HOUSING NEEDS IN CLARK COUNTY FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES

Review and analysis of current activities in the county and summary of findings of barriers experienced in finding housing

June 2018

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HOUSING IN CLARK COUNTY FOR PEOPLE WITH DISABILITIES AND THEIR FAMILIES
FINAL REPORT

A project of Parents Empowered and Communities Enhanced

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EXECUTIVE SUMMARY

PROJECT OVERVIEW

Parents Empowered and Communities Enhanced (PEACE) began work with the Clark County Department of Community Services Center for Community Health (DCS) to develop ideas to address the barriers to finding and sustaining housing for people with intellectual and developmental disabilities (I/DD) in 2017. As part of this effort, PEACE has developed this report to offer a summary of findings to detail the scope and depth of the housing problem, current work being done to address this problem, and conduct research on the identified barriers experienced by people with I/DD and their families.

METHODS

To conduct this work, PEACE completed research in two phases. In the first phase, a content analysis of the background to the problem and pertinent contextual issues was completed. This was done through interviews with key stakeholders, and a thorough review of current literature that is available. This analysis highlighted several key findings: the extent of market conditions that are driving the current housing crisis; the increasing demand on Medicaid-funded residential supports for people with I/DD; and the current efforts done through the county and city to mitigate the housing crisis. The content and literature available provided valuable information but pointed to the need for targeted research.

To explore this further, PEACE proposed conducting a qualitative study and analysis on the barriers that people with I/DD experience to finding housing. The study consisted of qualitative interviews and focus groups with people with I/DD, families, providers, and DDA staff. In the interviews, participants shared personal experiences of the barriers they've faced in finding sustainable housing in Clark County. The research team analyzed findings by coding interviews into 510 data points, and then grouped the data into themes and an eventual framework.

KEY FINDINGS

The research participants identified many overlapping themes that identified barriers to finding and sustaining housing for people with I/DD. The research framework divided these themes into three overarching categories: 1) State level barriers; 2) Local level barriers; and 3) Shared State and Local level barriers.

State level barriers – Participants identified barriers in the availability of services through the Department of Developmental Disabilities and the provider capacity. Often families and individuals with disabilities are faced with making choices based on what is available through their waiver or the provider that has staff, rather than based on true preference or choice. Another barrier experienced is the trade-off of losing access to the community by living in a 24/7 residential setting. There was

I think the biggest barrier is the definition of disability… And interests and capabilities are sidelined, when the rules and options are "this is what we have, this is what you get, if it doesn't fit uh you don't get it" and the other obstacle in conjunction with that is, it is not beneficial for families to find housing for their kids because they lose their help" – Parent

conversation on the need for innovation in services and not relying on the status quo or what is merely available.

Local level barriers – Participants commented on the need for resources in finding available housing. Many commented on not knowing where to start or how to navigate the system when looking for housing options. Another important element to a successful living situation is the dynamic experienced in looking for and keeping a roommate. Both parents and people with I/DD along with DDA staff commented on the necessity of finding a roommate to offset costs. Several focus groups commented on the barrier they experienced in working with local landlords and filling out rental applications and navigating leases. The lack of knowledge around accommodations, experiences, and the needs of people with disabilities was apparent and a tangible barrier. Another notable theme was the lack of transition or independent living skills trainings that are available in the area. Participants commented on the need for training and programs that provide practical life experience to make one successful in living independently or away from home.

Shared state and local level barriers - There were several themes that emerged in the interviews that require attention at both the local and state level of policy and services. Many of these needs focus on the importance of community, not just a neighborhood per se, but a circle of support that helps ensure that many of the barriers that people with I/DD have experienced are addressed.

RECOMMENDATIONS

To address these barriers several recommendations and next steps were developed. PEACE will work collaboratively with DCS to move these recommendations forward toward implementation:

1. **Continue work with state advocacy efforts -** The findings in this report emphasize the need for change beyond local policies and resources to make independent and integrated options available to individuals with I/DD.

2. **Further study and exploration to understand the problem** – To gain a deeper understanding of the problem and how it is experienced in diverse areas, further study is needed. Potential areas to focus on would be in rural areas of the county, with transition age specific individuals, and with persons experiencing multiple diagnoses.

3. **Development of housing resources** – The need for education materials, access to resources, networks and collaboration on housing was made transparent in the research.

