



POWERING POTENTIAL



From Invisibility to Inclusion

Increasing Housing Options for People Experiencing Intellectual and Developmental Disabilities



“Rather than view individuals who experience I/DD through the lens of perceived deficits, we need to recognize and honor each person’s unique attributes and gifts.”

— I/DD parent and advocate

“I hope that when we collectively consider solutions we aim high and think about home ownership too. Rent rises and people experiencing I/DD are not going to work themselves out of poverty. The job rate, social security payments, etc. are huge barriers to doing so. Home ownership can give people autonomy and build wealth.”

— Krista Milhofer, People First of Washington

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A Mounting Housing Crisis

Thirty years after the passage of the [Americans with Disabilities Act \(ADA\)](#), people who experience intellectual and developmental disabilities (I/DD) have limited housing options, face the highest rates of housing discrimination and are often excluded from plans to generate more affordable housing. Decades after the Supreme Court's ruling in the [Olmstead Lawsuit](#), one of the most pivotal civil rights decisions for the disability community, and the closure of Oregon's notorious Fairview Institution, we have largely failed to deliver on the promises of community-based, inclusive housing that were embedded in both historic events. In fact, Washington still has four state-run institutions housing people who experience I/DD.

Today, a growing population of people experiencing I/DD who want to live more independently or have access to a range of choices are faced with navigating systems, funding streams and limited housing options that were designed without them. For most, without available, affordable choices that meet their needs and preferences, they live at home with family and caregivers. This perpetuates isolation, defers the dignity of choice and faces inevitable crises as parents and caregivers age.

Individuals experiencing I/DD want the same things we all strive for: independence, self-determination, a sense of community and a safe place to call home. But that's not happening in the Pacific Northwest ...



How Did We Get Here?

Our nation has a dark history when it comes to the welfare of people experiencing disabilities: From so-called **ugly laws** intended to keep people out of sight, to forced eugenics to curb reproduction, to confining individuals to institutions, our systems and policies worked in tandem for more than a century to keep the disability community invisible. In the 1960s, states across the country began to recognize the abuse and **inhumane** living conditions in many of the large institutions. Federal policy intended to incent transitioning people out of institutions soon followed, ushering in a shift to community-based housing, allowing people experiencing disabilities to live, shop, work and play in the same places as everyone else, and receive support services as needed. While this well-intended policy shift set into motion the closing of many institutions around the country, it failed to establish a set of standards for community-based housing rooted in dignity, choice and affordability.

“We got away from the big institution but created mini institutions.”

— Kiersi C, Self-advocate

TIMELINE OF KEY MOMENTS IN DISABILITY RIGHTS AND INCLUSION

1840–50

DOROTHEA DIX

After seeing conditions in state prisons, advocates for state hospitals for the mentally ill secure agreement to build 32 institutions.

1881

UGLY LAW

Illegal for “any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view.” Portland is an early adopter; many cities/states follow.

Early 1900s

STATE EUGENICS LAWS

Indiana is the first state to enact a Eugenics law to sterilize “confirmed idiots and imbeciles” to ‘cleanse’ the human gene pool of undesirable traits. 24 states follow. The Supreme Court affirms.

1935

SOCIAL SECURITY ACT

Establishes a program with permanent assistance to individuals with disabilities.

1963–65

COMMUNITY MENTAL HEALTH ACT AND MEDICAID

CMHA: Intended to free thousands of Americans from life in institutions and offer community-based care. Medicaid: Offers higher reimbursement rates for community-based care and excludes payments to institutions.

1990

AMERICANS WITH DISABILITIES ACT

Excluded from the Civil Rights bill of 1964, the ADA is a civil rights law that prohibits discrimination against disabilities in all areas of public life, including jobs, schools, transportation, etc.

1999

OLMSTEAD DECISION

The Supreme Court holds that unjustified segregation of persons with disabilities violates Title II of the ADA, and that public entities must provide community-based services for people experiencing a disability.

