enrolled in state agency services, as well as another 7,200 adults. In Southwest Washington, the unserved population may be higher than 9,200 children and 1,700 adults with IDD (see Figure 4).

Figure 4. 2019 IDD Population Estimates Compared to State Agency Caseloads

Source: ECONorthwest analysis of data from the Washington Office of Financial Management and Portland State University Population Research Center, using adult prevalence rates from Larson et al., 2001, and child prevalence rates from Zablotsky, Black, and Blumberg, 2017; 2019 Caseload Information from the Oregon Office of Developmental Disabilities Services and the Washington Developmental Disability Administration.



Notes: Individuals living in congregate settings are included in caseload information.

⁵⁸ In Oregon this is managed through the Office of Developmental Disabilities Services (ODDS) and in Washington, it is through the Developmental Disabilities Administration (DDA).

Research and anecdotal evidence suggest that nationally, as many as 80 percent of people with IDD do not receive state agency services.⁵⁹ Washington appears to be near the national average, but Oregon appears to be falling short with an estimate of 86 percent of children in Oregon not receiving state services.

For adults, the percent receiving state services depends on the total population estimated from the prevalence rate. Using the Larson Study prevalence rate, Washington serves 61 percent of the estimated adults with IDD and Oregon serves 73 percent. If an updated prevalence study were to show higher rates of IDD in the adult population, those estimated program participation rates would fall and the “invisible,” unserved population would grow.

Researchers have posited a number of reasons that some individuals do not access or participate in state services:

- Eligibility criteria may not match the clinical definition of IDD or may change over time. Often, the definitions used to assure ADA protections can be wider and more inclusive than definitions used to determine service eligibility.⁶⁰ In addition, definitions might change over time as more information and awareness of conditions grow, while eligibility criteria can change for a variety of reasons (e.g., diagnostic changes).
- Outreach efforts may be insufficient and leave some otherwise willing participants unserved. Washington was exemplified by the Administration on Intellectual and Developmental Disabilities symposium for gathering information beyond its service-eligible population, but it is unclear whether either state conducts active outreach to individuals and caregivers who are not seeking services.
- Some eligible individuals (or caretakers) may not want or need to participate. This could be due to milder disabling conditions that require modest supports or due to not needing financial support. In addition, some may not want to participate in state services due to fear and uncertainty associated with stigmas surrounding institutionalization or perceptions of sub-standard quality of care.

⁵⁹ See footnote 44.

⁶⁰ Krahn, 2019.

Washington Policy Environment

The Washington DDA is part of the state's Department of Social and Health Services. It offers a variety of services for people with IDD including case management, in-home supports, community residential supports, employment and community support services, home and community-based waivers, and residential habilitation centers (state-operated residential settings providing 24-hour support and care).

The DDA is funded by the state's Department of Social and Health Services, while several service programs for people with IDD are funded through the DSHS Aging and Long-Term Support Administration.

Like Oregon and other states, Washington has moved toward a person-centered care program. It has increased its home- and community-based service provision while the number of residents in its four remaining institutions has fallen from 892 in FY13 to 748 residents in FY19.⁶¹

FY2019	Adults	Children	Total	
Clark	1,485	1,432	2,917	The table shows the number of adults and children enrolled in DDA by county of interest for the 2019 fiscal year.
Cowlitz	788	625	1,413	
Klickitat	64	50	114	
Lewis	303	202	505	
Pacific	71	17	88	
Skamania	27	26	53	
Wahkiakum	15	4	19	
Total	2,753	2,356	5,109	

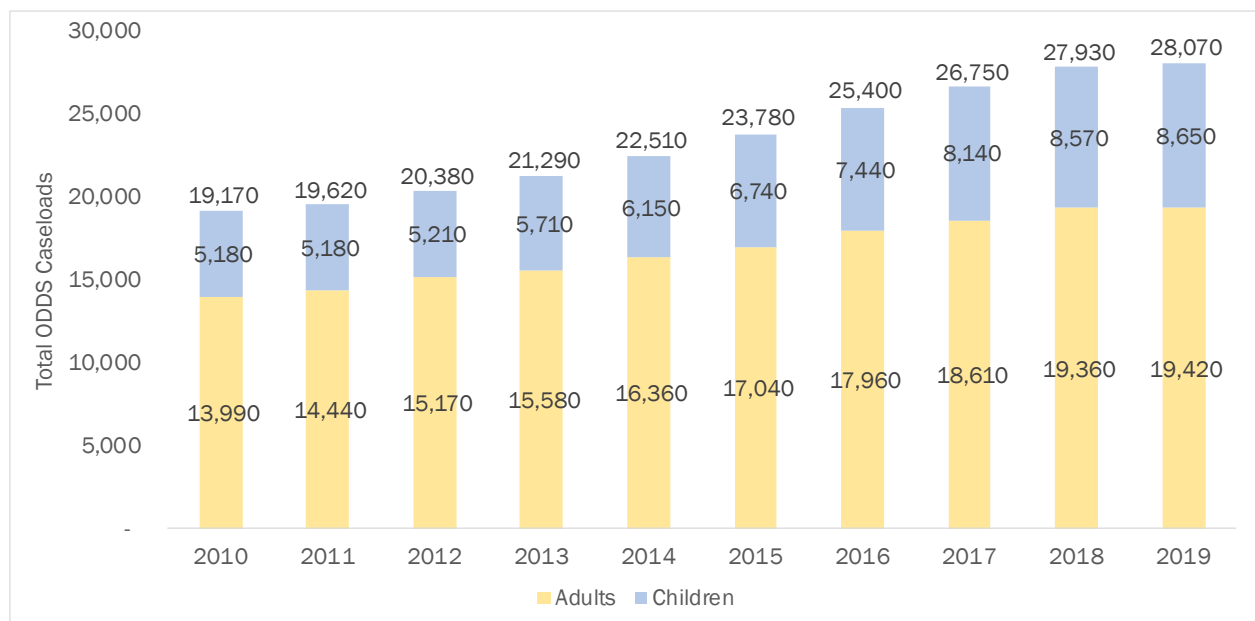
⁶¹ Washington Developmental Disabilities Administration, 2020.

Oregon Policy Environment

The Oregon ODDS is part of the Oregon Department of Human Services, included in its Seniors and People with Disabilities focus area. ODDS reorganized its service provision through the introduction of the “K-Plan” in 2013, which is a state Medicaid plan authorized under the federal Affordable Care Act. According to the ODDS website, the K-Plan allows “Oregon to provide home and community-based services and supports while receiving a six percent increase in federal medical assistance funds from the federal government for those services.” The new plan helps individuals with IDD receive in-home and community-based services instead of institutional care and reduces overall costs of service provision.

Along with numerous states, Oregon’s ODDS has moved toward a person-centered care model that attempts to maximize independence and individual choice. In 2007, Oregon closed its last state-run institution as part of a long process to move toward home and community-based services.

Oregon’s ODDS caseloads have grown significantly in the past 10 years. Between 2010 and 2019 enrollment for adults increased 39 percent, while enrollment of children increased 67 percent. Growth trends increased slightly when Oregon adopted the K-Plan and increased its in-home and community-based services. According to the 2019 OHA-DHS Spring Caseload Forecast Report by the Office of Forecasting, Research and Analysis, before the K-Plan, “children were only able to receive limited in-home services and could only access additional services if they met crisis criteria.”⁶² Now, children can receive meaningful in-home support (without meeting crisis criteria) if IDD service and Medicaid eligibility criteria are met.



⁶² Oregon Health Authority and Oregon Department of Human Services, 2019.