4. **Pursue independent skill development programming** – The importance of independent decision-making and choice was brought forward in the findings. Next steps in this theme include exploring what programs and services work to teach independent life skills and target areas within Clark County that could benefit from developing such programming.

INTRODUCTION

In 2016, Parents Empowered and Communities Enhanced (PEACE) was formed to assist families explore ways to help individuals with intellectual and developmental disabilities (I/DD) access full participation in life as members of their communities. The foundation of our vision, that individuals have the connection and support they need to live out the life of their dreams, must start with finding sustainable housing. Sustainable housing is critical in meeting the physiological and safety needs of everyone, regardless of abilities. The current housing crisis has had a disproportionate impact on those who are low income, many of whom have disabilities.[1]

In 2017, PEACE began to work with the Clark County Department of Community Services Center for Community Health (DCS) to develop ideas to address this community wide need. The report is a direct result of this partnership, and aims to provide meaningful responses to the question: what are the barriers for individuals who experience I/DD in finding, acquiring, and preserving safe and stable housing?

To complete this work, the project will be done in two phases. In the current phase of this project, this summative report details the analysis of current trends around housing for people with disabilities in the national, state-wide and local context, and the summary of research findings conducted by PEACE. Phase Two of the project will work on implementation of the agreed upon policy interventions.

DATA SOURCES

To conduct the analysis for this report, PEACE gathered information pertinent to the housing crisis, to Medicaid-funded services available to people with I/DD, and to community-based interventions. To do this, we utilized the following sources:

Interviews with key stakeholders – An essential element of the creation of this report was utilizing PEACE's connection to community resources for information and input. PEACE conducted informal interviews with key community contacts at the Arc of Southwest Washington, the state Arc, the Washington Developmental Disabilities Council, parent advocates, and others. These contacts were able to inform resource gathering strategies, and provided valuable information on the development of this report.

Available literature – PEACE's research team conducted a thorough review of available research and data relevant to housing needs on the national and local levels. The results of this search provided a wealth of information in the forms of scholarly research, policy briefs, consumer data,

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[1] "Priced Out: The Housing Crisis for People with Disabilities". Technical Assistance Collaborative, Inc. 2017.

and legislative reports. A close review of the sources available underpins the findings from this report, and informs the research proposed in the final section.

Focus Groups and Interviews – The report concludes with recommendations garnered from data collected in focus groups and interviews with people with disabilities, family members, providers, and DDA and county staff.

REPORT ORGANIZATION

This report is organized into four primary sections. In the first section, an overview of the housing problem, the factors that contribute to this crisis, and trends in housing are presented. In the second section, an overview of residential services available for people with I/DD and their families is discussed, as well as national trends in utilization and financing, and system complexities for people with I/DD. In the third section, current work being done in Clark County to address these problems is summarized. The final section includes the research methodology, data collection, findings, and recommendations for next steps.

THE HOUSING CRISIS

To describe the housing crisis in Clark County, this report will address both the broad realities and narrow applied factors that contribute to the housing crisis. This section will provide theoretical conceptualization of social factors that increase the risk of homelessness, lay out key national findings in homelessness, discuss the regional context, and review stakeholder comments on how this applies to the disability community.

CONTRIBUTING FACTORS TO HOMELESSNESS

One of the major risks of a housing crisis is homelessness. To better understand the risks of homelessness, it is essential to have a definition of the typologies or classifications of homelessness. Homelessness can be generally understood as the state of lacking residence or living without a permanent dwelling. Understanding homelessness through typologies helps move beyond a homogenous definition of being homeless.[2] One way to classify homelessness is to use a time-aggregated typology. For example, some people experience homelessness during times of transition, through episodes, or chronically.[3] By using time-aggregated typology, policy-makers can better predict the need for shelter usage and interventions. As some people only need transitional or short-term housing, while others experience a chronic need, both short-term and long-term interventions may be needed. This report will address the risk of homelessness, understood through this lens of a spectrum of needs. While some people with disabilities may *experience* chronic homelessness, or episodic homelessness, the policy and program interventions implied throughout will address the *risk* of homelessness.

Research has shown that there are social factors that greatly contribute to the risk of homelessness. While market considerations are a contributing factor to homelessness, social factors such as familial support breakdown, mental illness, chronic poverty, and a decrease of government assistance also play a part. Research invites further scrutiny and suggests that homelessness should be understood as dynamic.[4] For people who experience homelessness, there are a variety of factors at play, and the interaction between these factors is central to explaining the social relationship that may contribute to the cause of their homelessness.