Illuminating the Need

The Kuni Foundation is committed to ensuring that people experiencing I/DD have more choices when it comes to housing. To inform our understanding of the needs, gaps, preferences and opportunities, we spent the last year engaging with and learning from individuals with lived experience, advocates, housing agencies and developers, and caregivers in Oregon and Southwest Washington; we continue to work with an advisory committee representing these perspectives. Their collective voices and experiences helped us to better understand the current housing landscape, the needs and hopes of the I/DD community, and the barriers that stifle collaboration, innovation and options.

With concern for housing security now, and into the future, and in response to better data being the number one priority voiced by advocates, the Foundation commissioned ECONorthwest to quantify the number of people experiencing I/DD in Oregon and SW Washington. The full ECONorthwest study also documents current living situations (for people counted by current data), the gap in housing supply and possible housing solutions for the I/DD

community. The study was guided by an advisory committee comprised of individuals who identify as experiencing I/DD, advocates, parents of children experiencing I/DD and affordable housing advocates in the region.

The Findings Were Stark

There is no reliable figure for how many people in Oregon and SW Washington are living with I/DD, and data point to a population woefully undercounted. Estimates of the total population of adults with I/DD—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 I/DD live in Oregon and SW Washington?*—limits the broader conversation about affordable, stable housing for the I/DD community.¹

“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.”

— John Tapogna, ECONorthwest

¹ ECONorthwest study





This neglect in data collection is hugely problematic and renders an entire segment of our population invisible and undercounted.



Based on these 25-year-old data, there are an estimated 31,000 adults with I/DD in the region. Of that number, 24,000 face housing insecurity. Further complicating this math, recent state-level data from Ohio suggest that the overall number of people experiencing I/DD could be many times as large.² Does this mean the housing insecurity crisis is also exponentially higher? This neglect in data collection is hugely problematic, renders an entire segment of our population invisible, and makes decision about housing policy and funding very challenging.

The Gap Between Preferences and Options

In addition to the need for better data, one of the most prevalent themes expressed was a strong desire among many to live more independently or in a more inclusive setting, a place where people with disabilities are intermixed with other community members, not segregated to settings only for people with disabilities.

Families' desire to provide nurturing support for their loved ones leads to a default to family-based care and an aging baby boomer population caring for adult children with disabilities in their homes. As parents age without options for their loved ones, and more young people experiencing disabilities come of age and look for housing options, people with disabilities face uncertainty about where they will live now and when their family can no longer care for them.

Put simply, people who experience I/DD want the ability to determine where they call home. We believe that people should have a spectrum of options available to them so that each individual can choose the housing option that meets their needs and preferences.

“He’s really happy living with us, and we’re happy having him there, but we’re in our mid-60s and we’re not getting any younger ...”

— Lois and Peter G, Parents of a child experiencing I/DD

An Unsustainable System in Crisis

The affordability challenges far too many in our region face are compounded in the I/DD community by inadequate data on the size and needs of the population; high poverty rates; a lack of understanding about housing needs and preferences; and the exclusion of individuals with lived experience in planning, policy deliberations and decision-making. All of these barriers are undergirded by a pervasive narrative about the deficits of the disability community that ignores the potential, creativity and resilience of an extraordinary group of people longing to participate, belong and contribute to a community.

Calling for Solutions

The calls to action and solutions that follow were informed by feedback from people who experience I/DD, families, service providers, affordable housing advocates and the data findings from the ECONorthwest study. Additionally, this report benefits from insights gleaned from the advisory group we convened to help guide and shape a path toward more choice for the I/DD community.

The need to address these gaps is grounded in our belief in the power of human potential and a recognition that housing is intrinsically linked to health, well-being and community connectedness. The lack of affordable housing options are a denial of basic human rights, and we are committed to working in partnership with advocates, families, housing leaders, elected officials and other funders to use this data to ensure that the I/DD community is visible, valued and included in housing-related decisions.

In the pages that follow, we outline in detail the current housing situations, key barriers and gaps that prevent more independent options, and diverse models that illustrate what is possible. We end by calling out possible policies and advocacy priorities that advance inclusion or could increase housing options.

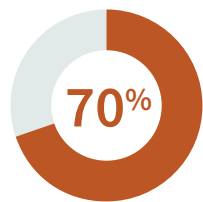
“Disability only becomes a tragedy when society fails to provide the things we need to lead our lives.”