Demographics of People with IDD in Oregon and Washington

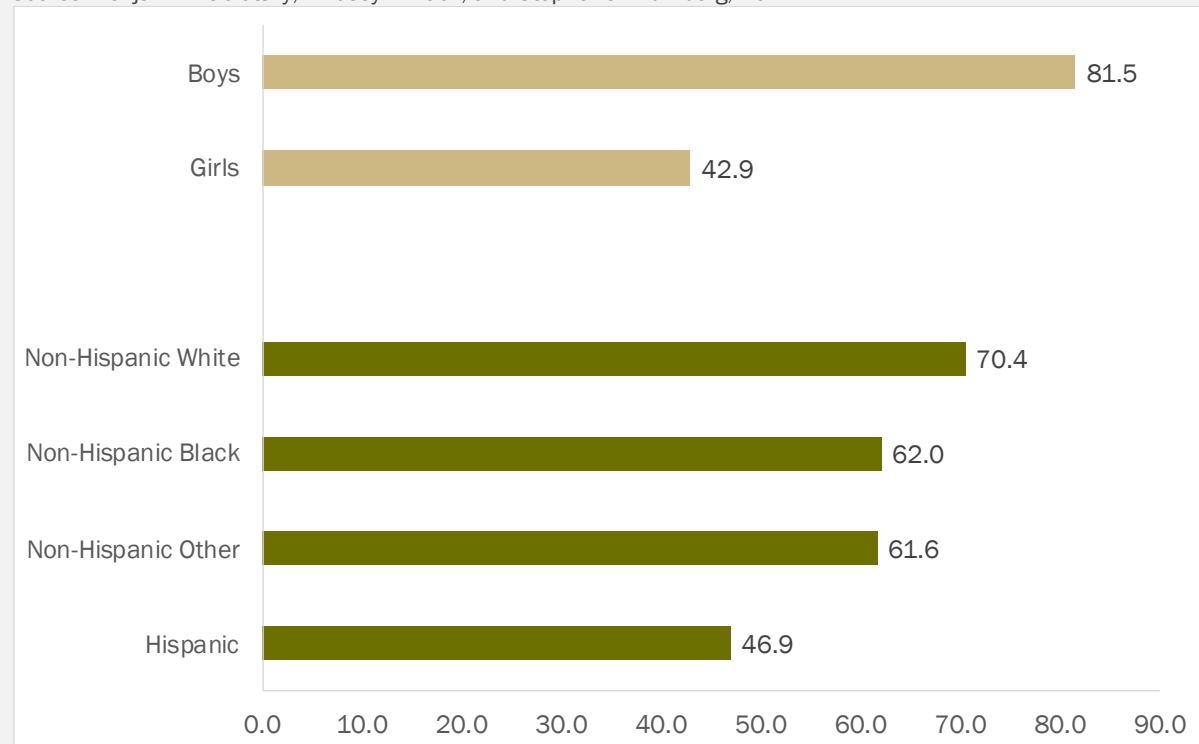
Little reliable information on the demographic makeup of the IDD population exists. Data on race and ethnicity for individuals in Washington are not disaggregated by county, limiting the ability to focus on the Southwest Washington geography of interest. Some demographic data was available from the Washington DDA's 2019 Caseload and Cost Report; however, no demographic data beyond age were publicly available in Oregon.

Lack of Demographic Data

While different prevalence rates have been estimated by age, less research exists studying differences across gender, race, ethnicity, or location (e.g., states). The Larson study did not estimate different prevalence rates for adults across these demographics, but instead estimated one prevalence rate for the nation. Subsequent research has shown that prevalence rates vary by gender, race, and ethnicity, including the Zablotsky Study (see Figure 5).⁶³ Variations across race and ethnicity would also suggest that different locations in the U.S. should have different prevalence rates, but most research uses this national rate applied across all geographies.

Figure 5. 2016 Prevalence Rates for IDD by Gender and Race/Ethnicity from Zablotsky Study

Source: Benjamin Zablotsky, Lindsey I. Black, and Stephen J. Blumberg, 2017.



⁶³ See for example: Benjamin Zablotsky, Lindsey I. Black, and Stephen J. Blumberg, "Estimated Prevalence of Children With Diagnosed Developmental Disabilities in the United States, 2014–2016," *National Center for Health Statistics Data Brief*, No. 291 (November 2017): 1-8, <https://pubmed.ncbi.nlm.nih.gov/29235982/> or Lynda Lahti

The National Core Indicators (NCI) surveys provide some insight into the demographic characteristics, such as age, gender, and race and ethnicity of people with IDD in Oregon and Washington. The NCI program is a voluntary nationwide effort to track and monitor the performance of state developmental disability agencies. The program conducts numerous surveys and in-person interviews each year in participating states to gather information from caregivers, family members, and individuals with IDD. Questions shed light on disability diagnoses, health conditions, living and employment arrangements, life satisfaction and autonomy, planning for the future, areas where more resources are needed, and numerous other topics of interest to policymakers, advocates, and agency staff.

While these surveys contain helpful information, they have small sample sizes (responses in the 2017-2018 survey ranged from 180-420 in Oregon, and 200-460 in Washington, depending on the question), are limited to individuals receiving state services, and may be biased from self-selection or from the presence of a direct support staff person, caregiver, or other person influencing answers.

Oregon NCI Survey

Oregon conducted its most recent NCI survey of adults with IDD during 2018-2019 as an in-person interview, with about 420 respondents.⁶⁴ Sample sizes are small, and the sample is not randomly drawn so it is not perfectly representative of the population receiving state services.

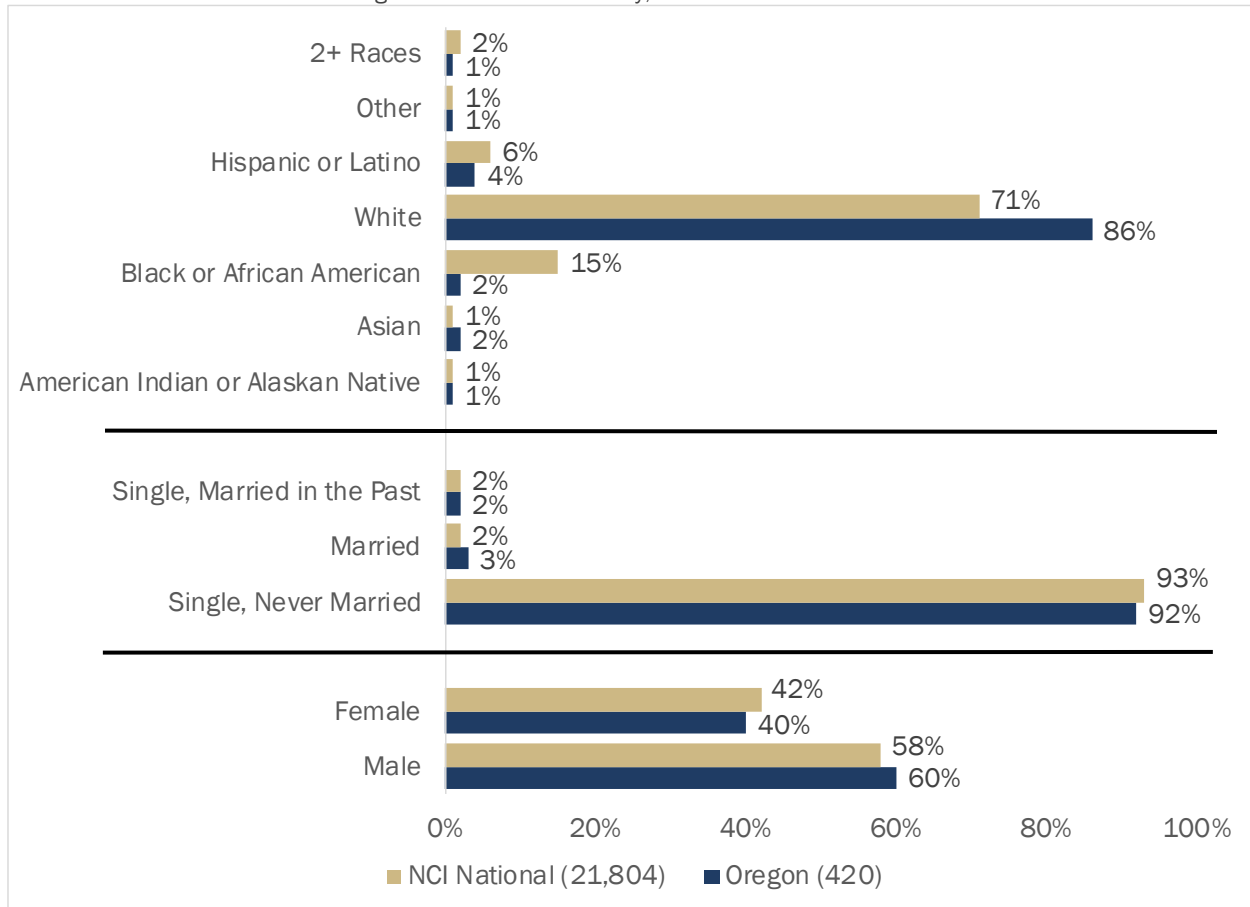
Oregon's NCI survey respondents lived in a variety of settings, not just with family or a caregiver. The average age of survey respondents was 42, equal to the national average, and the median age of Oregon respondents was 37, compared to a national average of 39. In general, adults surveyed in Oregon are more likely male, slightly younger, more likely to be married, and are less racially and ethnically diverse than national survey respondents (see Figure 6).

Anderson, Sheryl A. Larson, Sarah MapellLentz, Jennifer Hall-Lande, "A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000," *Intellectual and Developmental Disabilities* 57, no. 5 (October 2019): 421-438, <https://doi.org/10.1352/1934-9556-57.5.421>.

⁶⁴ National Core Indicators, *In-Person Survey (IPS) State Report: Oregon (OR) Report*, (Cambridge, MA: National Core Indicators, 2019), <https://www.nationalcoreindicators.org/states/OR/>.

Figure 6. Oregon and National Adult In-Person Survey Results, 2018-2019

Source: National Core Indicators Oregon Adult In-Person Survey, 2018-2019



Notes: Numbers in parentheses are the total number of respondents for each geography.