The relationship between homelessness and intellectual disability has only been recently researched. Research is an important tool to inform policy and provide understanding of the epistemology of complex social problems. In a recent study, individuals who experienced both

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[2] In Focus. Typologies of Homelessness. National HCH Council. January 2013.
[3] Ibid.
[4] Mago, et al. "Analyzing the impact of social factors on homelessness: a Fuzzy Cognitive Map approach." Journal of Medical Informatics & Decision Making. 2013.

homelessness and I/DD were asked a series of questions relating to the barriers they have encountered to escaping homelessness.[5] These interviews found that most people perceived economic problems to be the main causal factor to their homelessness. A secondary relationship was that their familial relationships and other social relationships were strained.[6] These findings suggest that projects that address housing risk for people with I/DD must address more than just the economic factors involved.

<div style="background-color: #b98bc9; padding: 8px;">MARKET CONDITIONS</div>

This report addresses the acute need in Clark County, but the shortage of adequate housing is a national and statewide dilemma. A recent report completed by Washington's Department of Commerce identified that Washington state has less than the national average of affordable and available units. Additionally, the statewide fair market rent for a two-bedroom apartment is $1,229 per month. Including rent and utilities and without paying more than 30% of income on housing a household would need to earn almost $50,000 annually to afford this.

There are several factors that contribute to the housing crisis in Clark County. A comprehensive housing market analysis completed by the US Department of Housing and Urban Development (HUD) of the Portland metro area (which includes Portland, OR, Vancouver, WA, and Hillsboro, OR) identified three main factors: 1) economic conditions, 2) a tight sales market, and 3) rental housing market conditions.

Coming off of the economic recession of 2008, the Portland metro area has seen rapid economic growth since 2010. In 2016, there was an increase of over 35,000 jobs, with an average payroll increase of 2.7%. This period also saw a decrease in the unemployment rate from 5.8% to 5.0%.[7] With an increase in job and economic development, came an increased need for housing. The housing sales market is subsequently tight. Home sales increased by 19% between 2015-2016 and increase in demand is expected for over 27,000 single family homes in in the next three years.[8] Similarly, rental market conditions are equally tight, with an estimated vacancy rate of 2.5%, compared to 5.9% in 2010.[9] Such low vacancy rates drive up rental costs.

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[5] Nishio, et al. "Causes of homelessness prevalence: relationship between homelessness and disability." Psychiatry and Clinical Neurosciences. 2016.

[6] Ibid.

[7] Comprehensive Housing Market Analysis: Portland-Vancouver-Hillsboro, Oregon-Washington. US Department of Housing and Urban Development. Office of Policy Development and Research. May, 2016.

[8] Ibid.

[9] Ibid.

The Vancouver City Council released data[10] acknowledging this crisis, and summarized:

- There are 17,690 very low-income households in Vancouver
- Of these households, 78% are renters
- Half (50%) of very low-income renters spend more than half of their income on housing

The Clark County Needs Assessment (CNA) is a survey administered by the Community Action, Housing and Development Unit and is conducted every three years as a requirement of the Community Services Block Grant Act. The survey is distributed to low-income individuals throughout the county. From 1,165 survey responses, the report publishes key findings of the needs of the community. Key findings from this year's report call attention to the number of people living in poverty in Clark County, at an estimated 49,314 people (or 11.1% of the population).[11]

Over 11% of Clark County's total population lives below the poverty line

The assessment also noted the sizeable population growth that Clark County has experienced, with the county growing by 86% between 2000 and 2014, and noting the growth of smaller cities within the county, "Residential growth has been particularly strong in the smaller cities, with Camas growing by 207%, Washougal by 213%, Ridgefield by 353% and Battle Ground by 397%."[12] This remarkable growth in population increases the needs for housing availability and affordable housing for low-income families. The Affordable Housing Task Force published a report in January 2016, that notes that the current challenges seen in affordable housing in Clark County may be more than just population increases. Other possible challenges include suppressed post-recession housing production, residents displaced from other growing areas (Portland or Seattle), and persistent economic inequality that limits the available housing options for low-income residents.[13]