— Judy Heumann, American Disability Rights Activist

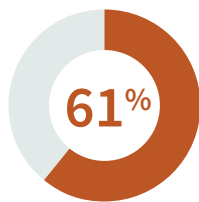
Need for a Continuum of Options

The Places People Experiencing I/DD Currently Call Home²

LIVING AT HOME WITH FAMILY



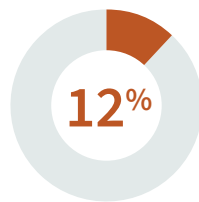
SW Washington



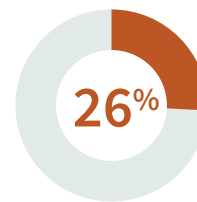
Oregon

LIVING IN A GROUP HOME

Supervised residential settings, such as group homes, foster care or 24-hour care settings



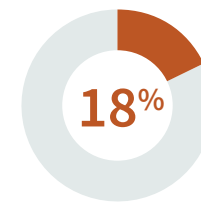
SW Washington



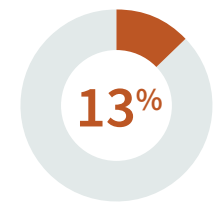
Oregon

LIVING INDEPENDENTLY

May own their own homes, live in apartments alone or with one or more roommates



SW Washington



Oregon

From focus groups with individuals to conversations with advocates, we heard one resounding theme: Affordable housing that gives individuals choice based on the independence and support they need, and desire is a **top priority**.

Above is a snapshot of current living situations for the individuals experiencing I/DD in Oregon and SW Washington as of 2017. It is important to note that the low percentage of individuals currently living independently is not, in most cases, a reflection of an inability to do so because of limitations related to care needs, but rather due to the barriers created by lack of options, high cost of housing in the Pacific Northwest and lack of representation of the disability community at housing decision-making tables. These figures also only

reflect the number of individuals who are included in current available data, and without more comprehensive data collection, provide an incomplete picture.

In the living independently and living at home settings, individuals may have any level of in-home supportive services according to their needs, ranging from 24-hour care to occasional visits from case managers. In-home support services range from infrequent visits to help with budgeting, household chores, social outings or up to daily visits assisting with a variety of activities.



Barriers to More Independent Housing Options

Affordability and supply affect many populations ... and for people with I/DD, there is a whole secondary set of barriers, some pervasive over time and others more recent ... all baked into a system. We outline the most pervasive below.

A Population Made Invisible

The discovery that decisions that affect people experiencing I/DD are based on 25-year-old data jumped out of the ECONorthwest study. The fundamental gap in accurate data on the number of people experiencing I/DD must be solved to advance sound policy, programmatic planning and solutions to the housing crisis.

Some background on why 25-year-old data persist: Top scholars in the I/DD field rely on a study conducted in 2001 that, in turn, used national survey data collected during 1994-1995. The study estimated that in the mid-1990s, about eight 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.³

3 ECONorthwest study

Recent state level data from Ohio suggest that the adult population could be many times as large as the estimates from 25 years ago,⁵ which raises many more questions than answers, and underscores the need for both more rigorous and coordinated data collection, and specific inquiries to understand if the increase can be explained by changes in data collection methods, increases in diagnosis or another factor.

The Need for Representation

Beyond incomplete and outdated data, there is a widespread lack of representation of people with I/DD at all levels of decision-making. The community is often either left out of discussions all together or discussed and debated in terms of programs instead of people. Without representation and inclusion in the design of new housing or in the policies and investments developed to create more affordable housing options, housing developers, policymakers and others have made assumptions about both what is needed and possible when it comes to housing for the I/DD community.

An example of this is housing in Oregon and SW Washington constructed to meet the minimum standards of the Fair Housing Act. This means that in both states, 5 percent of units are designed to be wheelchair accessible. Without engaging the disability community to better understand the spectrum of needs and housing preferences, there are assumptions made by developers and housing providers that disabilities are only physical. Wheelchair access has become the proxy for accessibility. Even if this kind of unit was the solution that met an individual's needs, once that building is constructed there is no consistent system to match individuals looking for housing with accessible units available, or to connect them with the services that would allow them to live in a housing option of their choice. In a market where affordability is a premium, accessible units often go to the next person or family on the waiting list, whether or not they have a need for the modifications.

