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New Report Finds People Experiencing Intellectual and Developmental Disabilities Are Severely Undercounted and Face Escalating Housing Insecurity

Vancouver, Wash. — People experiencing intellectual and developmental disabilities (I/DD) face a housing crisis that is hidden by woefully inaccurate data. Based on best estimates, more than 24,000 of the estimated 31,000 adults experiencing I/DD in the region are at risk of housing insecurity due to exclusion from planning processes, escalating housing costs and an unprecedented number of aging caregivers, according to a data study and set of recommendations released today by the Kuni Foundation.

Research used by states and nationally to count the I/DD population—and to estimate the number of people experiencing I/DD who are at risk of housing insecurity—rely on 25-year-old data. Current data on the adult population experiencing I/DD are not collected; in fact, relevant questions have been removed from national health surveys in recent years. More recent state-level data from Ohio, applied to Oregon and SW Washington, suggests that the actual estimate of people experiencing I/DD could be many times higher.

"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data on this population—the number of people, basic demographics and living arrangements—are some of the most outdated and assumption-laden this firm has experienced in 30-plus years working on public policy solutions," says John Tapogna of ECONorthwest. The firm conducted the study for the Kuni Foundation; the Foundation also sought guidance from an advisory group of advocates, nonprofits serving the I/DD community, people experiencing I/DD and regional housing leaders.

Released in the wake of the 30th anniversary of the Americans with Disabilities Act (ADA), the study documents persistent inequities.

"An entire segment of our population is undercounted, invisible and underserved," says Angela Hult, president of the Kuni Foundation. "The lack of options and access underscore the urgent need for affordable, inclusive housing options for people experiencing I/DD. By eliminating silos



between disability rights advocates and housing providers, and working together, we have an opportunity to pursue creative solutions in response to this crisis."

Near-term opportunities include dedicating resources for people experiencing I/DD within the Metro Regional Government's supportive housing measure in the tri-county Portland area. In Washington state, the Legislature needs to prioritize housing options for people with I/DD in current budget planning, especially in the face of COVID-19 related cuts. Longer-term, across Oregon and Washington, the Foundation points to a need for more accurate data, an increase in affordable and supportive housing options, better connections between housing and support services, and inclusion of people experiencing I/DD in housing planning and policy decisions.

Better collaboration offers immediate opportunity, as many available funding streams and incentives go untapped due to lack of awareness. For example, Oregon Housing and Community Services received \$2.3 million in rental assistance from the Federal Department of Housing and Urban Development in 2015 to support the integration of 75 affordable housing units for individuals experiencing I/DD in community-based rental properties. As of 2020 only one third of these rental assistance vouchers had been used.

"We need to get housing developers and service providers in the same room," said Bill Van Vliet, executive director of the Network for Oregon Affordable Housing and data study advisory group member. "I'm not sure all of the affordable housing developers are aware there is service money available to support people with disabilities that would help contribute to operating their properties."

Increase housing options and connection to services

The ADA helped advance inclusive access to education and employment, and many people experiencing I/DD want that same opportunity to choose more inclusive and independent housing. Unfortunately, systems and services are not aligned with these preferences and many people are left with few options: live with family caregivers, navigate complex funding and systems to secure rent assistance or regulated affordable housing, or live in group home settings.

Based on best available data, 70 percent of all people experiencing I/DD (adults and children) in SW Washington and 61 percent in Oregon live with family members. A quarter or more of those family members are aging caregivers, and without sufficient access to affordable options, individuals with I/DD could face difficult transitions and housing insecurity when their caregiver passes away. The COVID-19 pandemic accelerates this concern.

According to the most recent data available, only about 16 percent of people of all ages experiencing I/DD in the region live independently, but this is not, in most cases, a reflection of ability or preference. The lack of options, high housing costs and significant poverty rates (28 percent) among people experiencing I/DD converge to curb independence.



Beyond ADA-accessible housing, individuals want options ranging from home ownership, to integrated and inclusive environments, to living with peers in group settings.

"I hope that when we collectively consider possible solutions, we aim high and think about home ownership too," said Krista Milhofer, program administrator at People First of Washington and data study advisory group member. "Rent rises, and people experiencing I/DD are not going to work themselves out of poverty. The job rate and social security payments are huge barriers to doing so. The best way to build wealth and capital individually is through home ownership. Home ownership can give people autonomy and control."

Community Vision in Oregon helps people experiencing I/DD achieve home ownership, and innovative leaders are creating other options. These include Stephen's Place, a residential community in Vancouver, Wash.; Albertina Kerr's Workforce and Inclusive Housing Project in Portland, Ore.; and WeBUILT Community in Clackamas, Ore. for people who experience autism. Learning from this range of innovative projects, while also investing in new approaches, can advance the scalable, sustainable options that are urgently needed.

About Kuni Foundation and Housing Advocacy

The Kuni Foundation believes in the power of human potential. Based in Vancouver, Wash., we invest in scientists advancing cancer research and in accelerating the inclusion of people experiencing I/DD. Our goal is to help expand housing options through convenings, enhanced coordination between housing and support service agencies in Oregon and Washington, improved data collection and grantmaking. For more information, please visit kunifoundation.org.

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