The CNA identified six areas of need in the community, one of these needs was for housing services. Survey respondents identified needs that they themselves, or someone in their own home, needed support with. The top three areas identified in housing were for better access to affordable housing (52% of respondents), rent assistance (48% of respondents) and move-in cost assistance (39% of respondents). In addition to the survey, the assessors held a community forum. The forum identified several themes that reinforced market trend analysis, such as: 1) the community lacks affordable housing, 2) housing costs are too high, 3) there is a backlog in new home construction, 4)

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[10] Vancouver City Council. Housing Snapshot. Spotlight on very low-income residents. April 2016.
[11] Community Action, Housing and Development Unit. Clark County Community Needs Assessment Report 2017. November 2017.
[12] Ibid.
[13] City of Vancouver Washington. Affordable Housing Task Force Report. January 2016.

the aging population will add to housing needs, and 5) tenant education and assistance with landlords is important.

The available data has led to policy change in Clark County, and investment into creating affordable housing opportunities. The Affordable Housing Fund approved by the Vancouver City Council is addressed in a later section. The HUD and CNA analyses are an important example of how data can lead to policy change and implementation. This example offers an invitation to disability advocates to highlight the needs specific to their community in relation to housing.

People with disabilities often rely upon Federal Supplemental Security Income (SSI) to pay their housing costs. Studies show that adults who rely on SSI for this are among the groups that are most greatly affected by the affordable rental housing crisis.[14] Increased rental demand drives up rental cost, and with a fixed SSI monthly payment, people with disabilities are often priced out of competitive rental housing marketplaces.

It is essential to consider the consequences of this crisis for people with disabilities. A recent national report details the consequences of the affordable housing crisis for people with disabilities.[15] Without affordable housing options, people with disabilities have limited choices in where to live, and the consequences have resulted in institutionalization, homelessness, or living with aging family members beyond a point of sustainability. Without a dramatic shift in policy to address these systematic problems, the crisis will only be exacerbated.

National policy interventions have been implemented to addresses these problems. Programs such as the Money Follows the Person program (MFP) were designed to assist in the transition of individuals living in institutional settings that desire to live in community-based residential settings. Additionally, the Olmstead decision was a United States Supreme Court ruling making it unjustifiable to segregate persons with disabilities from the community. Signed on June 22, 1999 the decision determined that state and local governments are legally obligated to provide services to people with disabilities in the most integrated residential settings.[16] The MFP program and Olmstead decision are meaningful policy interventions, but only the tip of the iceberg in addressing long-term sustainable and integrated housing options for people with I/DD.

People with disabilities have been advocating and drawing attention to this crisis for some time. In 2017, the Washington State Independent Living Council (WASILC)[17] convened for a public forum to discuss gaps and barriers to services in Southwest Washington. The council identified key concerns in housing. They summarized their concerns regarding housing with the following key issues:

- Affordability – with a tight housing market, the average cost of rent is untenable for individuals relying on SSI to pay rental costs
- Access to low-income housing – the limitation of low-income housing in the area results in waitlists, and the housing that becomes available is often not accessible or appropriately accommodating for people with disabilities

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[14] "Priced Out: The Housing Crisis for People with Disabilities". Technical Assistance Collaborative, Inc. 2017
[15] Ibid.
[16] Information and Technical Assistance on the Americans with Disabilities Act. *Olmstead: Community Integration for Everyone.* https://www.ada.gov/olmstead/olmstead_about.htm. Accessed March 7, 2018.
[17] Minutes from Public Forum. Washington State Independent Living Council. October 2017.

- Cumbersome rental requirements – often, background and credit checks are required for people with disabilities with no credit or a poor credit history, which can be a barrier
- Accessible spaces – most homes do not meet ADA requirements such as 32 inches of clear passage space in doorways, zero-step entrances, or main floor bathrooms

There is a wealth of data detailing the depth of the housing crisis in the nation, and more specifically in southwest Washington and the Portland Metro area. The crisis is compounded by additional barriers for people with disabilities, and many interventions address only part of the policy problem, so there is much work to be done. The data available on the housing crisis addresses how market strains affect the general low-income population, but do not consider the specific implications for the disability community.

SERVICES FOR PEOPLE WITH DISABILITIES

Addressing residential options for people with I/DD does not just include the physical space which they occupy. This section will outline the history of services for people with disabilities nationwide, the current context of Medicaid funded supports and utilization, and relevant service limitations in the state and in Clark County.