“We aren’t designing the systems, the places we live ... it’s people who say, “I think it should work like this,” and the focus is often on the buildings themselves, so they meet the requirements, but the culture isn’t nice.”

— Nico S, Self-advocate

“We have been saying this for years and years, and we haven’t seen very much change ... we’re asking you to turn us into human beings instead of ‘its.’”

— John G, Self-advocate

Lack of Affordability

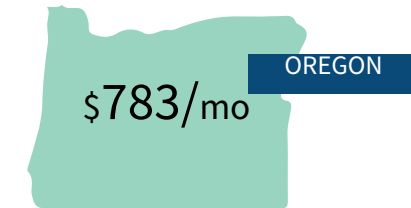
Due to assumptions about ability and outright discrimination, lack of willingness to make simple accommodations, or true physical and cognitive limitations, individuals experiencing I/DD often have fixed incomes and have some of the highest rates of poverty (more than 28 percent) among groups measured by the U.S. Census Bureau. The region's housing crisis—bad for everyone—is undoubtedly far more challenging for adults experiencing I/DD.⁴

In high-cost housing markets like the Pacific Northwest, regulated affordable housing is key to providing housing choice to low-income adults with I/DD. But this housing is in short supply. For example, 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.

On SSI, homeownership may have been a possibility in the 70s, but it's no longer a possibility. We are priced out of the housing market.

— John G, Self-advocate

2019 MEDIAN SOCIAL SECURITY INCOME MONTHLY

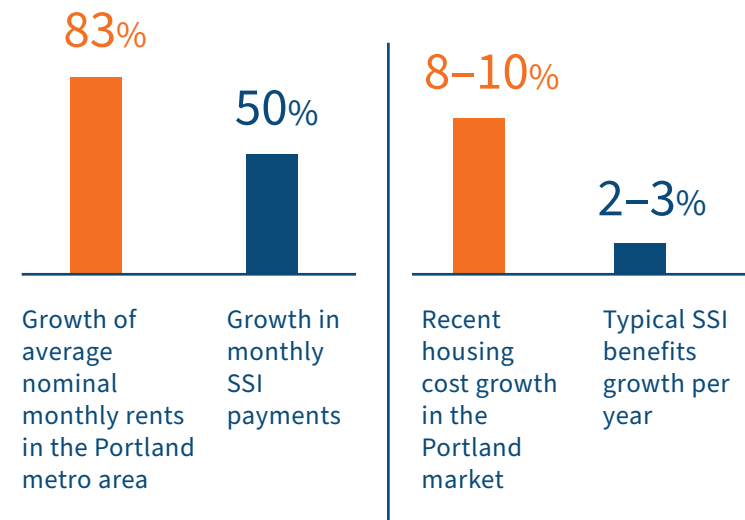


Less than the average monthly rent for a one-bedroom apartment in almost every major market



Slightly higher than the average one-bedroom monthly rent in Southwest Washington housing markets, but would leave little remaining for other basic necessities

THE PAST TWO DECADES



Limited Options and Choice

Despite the desire to live independently or in a housing setting of their choice, most people experiencing I/DD do not. In addition to facing a lack of affordable options, the ability to live more independently is impeded by a lack of connected support services or accessibility or outright discrimination. Nationally, the most housing discrimination complaints (more than 55 percent) are related to individuals experiencing disability.

Two trends at either end of the age spectrum are exacerbating this existing crisis and must be addressed.

Aging caregiver population: According to Family Caregiver Alliance, approximately 39.8 million caregivers provide care to adults 18 years or older with a disability or illness. Of those caregivers, 34 percent are 65 years of age or older. With 60 and 70 percent of individuals experiencing disability in Oregon and Washington respectively living at home, one quarter of them live with a caregiver older than 60, a growing number of individuals will soon be forced to seek independent housing and may face homelessness or other inadequate settings when affordable options are unavailable.⁵

Independent and Accessible Housing Expectations of Generation Z: As a generation that was born with ADA in existence and disability justice advocates expanding notions of what is possible, Generation Z appropriately expects a range of housing options that are integrated into the community including independent living and home ownership.