Washington NCI Survey

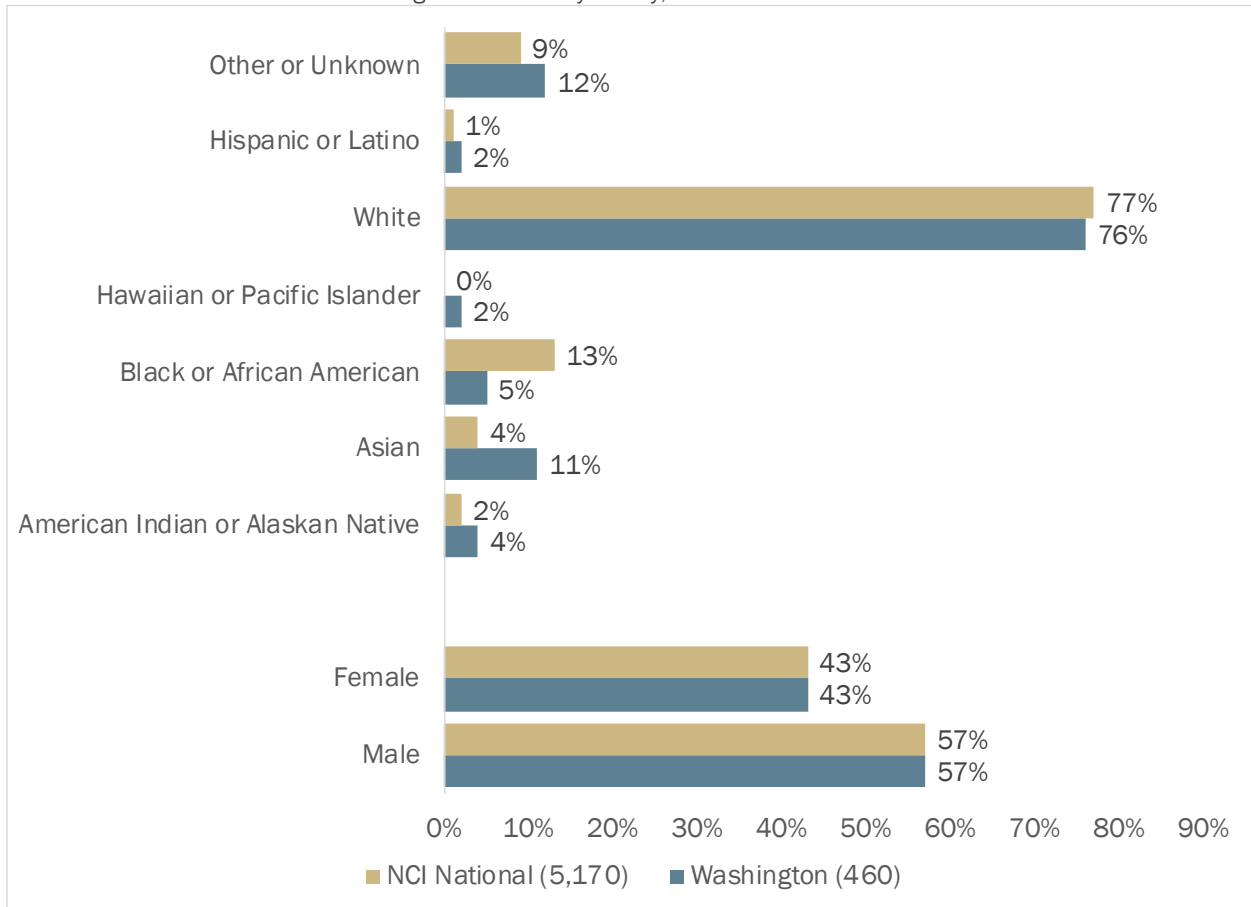
Washington surveyed about 460 adults in 2017-2018.⁶⁵ All respondents lived with families. Like Oregon, Washington’s small sample size—not randomly drawn from the full population—puts some limits on the survey’s value (see Figure 7).

In general, Washington survey respondents were just as racially and ethnically diverse as national survey respondents, although Washington had more Asian respondents and the national results had more Black or African American respondents. In this survey, Washington had the same gender breakdown as national results, but respondents were significantly younger, with an average age of 31.4 compared to the national average of 36.1 (not shown in the chart).

⁶⁵ National Core Indicators, *2017-18 Adult-Family Survey: Washington State Report*, (Cambridge, MA: National Core Indicators, 2019), <https://www.nationalcoreindicators.org/states/WA/>.

Figure 7. Washington and National Adult-Family Survey Results, 2017-2018

Source: National Core Indicators Washington Adult-Family Survey, 2017-2018



Notes: Numbers in parentheses are the total number of respondents for each geography.

3. Housing Options for People with IDD

Housing options for adults with IDD range from 24-hour supportive residential care to supportive housing to fully independent living options. Like other households, an individual's living arrangement will depend on many factors, including his or her age, preferences, desire and ability to live independently, and the availability and affordability of housing options. However, unlike some households, individuals with IDD might face limited housing choices due to affordability, availability, and accessibility as well as discrimination or decision-making pressure from family or caregivers.

The picture of where people with IDD live must be pieced together with incomplete information. State agencies have some data on living settings for the people they serve, but as discussed in the prior section, the share of the IDD community receiving state services is hard to determine. The University of Colorado's Coleman Institute provides the best available data on living arrangements for individuals with IDD. The Institute's *State of the States in Intellectual and Developmental Disabilities* identifies three broad housing categories for people with IDD:

- Living in supervised residential settings (such as group homes, foster care, or residential institutions),
- Living with family caregivers, or
- Living independently alone or with roommates (adults only).

Supervised Residential Settings

The *State of the States* research estimated that in 2017, about 12 percent of adults and children with IDD in Southwest Washington and 26 percent of Oregonians with IDD were living in supervised residential settings, such as group homes, foster care, or 24-hour care settings.

Group homes and foster care settings generally have about three to four individuals but can be larger. They are typically run by an agency or nonprofit organization and are staffed by direct support professionals. Foster care homes are typically owned by an individual, who may live at the home with the individual with IDD.⁶⁶ The 24-hour residential care settings and institutional facilities are typically larger than group homes and foster care settings and can be state run. A description of state-run institutions is described in the call out box on the next page.

⁶⁶ Oregon Department of Human Services Seniors & People with Disabilities Office of Developmental Disability Services, "COVID-19 Information for Developmental Disabilities' Residential Settings," <https://www.oregon.gov/DHS/SENIORS-DISABILITIES/DD/Pages/COVID19-Info-for-DD-Residential-Settings.aspx>.

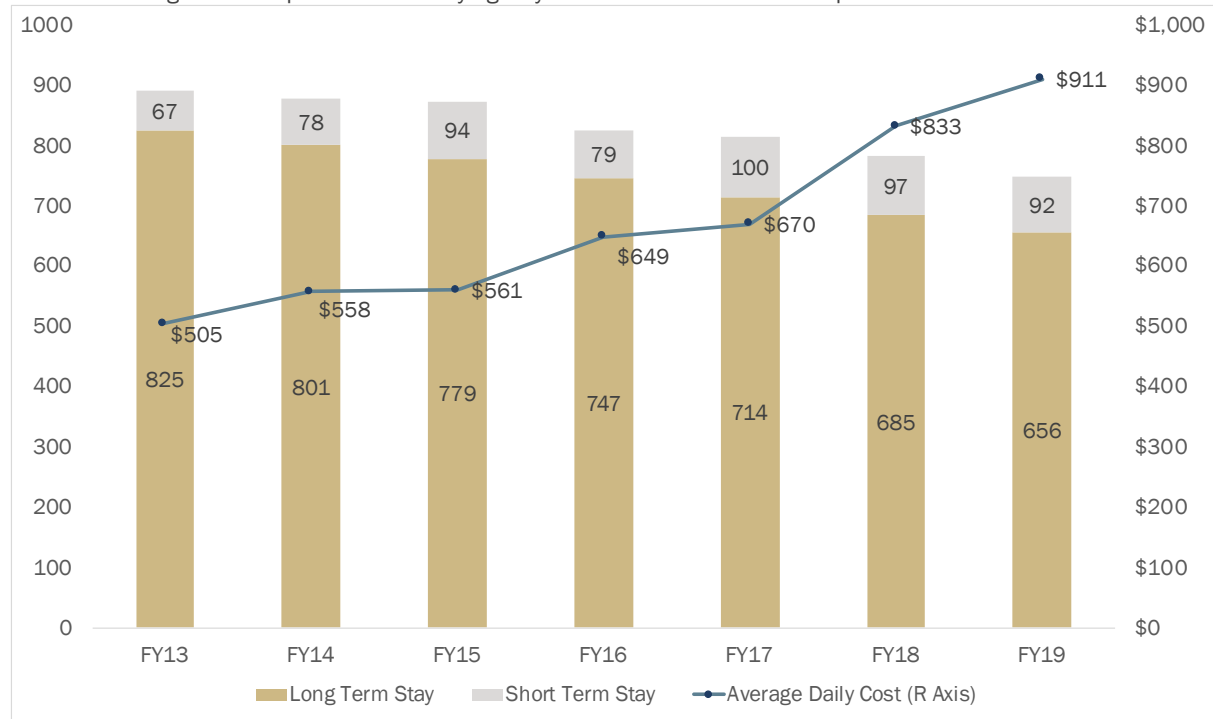
Residential Institutions

Deinstitutionalization efforts began in the United States in the late 1960s, spurred by several media exposés revealing sub-standard living conditions and poor health outcomes.⁶⁷ In response, communities rallied around improving housing choices and dismantling the structures and systems that emphasized congregate, one-size-fits-all approaches to care. In the past fifty years, communities have advocated for new programs centered around the needs of each individual. Communities have made some progress as states and the federal government have created new programs to fund and oversee these newer models of care. Work remains – often driven by lawsuits and advocacy efforts – to ensure that individuals with IDD have full access to the types of housing, services, and care that are needed to thrive.