HISTORY AND THE NATIONAL LANDSCAPE

Throughout history, people with I/DD have been segregated or separated from the rest of society. What would now be considered pejorative classifications, such as "feeble-mindedness" or abnormality, were the framework of the medical model of viewing disability. This model led to mass sterilization and sought to hide people with disabilities from society.[18] People with disabilities have a long history of being segregated from others. This culturally-accepted segregation did not begin to change until the mid-1960's, when political and media attention was drawn to Willowbrook State School, a large state institution in New York for the mentally retarded.[19] The institution was described as a "snake pit" where people with disabilities were "living in filth and dirt, their clothing in rags, in rooms less comfortable and cheerful than the cages in which we put animals in a zoo."[20] Willowbrook was one of many state-run institutions that kept persons with I/DD separated from the community in an environment that was often overcrowded, inhumane, and lacking in care for the most basic human needs.

As policies were developed to protect the rights of people with disabilities, the move toward community-based services began as an alternative to residential institutional settings. Since the 1960's, the use of institutions for people with I/DD has been on the decline. Currently, most people with I/DD who receive services do so through Medicaid waiver funded services. These services are provided in a community-based setting and aim to provide community options to shoulder the burden of providing care and services. With nearly 15% of Medicaid's 68 million enrollees having disabilities,[21] and another 200,000 with I/DD waiting specifically for waiver programs, the need for these publicly funded supports has never been greater. In fact, in order to serve all people with I/DD currently waiting for Medicaid waiver-funded Long Term Supports and Services (LTSS), these

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[18] Parallels in Time. A history of Developmental Disabilities. Minnesota Council on Developmental Disabilities. https://mn.gov/mnddc/parallels/four/4c/6.html Accessed February 3, 2018.

[19] Reiman, M. "Willowbrook, the institution that shocked a nation into changing its laws." *Timeline.* June 14 2017.

[20] "The Closing of Willowbrook" *Disability Justice* http://disabilityjustice.org/the-closing-of-willowbrook/ Accessed February 3, 2018

[21]Paradise, J., Lyons, B., and Rowland, D. "Medicaid at 50. People with Disabilities." *Kaiser Family Foundation.* http://www.kff.org/report-section/medicaid-at-50-people-with-disabilities/ Accessed February 27, 2018.

service systems would need to grow by a full 23%.[22] However, a large population of people with disabilities are not eligible for this public funding and current estimates are that 20% of the total population has some form of disability, regardless of whether they need services.[23] These estimates demonstrate the critical need of finding sustainable long-term service and support options for people with I/DD. Given the history of marginalization, separation, and exclusion from society, it is necessary for these supports to be community-focused.

TABLE 1: NUMBER OF PEOPLE WITH I/DD BY YEAR AND RESIDENTIAL SETTING

Year	Home of a Family Member	1-6 Person Setting	7-15 Person Setting	16+ Person Setting
1997	296,946	194,968	53,914	93,362
2007	552,559	316,291	58,920	62,496
2014	630,492	384,973	56,170	42,651

(Source: RISP 2014)

The emphasis on supporting people with I/DD in the community can be seen in Medicaid waiver utilization by residential setting. As Table 1 displays, there is a growing number of people receiving services while living in the home of a family member (in 2014, 630,492 people in the US).[24] Concurrently, providing services in large congregate settings is declining (with continued decreases in settings of 7+ individuals since 1997). Transitioning to community-based services creates a different set of policy considerations. Serving people in the home of a family member drives the use of supports that continue to keep individuals with I/DD active in the community. Current Medicaid-funded services cover services such as respite care, in-home attendant care, community engagement, job training, and skills training. While not a comprehensive list, these services are examples of the diverse range of supports needed to keep people with I/DD healthy and safe, and to assist them to actively participate in their communities.

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[22] Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. https://risp.umn.edu/publications

[23] Courtney-Long, E et al. "Prevalence of Disability and Disability Type Among Adults in the United States." *Morbidity and Mortality Weekly Report.* July 31, 2015.