5 ECONorthwest study

“The expectations of today’s generation are not aligned with current resources. We absolutely have a crisis.”

— Jeff Carr, Chief Executive Officer, Albertina Kerr

“Everyone deserves a safe, affordable, accessible place to call home. Today, there are not enough housing options available for people experiencing disability. This pushes many people with disabilities into housing situations they did not choose. We need community housing systems equipped and ready for families, youth and adults who experience disabilities so they can live, work and learn as community members.”

— Leslie Sutton, Policy Analyst, Oregon Council on Developmental Disabilities

“When I tried to apply for the voucher program they told me that I wasn’t able because of staying at my parent’s home. I have to be staying in a facility. My point is, if something happens to my mom, it’s not consistently safe. I would end up in a facility.”

— Josh, Self-Advocate



An Impossible System to Navigate

The pathways that do exist to support affordability or inclusive housing and support services to make independent living a reality are difficult to unlock due to navigation barriers, or there is simply no awareness that they exist at all.

Disconnect between agencies that serve the I/DD community:

States across the country (including Oregon and Washington) have distinct agencies that provide services and housing respectively for the I/DD community. Despite the critical connection, there is limited coordination and communication between agencies. This creates unnecessary and daunting complexity for families and individuals to navigate as they piece together funding that comes from multiple state and federal agencies, and attempt to find suitable, affordable housing options.

“Beginning in the early seventies, housing practices for people experiencing disabilities focused on creating group living. These environments where individuals experiencing disability live with peers, based solely on disability, has impeded the opportunity for individuals to exercise self-direction, and to be afforded the opportunity to live independently in community as we know many would prefer.”

— Joe Wykowski, CEO, Community Vision

Lack of a formal structure for collaboration between advocates and service providers and the housing world:

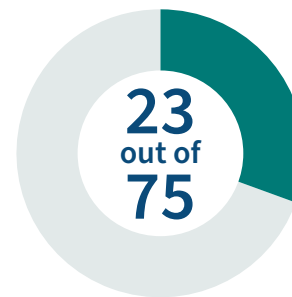
In addition to state agencies, housing developers and disability advocates don't have a formal structure for collaboration, and often don't know each other or have full insight into each other's worlds. In fact, when the Foundation convened the data study advisory group, it was the first time many of

the disability and affordable housing advocates had met each other, and barrier-busting ideas were firing immediately.

“We need to get housing developers and service providers in the same room. I'm not sure all of the affordable housing developers are aware there is service money that is available to support people with disabilities that would help contribute to operating their properties.”

— Bill Van Vliet, Executive Director of the Network for Affordable Housing and Data Study Advisory Group Member

Lack of awareness of incentives or investments that exist to build affordable housing for the disability community: Affordable housing developers and investors are often unaware of funding that has been made available to incent the building of more affordable,



Vouchers used

accessible housing options. In one recent example from Oregon, in 2015, OHCS received \$2.3M in rental assistance from HUD to support 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.

“From the perspective of a housing owner, there is a general lack of understanding about who the providers are that can provide support, where to find them, and how to maneuver through the system. I never thought there would be a more complex system than general subsidized housing until I started working on housing solutions for people with developmental disabilities.”

— Terri Silvis, Chief Executive Officer of Horizon Project Inc.

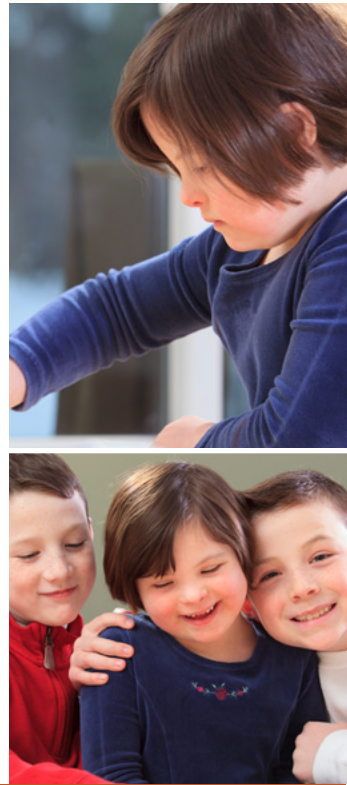
Housing Models & Inspiration

While the solutions needed are systemic, integrated and designed to endure beyond a single project or administration, there are a handful of examples of inclusive community building that should be used as inspiration when designing policy and investment solutions to create more independent living options.