Oregon no longer operates state-run institutional settings for people with IDD. The de-institutionalization effort began in 1987 and the last person moved out of a state-run center 2011.⁶⁸ Washington decreased the number of state-run institutions (referred to as residential habilitation centers or RHCs) in recent years while it has moved toward a person-centered care program. The state has increased its home and community-based service provision while the number of residents in its four remaining institutions has fallen from 892 in FY13 to 748 residents in FY19.⁶⁹ While the number of residents has fallen 16 percent from FY13 to FY19, the average daily costs have risen 80 percent.

Figure 8. Residents and Average Daily Costs at Washington State Residential Habilitation Centers, FY13 through FY19

Source: Washington Developmental Disability Agency 2019 Caseload and Cost Report



⁶⁷ Engquist, Johnson, and Courtland Johnson, 2012.

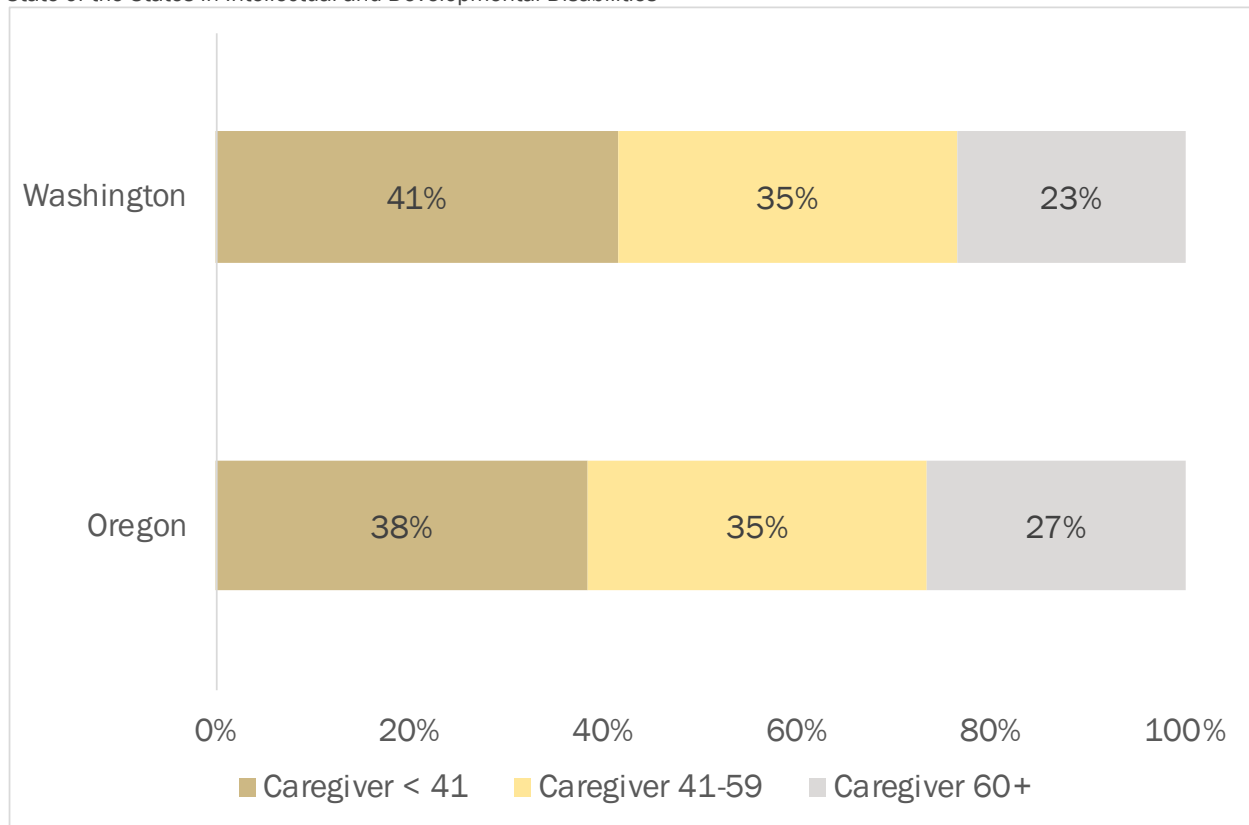
⁶⁸ National Council on Disability, "Oregon and Georgia: Closing Institutions and Building Community Support Systems," <https://ncd.gov/publications/2012/Sept192012/Oregon>.

Living with Caregivers

The *State of the States* also estimated that in 2017, about 70 percent of the total population of individuals with IDD in Southwest Washington lived with caregivers, along with about 61 percent of individuals with IDD in Oregon.⁷⁰ As states have moved away from institutional settings and toward community and home-based service provisions, the number of people living with caregivers has increased.

The *State of the States* then uses Census data to estimate how many individuals with IDD are living with caregivers of different ages: under age 40, between ages 41 and 59, and those over age 60 (See Figure 9).

Figure 9. Share of Individuals with IDD who are Living with Caregivers, by Caregiver Age, 2017
State of the States in Intellectual and Developmental Disabilities



Note: Data shown above are not shares of the total estimated IDD population in each state; these are breakdowns of the share of individuals who are estimated to have IDD and live with family caregivers. Data should be read as “of the 61 percent of individuals with IDD in Oregon who live with a caregiver, 27 percent have caregivers over age 60.”

⁶⁹ Washington Developmental Disabilities Administration, 2019.

⁷⁰ The State of the States in Intellectual and Developmental Disabilities, 2020.

Independent Living Options

The *State of the States* also estimated that in 2017, fewer than 1-in-5 adults with IDD in Oregon and Southwest Washington were living alone or with roommates. These individuals may own their own homes, live in apartments alone or with one or more roommates, and may have any level of in-home supports. In-home support services range from infrequent visits to help with budgeting, household chores, or social outings, up to daily visits assisting with a variety of activities.

Housing Preferences and Choice

Like all households, people with IDD choose housing based on location, proximity to family and community, housing type, size, desires for independence, affordability, and accessibility (e.g., designed in accordance Americans with Disabilities Act standards). However, some people with IDD face limited housing choices due to a lack of affordable, available, and accessible housing, or due to outright discrimination. In addition, anecdotal evidence suggests that people with IDD who are able to live semi-independently may face pressure from family and caregivers to remain in a family-supported situation.

Ideally, individuals with IDD would be able to live as independently as desired. However, without enough affordable, available, and accessible housing options, individuals with IDD who want to live independently may end up choosing a setting that has less independence than desired – such as a group home, foster care home, or with family. These settings provide important, successful housing options for individuals who want and need this support, but they can limit independence for those who cannot find affordable and available housing options elsewhere. State agencies transitioning individuals out of institutional settings cite the lack of affordable and available housing options as a challenge,⁷¹ and research points to this as a challenge for individuals seeking to move out of family homes as well.⁷²

“For many adults with intellectual or developmental disabilities, a suitable home is hard - sometimes almost impossible - to come by. Hundreds of thousands of adults with disabilities across the U.S. sit on housing “wait lists” for home and community-based services. Even if they’re ready to make the move out of their parents’ home into community or independent living, the housing options and funding supports often don’t exist.”

-Harvard Joint Center for Housing Studies, 2015

Data on living choices and preferences is scarce. While the NCI surveys point to high levels of housing satisfaction for respondents in Oregon and Washington, satisfaction levels are below the national average (see Figure 10), and there are limitations with the sample sizes and