[24] Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. https://risp.umn.edu/publications

The Medicaid Home and Community Based Services (HCBS) is a waiver service program that states utilize through the federal Social Security Act.[25] Medicaid HCBS services are funded by both the federal and state government. The federal government reimburses state expenditures at a percentage of the state's per capita income. This reimbursement percentage is known as the Federal Medical Assistance Percentage (FMAP). For Washington, the FMAP percentage was 50% for Fiscal Year 2017[26]. This means that a $100 waiver service costs $50 to the state and $50 to the federal government. Washington utilizes HCBS waiver services in a variety of residential settings.

HCBS services in Washington are administered through the Developmental Disabilities Administration (DDA). An individual seeking supports applies for services by determining if their needs meet eligibility requirements. An individual who is eligible for services navigates the system through the support of a Case Manager. With the Case Manager, the support of family members, or other social support, the individual develops an Individual Support Plan to determine their preferences and needs for how and where they will receive support. In 2017, 36,404 individuals received supports in an in-home setting in Washington.[27] Over the last five years, the in-home setting has consistently been the most utilized residential setting for people receiving Medicaid waiver services nationally, and in Washington. Statewide HCBS waiver funded supports grow annually with an increased caseload of approximately an additional 1,200 people receiving services per year.[28] This number does not take into account the number of individuals who apply for services but are not deemed eligible.

Residential Type Definitions
In Home: Own Home, Relative's Home, Parent's Home
Community Residential: Supported Living, Group home, Adult Family Home, Child Foster Home/ Group Care/ Licensed Staff Residential, Alternative Living, Companion Home, Community ICF/DD, Assisted Living Facility, Nursing Facility, Correctional Facility, State Operated Living Alternative, Psychiatric/ Medical Hospital, Homeless
Residential Habilitation Center (RHC): Fircrest, Rainier, Lakeland Village, Yakima Valley

Medicaid waiver-funded supports can cover the services and supports an individual may need as part of their activities of daily living (ADL), or instrumental activities of daily living (IADL). ADLs may include help with basic living needs such as eating, dressing, or using the bathroom, and IADLs may include assistance with managing medications, and finances, grocery shopping or more complex

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[25] Centers for Medicare & Medicaid Services. Home & Community Based Services. https://www.medicaid.gov/medicaid/hcbs/index.html. Accessed February 28, 2018

[26] Federal Register. Vol. 80, No. 227. https://aspe.hhs.gov/system/files/pdf/167966/FMAP17.pdf. Accessed February 28, 2018.
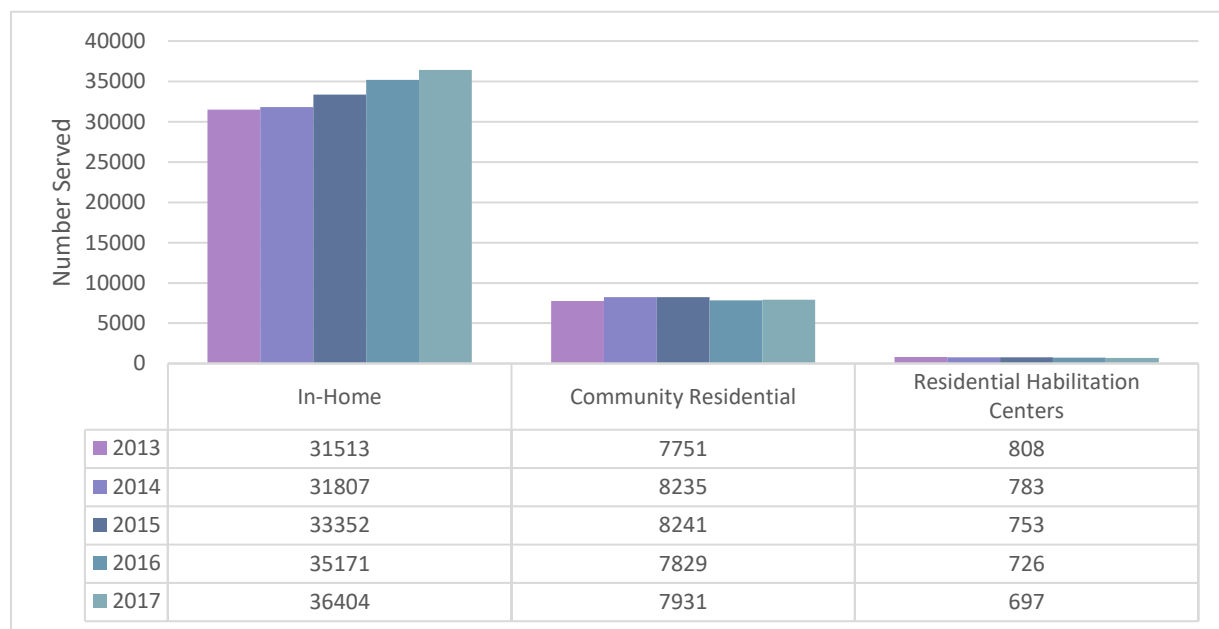
[27] Developmental Disabilities Administration. Caseload Data. July 2017.