Homeownership model: Based in Oregon, WeBUILT (We Build Unique Independent Lives Together) is a co-housing community owned and managed by individuals who experience autism and other sensory challenges. A portion of the 24 units are rented to neurotypical individuals. The owners who experience I/DD formed a limited liability corporation (LLC) and own a share in the community, which they can put into their own special needs trust and continue to qualify for SSI and K Plan benefits, if needed. Once bills and reserves are satisfied, quarterly disbursements will be made to each member, providing income.

Independent with family model: Edwards Place in Beaverton, Oregon, is a pocket neighborhood and community center designed to provide families the opportunity to live and age in place together. The community includes four homes and accessory dwellings, which house multiple families. Some are families of children who experience I/DD and some are families whose adult children who experience I/DD choose to live alone, but nearby. The homes are designed to accommodate shared housing or other combinations based on family preference.



“Rather than view individuals who experience I/DD through the lens of perceived deficits, we need to recognize and honor each person’s unique attributes and gifts.”

— I/DD parent and advocate



Inclusive housing model: Albertina Kerr’s Workforce & Inclusive Housing Project will provide 150 units of affordable housing. Located on Kerr’s Gresham, Oregon, campus, the project is set for completion in 2021 and will include 30 units for adults who experience an intellectual or developmental disability.

Inclusive (universal) design approach: There are not residential models nationally that use inclusive design. Office and retail spaces—such as Seven Corners in Portland, and Ability360 in Phoenix, Arizona—are paving the way for reimagining the kinds of residential spaces that could be designed to be inclusive and accessible to a wide range of people and abilities.

With universal design, individuals experiencing a disability who can and want to live independently could live in any unit at a property (and coordinate support as needed), rather than just a few that are set aside in compliance with ADA standards. Buildings designed inclusively often include: bathrooms that are large enough to accommodate wheelchair accessibility but also support gender equity; elevators with plates that you can kick with your feet to open to account for variations in mobility and also help people with their hands full trying to get on an elevator; noise and light adjustments that support a variety of sensitivities; movable cabinets that help people with limited mobility as well as people who are short or tall; and an open design that allows for wheelchair users to turn around, and also accommodates modern design ideals of open space.

In the context of constrained affordable housing resources, inclusive design offers a solution that creates more accessibility for a broad spectrum of people, and in most cases, does not add significant additional expense.



A Path Forward: Advocacy and Partnership Imperatives

The lack of housing options for the I/DD community is a denial of basic human rights. Reflecting our belief in the power of human potential and recognition that housing is intrinsically linked to health, well-being and community connectedness, we added advocacy to our theory of change.

The thousands of individuals experiencing I/DD in our region deserve to choose a home that meets their needs and preferences while providing safety and a sense of community. We are committed to working collaboratively to immediately improve data collection and ensure each person who experiences I/DD is visible and counted. With partners, we will help increase awareness of existing investments in affordable housing that could increase options for the I/DD community. And, working with cross-sector stakeholders, we will help advance policies and models that increase options and address the current housing crisis.

Elected officials, service providers, people with lived experience, funders and affordable housing leaders must link arms to advance this basic human right. Together, we have a responsibility and an opportunity to make Oregon and Washington models for the nation.

“We need to be integrated into the community. That is the way that we get jobs. Segregating people into different communities is not right ... We want to be able to live in our own place and have a worker come over and help us and be able to have people come over and go out and work and go to the movies.”