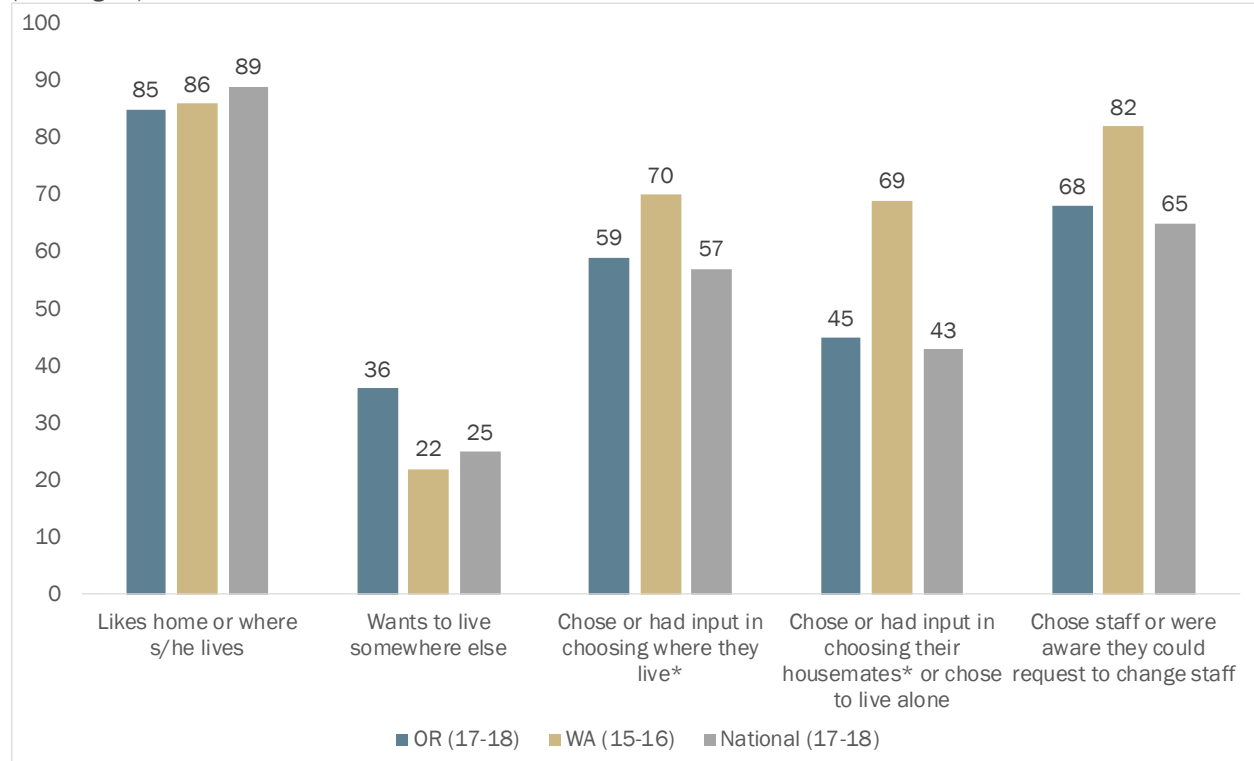
⁷¹ Rebecca Coughlin, Johanna Ward, Noelle Denny-Brown, Brynn Hagen, Kristin Maurer, Eric Morris, Jason Smoot, Allison Steiner, and Bryan Perez, *Money Follows the Person Demonstration: Overview of State Grantee Progress, January to December 2016*, (Cambridge, MA: Mathematica Policy Research, September 2017), <https://www.mathematica.org/our-publications-and-findings/publications/money-follows-the-person-demonstration-overview-of-state-grantee-progress-january-to-december-2016>.

⁷² Connery, 2016.

selection.⁷³ Survey respondents in Washington indicated much greater autonomy in choosing housing while Oregon respondents indicated slightly more autonomy than the national average.

Figure 10. Oregon, Washington, and National Survey Results for Adults with IDD

Source: National Core Indicators 2017-2018 Adult In-Person Survey (Oregon) and 2015-2016 Adult Consumer Survey (Washington)



*Denotes question was asked for individuals not living in their family home. Washington results are statewide and not necessarily representative of the Southwest Washington counties of interest.

Housing Affordability Challenges

Housing unaffordability has two root causes: 1) unusually high cost of housing because of market conditions, government regulatory policy, or both and 2) low incomes of the people accessing the housing. In the Pacific Northwest, many adults with IDD face challenges on both fronts.

Challenges Related to the Price of Housing

The 2010s saw a sharp upturn in the share of households that are housing cost-burdened across the United States and especially in many West Coast metropolitan areas. Slow wage growth is partly to blame, and some communities have responded with increased minimum wages and

⁷³ The NCI surveys have small sample sizes: responses ranged from 180-375 in Oregon and 200-375 in Washington, depending on the question, are limited to only individuals receiving state services, and may be biased from self-selection or from the presence of a direct support staff person, caregiver, or other person influencing answers.

other labor-related policies. But the problem’s geographic nature—on the West Coast, along the Washington-Boston corridor, and in Florida—points to the underproduction of housing as an important driver of the cost-burden trends.

A historical comparison of housing construction and household formation sheds light on the extent of underproduction.⁷⁴ The U.S. housing market built 1.1 units for every new household during the half century from 1960-2016. New construction kept pace with household formation while allowing for some vacancy and the demolition of older, unsafe stock. The national pace of building slowed considerably in the immediate years after the Great Recession, with only 0.72 units built per new household formed during 2010-2016.

The problem was particularly acute in Oregon and Southwest Washington. Housing starts fell well below the pace of household formation in the region during 2010-2016: 0.59 in Multnomah County, 0.71 in Washington County, 0.78 in Clackamas County, and 0.90 in Clark County. A ratio of 0.59 indicates that about six new units of housing were produced for every 10 new households formed between 2010 and 2016. The underproduction has decreased vacancy rates, put upward pressure on housing costs, contributed to high rents and helped put half of the region’s renters in cost-burdened status.

Oregon has gained national attention for enacting a package of laws aimed at accelerating housing production.⁷⁵ If the laws meet their intended goals, housing production should accelerate over the next decade and the rate of housing inflation should slow. This new production will not directly increase the supply of housing affordable to those with low incomes—properties serving low-income households require government funding to become feasible to build. But the increased supply of housing at all price points can help quell price increases in the face of growing demand and this reduction in price pressure can help households of all incomes.

Challenges Related to Household Incomes

No reliable, comprehensive data exist on the incomes of households that include an adult with IDD. That said, a review of Social Security Income data and trends can provide insights on related income and housing challenges faced by some adults with IDD.

A 2017 report by Social Security’s Office of Retirement and Disability Policy estimated approximately 1.3 million people with IDD received Supplemental Security Income (SSI), Social Security Disability Insurance

Nominal SSI payments have grown about 50 percent since 2000, while the average (nominal) one-bedroom rent in the Portland metro area grew 83 percent in that timeframe.

⁷⁴ Madeline Baron, Marley Buchman, Mike Kingsella, Randall Pozdena, and Mike Wilkerson, *Housing Underproduction in the U.S.*, (Washington, DC: Up for Growth National Coalition).

⁷⁵ Laurel Wamsley, “Oregon Legislature Votes to Essentially Ban Single-Family Zoning,” *NPR*, July 1, 2019, <https://www.npr.org/2019/07/01/737798440/oregon-legislature-votes-to-essentially-ban-single-family-zoning>.

(SSDI), or both.⁷⁶ The federally funded income supplement supports low-income individuals who are older or disabled.⁷⁷

If those 1.3 million recipients were proportionately distributed across the country, about 17,000 would live in Oregon and 3,000 would live in Southwest Washington.⁷⁸ Notably, these estimates roughly align with the number of adults receiving state services in the region.

Not all adults with IDD receive federal disability payments, but for those who do, the housing affordability challenge is especially acute. According to the Technical Assistance Collaborative’s 2020 *Priced Out* report, individuals relying solely on SSI cannot afford the average one bedroom or studio apartment rent in most areas in Oregon and would have little income remaining after housing costs in Southwest and rural areas in Washington (see Figure 11).⁷⁹

Figure 11. SSI and Housing Costs in Oregon and Southwest Washington, 2020

Source: The Technical Assistance Collaborative’s 2020 *Priced Out* report.

Housing Market	SSI Monthly Payment	SSI as % of Median Income	% SSI for 1BR Apt.	% SSI for Efficiency Apt.
Oregon	\$783	20.6%	134%	121%
Portland-Vancouver-Hillsboro MSA	\$783	14.6%	165%	152%
Albany	\$783	20.6%	134%	121%
Bend-Redmond MSA	\$783	17.5%	126%	107%
Corvallis	\$783	16.6%	127%	111%
Eugene-Springfield	\$783	18.6%	114%	99%
Grants Pass	\$783	23.2%	104%	103%
Medford	\$783	20.6%	101%	93%
Salem	\$783	19.0%	97%	91%
Non-Metropolitan Areas	\$783	25.0%	94%	80%
Washington				
Longview	\$823	20.7%	91%	78%
Non-Metropolitan Areas	\$823	25.0%	91%	79%

Further, the increases in SSI payments have not kept pace with costs of living: nominal SSI payments have grown about 50 percent since 2000, while the average (nominal) one-bedroom rent in the Portland metro area grew 83 percent in that timeframe (see Figure 12).

⁷⁶ Gina A. Livermore, Maura Bardos, and Karen Katz, “Supplemental Security Income and Social Security Disability Insurance Beneficiaries with Intellectual Disability,” *Social Security Bulletin* 77, no. 1 (2017), <https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html>.