[28] Ibid.

housework. These supports are known as Long Term Services and Supports (LTSS). While these supports are necessary for many people with I/DD to live healthy, safe, and meaningful lives in their communities, they only account for a portion of the assistance many need. LTSS do not cover living costs related to a person's housing needs-- such as rent, food, or utilities. Persons receiving supports must rely on other forms of income to cover these costs.

Several obstacles arise in navigating Medicaid waiver-funded supports for people with I/DD and their families. First, the service system is complex. There are five waivers available through DDA,[29] and each waiver offers a different menu of services. Navigating eligibility requirements, alongside waiver enrollment, and service availability can be complex and burdensome. Second, as mentioned above, while waiver services may cover supports for living, they do not provide support in finding residential options. A Case Manager may be able to identify how an individual may receive services, but not be able to assist in where that person will receive those services. Finally, for people with disabilities who live in rural areas, there may be a lack of providers who provide the support they need.[30] However, provider density exists in metro areas where the cost-of-living is higher than the rural market. People with disabilities are faced with the complex decision between choosing a lower-cost-of-living with limits to available services and living in more populous areas with a higher cost-of-living and greater access to services.

TABLE 2: NUMBER SERVED BY RESIDENTIAL TYPE 2014-2018

	In-Home	Community Residential	Residential Habilitation Centers
2013	31513	7751	808
2014	31807	8235	783
2015	33352	8241	753
2016	35171	7829	726
2017	36404	7931	697

Source: Developmental Disabilities Administration 7/1/2017

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[29] DDA Services & Programs. https://www.dshs.wa.gov/dda/consumers-and-families/home-and-community-based-waivers-hcbs. Accessed February 28, 2018.
[30] Rural People with Disabilities. https://www.ruralhealthinfo.org/topics/people-with-disabilities. Accessed February 28, 2018.

This high-level view of the landscape of services for people with disabilities highlights the challenges and obstacles that are presented in receiving the spectrum of necessary supports needed to live a good life. With many overlapping policy challenges, policy-makers and advocates must be thoughtful in addressing priorities and change. While great strides have been made in providing integrated, person-centered supports, the work ahead for researchers, advocates, and policy-makers is significant.

CURRENT WORK

The following section will address current work that is being done at state and local levels around housing and disability. Because these topics encompass more than just the physical space that persons with I/DD and their families possess, the current work being done covered in this section is broad. Future research will work to narrow this broad definition of policy interventions meant to support developing housing for people with I/DD and their families. This will be addressed in further detail in the Assessment Proposal and Next Steps sections of the report.

It is important to note that this section is not an exhaustive review of the work being accomplished. Rather, it offers a summary of collaborative efforts and initiatives around housing for people with I/DD. The highlighted subjects provide a broad overview of the current work and may allude to further policy work and collaborations needed. The following areas are covered in this section:

- The HOME meetings in Clark County
- The Communities of Practice initiative
- Programs and interventions to prevent homelessness in Clark County
- Housing developments in Vancouver from the city council

HOME MEETINGS

In 2012, a local group of concerned family members organized by the Clark County Parent Coalition began to discuss housing options and supports for their loved ones. This group named themselves Housing Options Must Exist (HOME) and is now a program of The Arc of Southwest Washington. The Arc provides several supports to families and people with I/DD in Southwest Washington, through advocacy efforts, direct support, and promotion of full participation in the community.[31] The group provides support and offers a place for families to share resources. Meetings often consist of updates on changes in housing regulations, waiver services, or having guest speakers connect the group to information and resources. The HOME group continues to meet monthly at The Arc.

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[31] The Arc of Southwest Washington. About, Our Mission. http://www.arcswwa.org/about/. Accessed March 7, 2018.