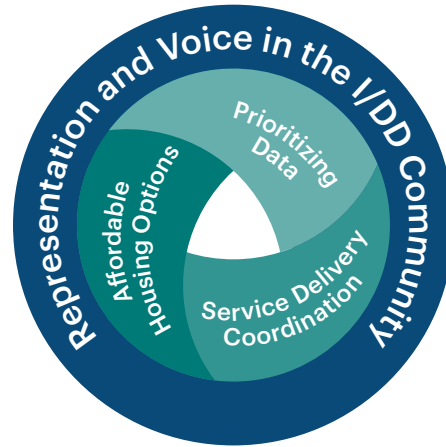
— Kiersi C, Self-advocate

The priorities outlined below reflect recommendations from the ECONorthwest study and input from the advisory group we convened. These imperatives reinforce the critical need for representation and voice from individuals with lived experience in the design of person-focused housing solutions.

Three Imperatives for Inclusion

1) Prioritize data collection, coordination and analysis:

We collect data to learn and understand more about what we deem a priority. For decades, opportunities to collect more data at the federal and local levels have been removed or ignored altogether. The I/DD community in our region deserves to be acknowledged, valued and supported. This starts with data and continues with policy and investment strategies that are informed by both the data and those with lived experience.



Over the next year, the Kuni Foundation will:

- Work with the disability community, advocates, state agencies and other key stakeholders to determine the specific data that would be most helpful to collect, and the agencies and mechanisms to best collect it; and call for its collection.

2) Create more affordable housing options: The lack of affordable housing options is not only a crisis, it is a denial of basic human rights. The I/DD community deserves the same opportunity for self-directed housing options that should be afforded to all people. Oregon and SW Washington must leverage existing funding streams and incentives to create more affordable housing options. At the same time, with gaps, barriers and limitations identified, new mechanisms to create choice and a spectrum of affordable options should be created. Determining the full spectrum of needed options, and the policy, investment and partnership levers to put them in place, should be done with the I/DD community as central idea generators alongside affordable housing advocates, policymakers and other cross-sector stakeholders.

“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.”

— ECONorthwest study



In the short term, the Kuni Foundation will:

- Challenge affordable housing advocates, developers, investors and other housing leaders to use the vouchers and support service funds that are already available from state agencies (OHCS and ODDS) to fund their project and ensure more housing options are built for the I/DD community.
- With advocates and allies, seek dedicated resources for the I/DD community within the Metro affordable housing bond measure and the supportive housing support services ballot measure.

“There is a need for both housing and services for folks to be stable ... affordable housing is often a necessary but insufficient ingredient. ... The new Metro supportive housing measure will help provide rent assistance and support services, and there seems to be a lot of overlap with the I/DD population.”

*— Steve Rudman, Housing consultant
and former Executive Director of Home Forward*

Over the course of the next several months, the Foundation, led by the voices of the I/DD community, will engage with elected officials, policymakers and affordable housing advocates to shift perceptions about what is possible, preferred and needed when it comes to housing. We will convene cross-sector stakeholders to co-generate long-term transformative policies and resourcing strategies that create a sustainable range of housing options for the I/DD community.

3) Improve coordination and alignment between housing and support service agencies and providers: Operating in silos is not unique to the agencies providing services to people experiencing I/DD, but the lack of coordination has catastrophic impacts for health, well-being and quality of life. Individuals experiencing I/DD, along with their families and caregivers, deserve clear communication about the options available to them and the ability to easily navigate to take advantage of resources, programs and opportunities that improve housing security and quality of life. The Kuni Foundation will do the following to help facilitate greater cross-agency and sector communication:

- Host convenings between state agencies, provider organizations and other entities providing housing or support services to the I/DD community to facilitate shared learning, elevate key barriers and co-develop cross-sector solutions.
- Explore investments or policies that create a conduit role to enhance coordination between housing and support service agencies in Oregon and Washington.



Will You Join Us?

Thirty years since the Americans with Disabilities Act, far too many individuals experiencing I/DD are still awaiting the housing rights afforded to them. Though the majority of institutions are closed, the role they played to make the I/DD community invisible and silent persists today with woefully inadequate data that undercounts thousands of people in Oregon and SW Washington.