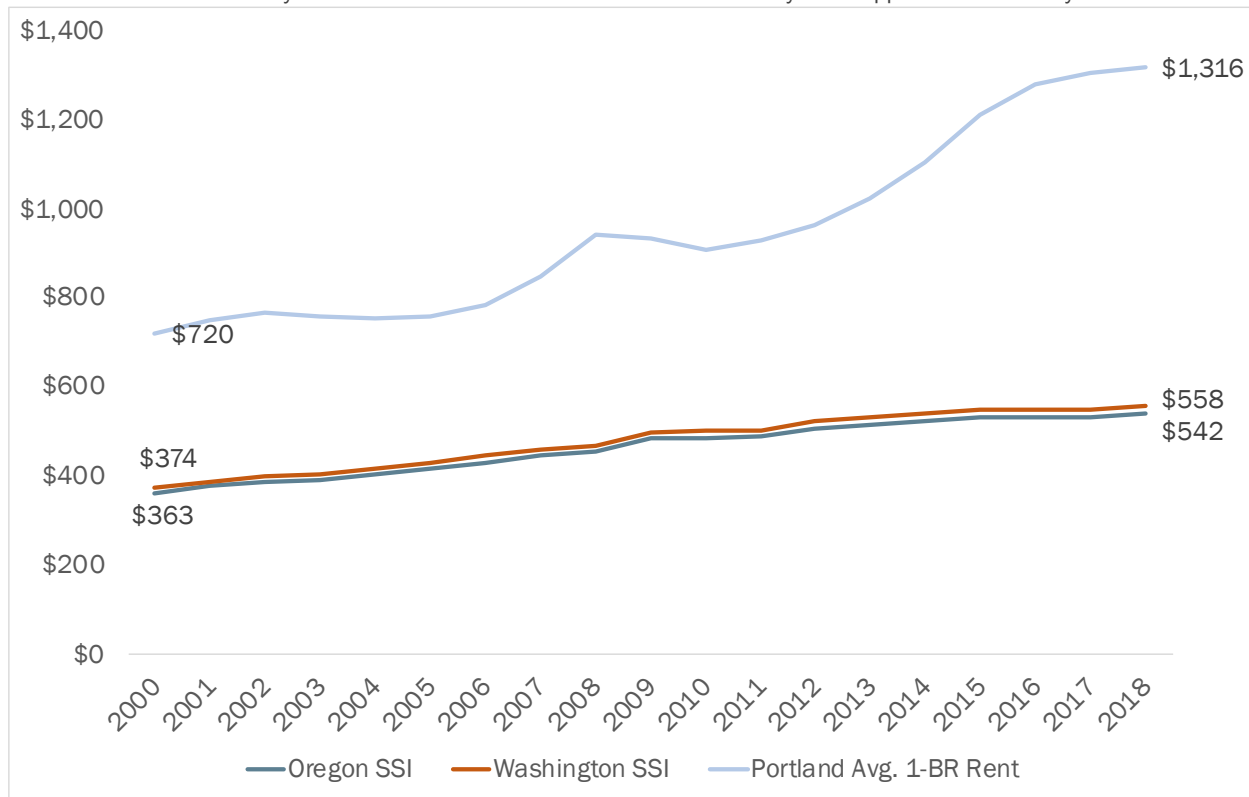
⁷⁷ Ibid.

⁷⁸ In 2017, Oregon accounted for about 1.3 percent of the total U.S. population, while Washington accounted for about 2.3 percent. Assuming these states’ shares of the national population are the same as their shares of the population with IDD, this would translate into roughly 17,000 individuals in Oregon and about 3,000 individuals in Southwest Washington who have IDD and received SSI benefits in 2018 (assuming the six counties in Southwest Washington have the same share of the IDD population as they do the general population).

⁷⁹ Technical Assistance Collaborative, 2020.

Figure 12. SSI and Housing Costs in Oregon and Washington, 2000 through 2018

Source: ECONorthwest analysis of 2020 CoStar data and 2019 Social Security and Supplemental Security Income Data.



Note: Rent data were not available for the Southwest Washington geography of interest.

Faced with few housing options, declining affordability, lower incomes, and reduced earning power from the labor market, adults with IDD – like many other precariously housed individuals – are vulnerable to housing challenges and changes in the housing market. Individuals may live with family, enter a supervised residential setting, or face homelessness when affordable housing options are unavailable.⁸⁰

Regulated Affordable Housing

In a high-cost housing market like the Pacific Northwest, regulated affordable housing is key to providing housing choice to low-income adults with IDD. This type of housing is regulated based on the funding used to develop the property and it is typically restricted to be affordable to low-income households. This is different from other, unregulated properties that are affordable by virtue of their location, age, condition, or lack of amenities. Often, regulated affordable housing properties have units “set aside” to serve certain incomes or certain populations (such as individuals with IDD). Offering unit set-asides for people with IDD is one way to ensure regulated affordable housing options are available for this population, given the extremely high demand for affordable housing in general.

⁸⁰ For a discussion of individuals with IDD experiencing homelessness see page 34.

Oregon Housing and Community Services – the state housing finance agency overseeing most regulated affordable housing in Oregon– estimates that about 2,650 units are reserved for individuals with “developmental disabilities,” though a definition of eligibility was not available online.⁸¹

In Washington, an estimate of the number of units set aside for people with IDD was not available from public sources. Data from the U.S. Department of Housing and Urban Development (HUD) and the Washington State Housing Finance Commission (WSHFC) – the state housing finance agency – do not distinguish set-asides for people with IDD from set-asides for other disabilities.

The Low-Income Housing Tax Credit (LIHTC) program is the largest source of newly constructed affordable housing in the nation.⁸² The more valuable tax credits are competitively awarded each year based on a state’s priorities as outlined in their Qualified Action Plans (QAPs). Neither Washington’s nor Oregon’s QAP calls out specific advantages for projects that include set-asides for people with IDD. Their QAP documents state the following:

- Washington’s QAP offers additional points to new construction project applications if the development includes at least 20 percent of its units for people with disabilities.⁸³
- Oregon’s QAP offers additional points to preservation projects that house tenants who are at risk of displacement – but this wide definition includes all disabled households, along with frail elderly households and large family households. It does not appear to offer additional points for including disabled populations in new construction.⁸⁴

People with IDD can also find affordable housing options through housing vouchers, which typically allow a household to pay a portion of their income toward housing, and the voucher pays the remainder. There are many types of housing vouchers, from permanent project-based vouchers that are dedicated to a unit in a regulated property to tenant-based vouchers that allow an individual to choose a market rate unit (subject to rent limits). In addition, HUD offers vouchers for non-elderly disabled households. However, as discussed in the recommendations section, these vouchers have been underutilized in Oregon.

Research and interviews suggest that a large disconnect exists between housing options and supportive services for people with IDD. Research, anecdotal evidence, and interviews suggests that the state agencies providing services for people with IDD are “not in the business of providing housing,” and the state housing agencies do not have priorities or preferences for this

Properties setting-aside units for people with IDD can help to ensure affordable housing options are available for this population, given the competitive need for affordable housing.

Yet Oregon and Washington housing finance agencies do not offer competitive advantages for properties including these set-asides in their largest funding programs.

⁸¹ Oregon Housing and Community Services, 2020.

⁸² Payton Scally, Gold, and DuBois, 2018.

⁸³ Washington State Housing Finance Commission, 2019.

⁸⁴ Oregon Housing and Community Services, 2019.

vulnerable population. Better integration and coordination are needed to provide more housing options and better housing security for individuals with IDD.

4. Adults with IDD Facing Housing Insecurity

Estimating the number of adults with IDD facing housing insecurity is the central question of this report, but numerous gaps in the data must be bridged using some rough assumptions. The 2020 edition of the *State of the States in Intellectual and Developmental Disabilities* provides a backbone for some exploratory analysis.

Using the *State of the States'* three housing settings: supervised residential settings, family caregivers, or living independently, this report attempts to isolate the adults who are living in unstable housing, using the following assumptions:

- Assume nothing about the relative stability—or desirability—of housing in supervised residential settings. That analysis is left for further study.
- Assume 98 percent of people with IDD living with caregivers over age 60 are adults⁸⁵ (see page 24 for more discussion on caregiver age) and all of those adults are assumed to be housing unstable because of the advanced age of the caregiver.
- Assume all people with IDD living alone or with a roommate are adults. Cost burdening can estimate housing insecurity – it occurs when a household spends more than 30 percent of its gross income on housing costs. A rough estimate is that 37 percent of adults with IDD in Oregon and 36 percent in Southwest Washington are cost burdened.⁸⁶

This approach generates an estimate that as many as 24,500 adults with IDD in Oregon and Southwest Washington may have been living in unstable housing in 2017 (see Figure 13).

⁸⁵ To estimate the share of adults with IDD living with a caregiver over age 60, we use a proxy from Census data. We use the Public Use Micro Sample (PUMS) data to calculate the number of adults and the number of children with a “cognitive difficulty” who are living with a related head of householder age 60 or older. Of the total number of individuals meeting these criteria, approximately 98 percent in both Oregon and Southwest Washington were adults.

⁸⁶ To estimate cost burdening for people with IDD, we use a proxy cost burdening rate from Census data. We use the PUMS data to calculate the cost burdening rate for individuals over age 18, living alone or with a roommate but not with family, who have a “cognitive difficulty” in both Oregon and Southwest Washington. This comes out to 37 percent for Oregon and 36 percent for Southwest Washington.

This method is a proxy and is an imperfect assessment of cost burdening. One major challenge with this approach is that the “cognitive difficulty” variable catches a wide array of health conditions. It is defined in the survey questionnaire as “cognitive difficulty: because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions.” This variable may include people who have IDD but may also include people with traumatic brain injuries or people suffering from dementia or Alzheimer’s disease. However, given the limitations of data on individuals with IDD, it is the most appropriate proxy we can devise.