As we begin to rebuild from the 2020 pandemic and economic crisis, the I/DD community and others disproportionately impacted must be at the center of housing and economic solutions. We have an opportunity to boldly reimagine what can and should be. We have an opportunity to create policies and resourcing that restore decades of injustice and ensure the dignity of housing choice for all.



Appendix

Key Definitions:

- **Aging in place:** A person living in the residence of their choice, for as long as they are able, as they age. This includes being able to have any services (or other support) they might need over time as their needs change.
- **Universal/inclusive design:** Design that works for the widest spectrum of users without the need for specialized adaptation. It centers around the user experience with a focus on social sustainability. Although initially focused on disability rights, universal design can focus on any civil rights issue because, ultimately, design for diversity is concerned with social justice for all, and particularly for groups that have been excluded from full participation.
- **Group homes:** A home where a small number of unrelated people in need of care, support or supervision can live together.
- **Person-focused:** Options that meet each person's unique preferences and needs.
- **Inclusive housing:** Rather than having disability housing being something for “other people,” “over there,” inclusive housing ensures people with disabilities are visible, connected and engaged in their communities, and that policy and other issues related to disability are brought into the mainstream.⁶
- **Ableism:** A set of beliefs or practices that devalue and discriminate against people with physical, intellectual or psychiatric disabilities, and often rests on the assumption that disabled people need to be “fixed” in one form or another.

Contributors

A special and heartfelt thank you to the following individuals and organizations whose insight, candor and lived experience helped to shape our understanding of the most significant needs and opportunities for the I/DD community. Thank you for your time, thoughtfulness and for all you do every day!

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Walsh Construction Co.

Alicia DeLashmutt
Inclusive Community Collaborative

Alison McIntosh
Neighborhood Partnerships

Andrew Noethe
L'Arche Portland

**Angela Jarvis Holland, Angela Frome
and Maria Rangel**
Northwest Down Syndrome Association

Ann Wilkinson
WeBUILT

Bill Bailey
Waterleaf Architecture

Bill Van Vliet
Network for Oregon Affordable Housing
(NOAH)

Brad Parrott
Parent, Advocate, Business Owner

Brian McCarl
Specialized Housing, Inc. (SHI)

Daniel Jarvis Holland
Self-Advocate

Diane Linn
Proud Ground

Faythe Aiken
Prosper Portland, L'Arche Portland

Heather Stenberg
Stephen's Place

Jay Klein
Arizona State University, formerly of
National Home of Your Own Project

Jeff Carr
Albertina Kerr

Jen Knapp and Joe Wykowski
Community Vision

Jenny Stadler
PHAME

**Jeremy-Norden Paul and
Donna Patrick**
Washington State Developmental
Disabilities Council

Jes Larson
Metro, Portland

John and Karen Krejcha
Autism Empowerment

Lois and Peter Grote
Parents of a 27-year-old son with autism

**Julia Doty, Ray Hackworth
and Trell Anderson**
Northwest Housing Alternatives

Krista Milhofer
People First of Washington

Leslie Sutton
Oregon Council on Developmental
Disabilities

Lois Gibson
Oregon Resource Association

Marcie Roth
World Institute on Disability

Margaret Van Vliet
Housing Consultant and CIP Homes
Workgroup Facilitator

Mark Edlen and Jill Sherman
Gerding Edlen

Micaela Connery
The Kelsey, California

Molly Rogers and Shannon Callahan
Portland Housing Bureau

Paul Lipscomb
L'Arche Portland and parent of a child
experiencing I/DD

Peg Malloy
Portland Housing Center

Roberta Dunn
FACT Oregon

Senator Sara Gelser
Disability Advocate and
Oregon State Senator

Steve Rudman
Metro (Affordable Housing Bond),
formerly of Home Forward

Terri Silvis
Horizon Project Inc.

In addition to the names listed above, we conducted two focus groups with self advocates and families representing a spectrum of current housing situations, needs and desires. We are deeply grateful for the time and brave candor that each participant shared.

Who else should we learn from? At the end of every interview or conversation we asked, "Who else should we be talking to?" Send your suggestions to: angela.hult@kunifoundation.org



POWERING POTENTIAL

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This report is available as a 508-compliant document for use with screen readers to ensure universal access.

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