Figure 13. Estimate of Adults with IDD in Oregon and Southwest Washington Facing Housing Risk, 2017

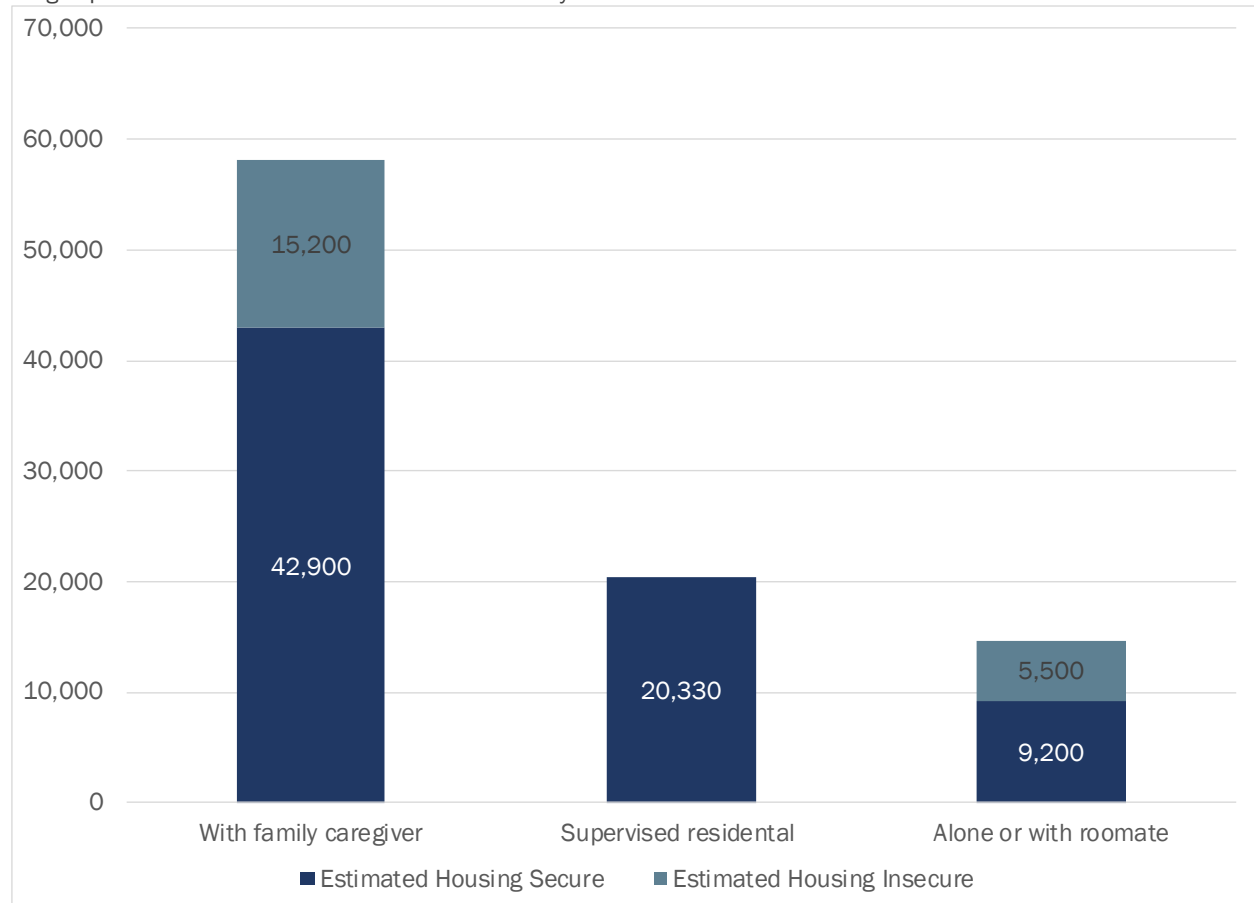
Source: ECONorthwest analysis of data from *The State of the States in Intellectual and Developmental Disabilities, 2017* Oregon and Washington profiles, U.S. Census Bureau PUMS 2018 1-year data, and Washington State Office of Financial Management data.

	Oregon	Southwest Washington
Living with aging caregiver	15,200	2,700
Living independently but cost burdened	5,500	1,100
TOTAL	20,700	3,800

Figure 14 uses the *State of the States'* data on 2017 living arrangements for individuals with IDD in Oregon and displays housing insecurity by living arrangement.

Figure 14. Estimate of Individuals with IDD in Oregon Facing Housing Risk by Living Arrangement, 2017

Source: ECONorthwest analysis of data from *The State of the States in Intellectual and Developmental Disabilities, 2017* Oregon profile and U.S. Census Bureau PUMS 2018 1-year data.



Notes: Estimate of housing risk is limited to adults with IDD. Data are for 2017. The total population in these three living arrangements will differ from the total populations estimated in Figure 3, which are for 2019.

This estimate of housing insecurity builds off the data and housing categories that the *State of the States* reports have been documenting for years. However, this approach excludes people

with IDD who are experiencing homelessness. The Washington DDA estimated that 124 individuals with IDD were experiencing homelessness in 2019.⁸⁷

Oregon does not have a similar statewide estimate and data collection is extremely limited. In the Portland tri-county area only Multnomah County included information relating to people with IDD experiencing homelessness in its Point-in-Time count.⁸⁸ According to the 2019 report, there were 198 people with a “developmental disability” experiencing homelessness in Multnomah County. This was a 52 percent increase from 2017, when 130 people with a developmental disability were counted in the outreach effort. No definition of eligible conditions is available to ensure that the data align.

The bottom line: these rough estimates point to more than 24,000 adults with IDD in the region who are housing insecure and hundreds more who are homeless. At best, these should be characterized as sketch estimates. Any estimate has risks that the actual number is higher or lower, but here, most signs point to a higher number—primarily because it appears that the adult population with IDD is undercounted. If future surveys were to conclude that adult prevalence rates are closer to those recently measured for children, then the size of the acknowledged population with IDD would grow and the number who are housing insecure would grow alongside it.

⁸⁷ Washington Developmental Disabilities Administration, 2019.

⁸⁸ City of Portland Oregon, Home Forward, A Home for Everyone, Multnomah County, and City of Gresham, 2019.

5. Recommendations

To launch its advocacy platform, the Kuni Foundation posed a straightforward question: *How many of the region's adults with IDD are at risk of housing instability?* This report found that the region—and the nation—need to answer a more basic question: *How many adults live with intellectual or developmental disabilities?*

The recommendations start with the decades-old call for better data on the population. Public policy is lost without it. But action cannot wait for better data. The needs are too urgent. Two trends—aging caregivers and rising housing costs—will make the conditions outlined in this report even more challenging over the next decade.

The good news is the region is embarking on nation-leading efforts to increase housing production, improve affordability, and prevent homelessness. Improving housing conditions for adults with IDD should be among the top priorities of those efforts. The following recommendations can help Oregon and Washington leaders continue to advance community integration, individual choice, and person-centered care for this community.

Improve Data Collection Efforts

While most recommendations relate to housing choices and stability, it is critical to have a better understanding of the needs, desires, and current living arrangements of adults with IDD in the region. Without a fundamental understanding of the existing housing conditions for this population – how many people live in what type of setting, and whether those are desirable, life-affirming options – it is difficult to implement policies and move toward person-centered care ensuring that all individuals are living in housing that maximizes well-being.

The lack of quality data is not a new issue, as calls for better data have been made since the mid-1990s.⁸⁹ But instead of improving data collection efforts, data collection efforts have gone backwards: questions that could help identify people with IDD were removed from two promising national surveys in 2019.^{90,91} As such, the best way to estimate the full number of adults with IDD is through prevalence rates that are based on 25-year old population survey data. The following recommendations could help Oregon and Washington better understand the population of adults with IDD in each state along with current housing choices and future needs.

- **Align with national efforts to update the prevalence rate of adults with IDD.**
Advancing public policy requires three steps: defining a problem, designing solutions to

⁸⁹ Larson, Lakin, Lahti Anderson, Kwak, Lee, and Anderson, 2001.

⁹⁰ Havercamp, Krahn, Larson, Fujiura, Goode, Kornblau, and the National Health Surveillance for IDD Workgroup, 2019.

⁹¹ Bonardi, Krahn, Morris, and the National Workgroup on State and Local Health Data, 2019.

address the problem, and finding the political ways and means to implement a solution. Clearly there is a great need for better, more accurate, and more recent data on the population of adults with IDD. Oregon and Washington stakeholders lack the needed funding to carry out census-style surveys but should put their weight behind national efforts and calls for better data.

- **Enhance state data collection efforts.** Oregon and Washington should not wait for federal efforts to improve national health surveillance survey data but can work toward improving their own state data collection and analysis efforts. The best place to start is expanding the data collected and analyzed at Washington’s Developmental Disabilities Agency (DDA) and Oregon’s Office of Developmental Disabilities Services (ODDS) since they already have the means to contact and work with individuals known to have IDD.

These agencies should collect more information on the individuals and families they serve, including preferences and satisfaction with living arrangements, employment, and social activities, as well as measures of autonomy and life direction. The questions used in the National Core Indicators annual surveys can serve as an example of what types of information should be collected and analyzed. A parallel effort should be undertaken to collect information on individuals and families who are not known to or served by the state agencies.

- **Align intra-agency capacity and ability to link and analyze data.** The Oregon ODDS and Washington DDA should work with other state agencies interacting with and serving individuals with IDD – such as the education department or agencies responsible for Medicaid and SSI benefits. Efforts should be made to link data from different department databases to leverage collection efforts and provide enhanced understanding of the health and service needs of this population. In addition, harmonizing the different definitions of IDD and differing eligibility criteria across these agencies can help to improve each agency’s ability to use and analyze data and conduct outreach. Streamlining these different definitions can also greatly improve clients’ ability to access and receive services.
- **Conduct additional outreach to find and serve individuals unknown to state agencies.** DDA and ODDS should work with other state agencies serving adults and children with IDD and should also expand into the community, including faith based organizations, community service organizations or homeless shelters, to conduct outreach to families and individuals in an effort to help identify people with IDD previously unknown to the agencies.

Increase Housing Options

The housing markets along the West Coast are some of the most expensive in the nation because of a decade of underproduction and continued growth in the number of households. People who have fewer housing options – those with low incomes or large families, those who need accessible units, or those who need in-home supports – are often neglected by the majority of private market housing developers, who focus on building new housing for the general

population and mass market needs. This can leave households of all types in precarious situations – living in undesirable locations or settings, living doubled up with friends or family, or paying too much for housing.

This report’s finding that 24,500 adults with IDD in the region – and potentially many more – may face housing instability warrants policy action to increase housing options and reduce risk. These individuals may be at risk of homelessness, curtailed independence, or a rapid, traumatic transition in care if a caregiver is suddenly unable to provide care or if housing costs increase. The following recommendations are a starting point to help increase housing choices, accessibility, and affordability for individuals with IDD in Oregon and Southwest Washington.

- **Elevate the needs of adults with IDD when allocating scarce housing resources.** Agencies charged with allocating scarce housing resources could do more to prioritize support for adults with IDD. For example, Qualified Action Plans (QAPs) govern the distribution of the Low-Income Housing Tax Credit (LIHTC), the largest source of funding for newly constructed affordable housing in the nation.⁹² Neither Oregon’s nor Washington’s QAP calls out specific prioritization or funding boosts for projects that include set-asides for people with IDD. Oregon’s QAP offers additional points to preservation projects that house tenants who are at risk of displacement – but this wide definition includes all disabled households, along with frail elderly households and large family households. It does not appear to offer additional points for including any disabled populations in new construction projects.⁹³ Washington’s QAP offers additional points to new construction project applications if the development includes at least 20 percent of its units for people with disabilities⁹⁴ but does not specify between disability types.
- **Use the newly approved Metro resources to end homelessness for adults with IDD in tri-county Portland.** In May, Portland-area voters passed a tax initiative to address the region’s homeless crisis. Local governments will use the resources to provide supportive housing for people experiencing, or at risk of, chronic homeless and for people with disabilities at risk of homelessness. Thus, the initiative provides an opportunity for targeted attention on building new housing for low-income individuals with IDD.

Data on the counts and characteristics of people experiencing homelessness are notoriously unreliable and decidedly low. As discussed, the data used to estimate adult IDD prevalence are 25 years old. Thus, identifying the number of people with IDD who are experiencing homelessness lies at the intersection of challenging, faulty data. However, larger counties with substantial homeless populations do make an effort. In 2019, Multnomah County’s Point-In-Time count estimated that 198 people with a “developmental disability” experienced homelessness on a given night in January.

⁹² Payton Scally, Gold, and DuBois, 2018.

⁹³ Oregon Housing and Community Services, 2019.

⁹⁴ Washington State Housing Finance Commission, 2019.

The size of the Metro services measure should be sufficient to end chronic homelessness for all adults with IDD in the tri-county area, as well as lower the rents of low-income adults with IDD who face cost-burdening and may be at risk of homelessness.

- **Get behind calls to preserve existing affordable housing.** It is clear that more housing units and more housing options are needed to serve the adult population with IDD. However, it is equally important to ensure that current housing options are maintained and preserved for continued use. Interviewees noted that much of the housing stock that serves adults with IDD – such as group homes or regulated affordable housing – was built in the 1990s in the wake of lawsuits and deinstitutionalization efforts. These properties are now aging, and many have insufficient operating budget and reserves to pay for deferred maintenance and necessary capital improvements. Without a robust preservation strategy, these looming capital obligations put this existing housing stock at risk.

Regulated affordable housing is an important housing option for people with IDD to live as independently as possible: without sufficient accessible and affordable housing options, many individuals with IDD live in housing that has less independence than might be preferred (such as a supervised residential setting or remaining with family). Advocates, researchers, and policy makers should support efforts to fund and preserve this important component of housing stock to increase independent housing options for people with IDD.

Improve Housing and Service Coordination

Data and housing solutions are needed to understand the scale of the issue and reduce housing instability for individuals with IDD in the region. But without improved coordination and communication between housing and service providers, the system will remain difficult and complex for families and individuals to navigate as they piece together funding, prove eligibility, and find suitable housing options. The following recommendations can help streamline these complexities and encourage families and individuals to plan ahead for housing options in an environment of aging caregivers and declining affordability.

- **Provide family caregivers—especially aging caregivers—resources and education to prepare for care transitions.** Surveys conducted by the National Core Indicators program can shed some light on what caregivers of individuals with IDD need. In 2018-2019, 55 percent of Oregon survey respondents and 56 percent of Washington survey respondents (caregivers of individuals with IDD of all ages who receive state supports) suggested they needed help planning for housing, above the 48 percent national average.

Importantly, housing options need to be available for family caregivers to plan for. Just as the deinstitutionalization process was not paired with a plan for housing alternatives, caregivers cannot plan for transitions without meaningful housing options that will maximize well-being for their family members.

- **Bridge the gap between housing supports and services.** To live independently, some adults with IDD require a combination of rent subsidies and wraparound support services. But the provision of subsidies and services is disconnected. Research, anecdotal evidence, and interviews suggests that agencies providing services for people with IDD are “not in the business of providing housing,” and the state housing agencies do not prioritize adults with IDD in their eligibility criteria. Better integration of housing with services and coordination amongst these agencies are needed to provide more housing options and better housing security for individuals with IDD.
- **Help developers understand the in-home support funding for individuals with IDD to incentivize more affordable housing units affordable at 0-30 percent of AMI.** Developers looking to build affordable housing at this income level often have difficulty securing funding for the resident services that help tenants thrive. Due to the lack of coordination between housing developers and service providers, many developers are unaware that individuals with IDD have supportive services funded through the state IDD agency. Better awareness of the synergies between housing development opportunities and already-funded support services could help encourage the development of more affordable housing units for this population.

This recommendation would be particularly helpful paired with the “universal design” concept, where units are architecturally designed to be universally accessible to a wide range of people and abilities. With universal design, individuals with disabilities who can and want to live independently are able to live in any unit at a property, rather than just a few that are set aside in compliance with the Americans with Disabilities Act (ADA) standards. If the cost of building to universal design standards is not prohibitively higher than baseline costs (perhaps an area of future study), this can provide the developer with flexibility in the funding subsidy and provide tenants with more unit availability rather than needing to wait for a select few units to become available.

Future Study

While the scope of this research study focused narrowly on housing instability for adults with IDD in Oregon and Southwest Washington, it uncovered several additional topics worthy of future study, including the following:

- **Harmonizing data to get a better sense of how many people with IDD are in need of housing assistance.** The research calls for many changes to increase collection, streamline definitions and eligibility criteria, and enhance the alignment between different service agencies. Additional research is needed to assess the accuracy of IDD prevalence rates and needs for housing assistance. Reviewing information held by agencies administering Aging and Long-Term Support Services or working in the education system may be a promising start.

- **Housing instability in supervised residential settings and wages of direct support staff.** This study reserved judgement on the housing stability of supervised residential settings such as group homes, foster care, or intermediate care facilities. However, research and interviews suggest that these settings are far from stable—in addition to questions about their desirability. An important component of both stability and desirability at many of these settings comes down to the direct support staff, their wages, and the direct impact they can have on residents.⁹⁵ Further exploration is warranted.
- **Cost comparisons of universal design standards.** Encouraging housing developers to adopt universal design standards could help to expand the number of housing units available to adults with IDD living independently. With universal design, individuals with disabilities can live in any unit at a property, rather than just a few that are set aside in compliance with the Americans with Disabilities Act (ADA) standards. However, resources for affordable housing are limited, while development costs have grown. Future study into the cost of building to universal design standards and how it compares to baseline multifamily housing development costs could help increase awareness of this concept and potentially expanded housing options for adults with IDD who are interested in living independently.

⁹⁵ Connery, 2016.