In reviewing the minutes from 2012-2017,[32] several key themes have emerged from these meetings:

- The importance of finding **innovative housing options**: The group shared interest in exploring alternatives for finding housing for their family members with disabilities.
  - Accessory Dwelling Units (ADUs) – a second unit on a single-family dwelling. Conversations explored the viability of building ADUs on existing family lots as long-term option for people with I/DD to live independently while remaining close to family and support. Meeting members received updates on city and county ordinances, acknowledging barriers, remodeling costs, and other practical considerations.
  - Roommate matches – family members discussed the importance of developing a centralized database that can match potential compatible roommates. Currently, the Housing Coordinator at the Arc serves in this capacity by connecting potential roommates to one another. Interested families contact the coordinator to post vacancies and opportunities, and the coordinator sends the information out to her network.
  - Shared housing models – a model where families and/or individuals can pool resources to create a housing option where individuals pay rent for their rooms and share personal attendant hours.
  - Shared interest in diverse, multi-generational communities – 1) a model where several homes (within "close" proximity) throughout an existing community are retro-fitted for individuals with I/DD, elderly, aging parents, individual Providers, single parents, etc. and 2) developing cottage style communities in Clark County with the same diverse mix of individuals as stated above. Cottage-style communities are houses on a shared or individual lot orientated to a common green space.
- The need for a central place for families to connect to necessary and relevant housing **resources and trainings**: With the development of a Housing Coordinator position in 2015, the group has a paid staff support position to act as a central resource for connecting people to resources. In 2016, the Housing Coordinator position evolved into what is currently the Housing Resource & Training Coordinator. Other topics of resources and trainings were also discussed, such as:

Innovative Options | Resources & Trainings | Support Network

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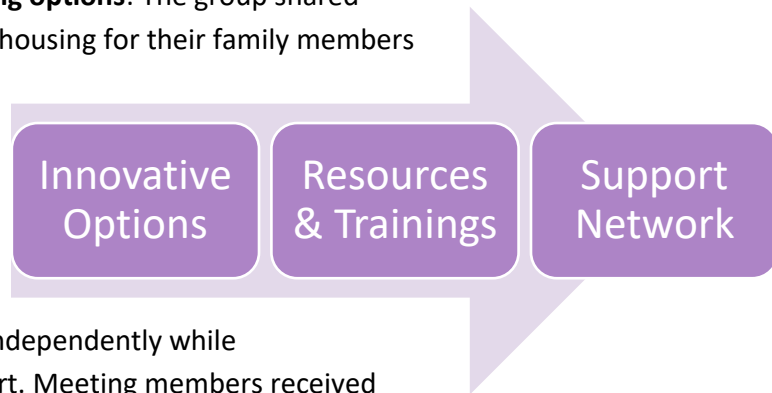
[32] HOME Meeting minutes were reviewed from May 2012 to November 2017.

- Independent living skills trainings – families noted the need for their sons and daughters to gain skills in living independently. Topics included maintaining a home, grocery shopping, cooking simple meals and budgeting, for example.
- Connecting with Developmental Disabilities Administration (DDA) resources – many sessions were devoted to understanding the funded resources and services available through DDA. Questions around eligibility, providers of services, sharing supports, and attendant care hours were often discussed.
- Learning about other communities or housing resources within and outside of Clark County – the group toured Stephen's Place in Washington, Edwards Center in Oregon, and Edwards Place in Oregon. Different speakers shared resources about services and housing options available in other regions. The group learned about the brokerage system in Oregon.
- Tenant/Landlord roles & responsibilities training – in May of 2016, The Housing Resource & Training Coordinator became a certified Rent Well Program instructor, specifically supporting the I/DD population. Rent Well is a 15-hour class, typically delivered over 6 to 12 weeks, and covers key information for being a responsible and stable tenant. Participants explore any screening barriers they may have, take steps to address those barriers, develop a housing portfolio that will show landlords a participant's qualifications as a tenant, and prepare them to be successful tenants in the future. Landlords who rent to Rent Well graduates are eligible to apply for the Rent Well Landlord Guarantee, which provides landlords with up to $1,000 of financial coverage for damages, unpaid rent or eviction costs, if needed. In July of 2017 the program was fully funded, and all 3 of its students received a Graduation Certificate verifying successful completion of the Program, and many more are expected in 2018.

- The minutes reflect the HOME group is an important place for families to share **support** and empathy: the search for sustainable housing and access to resources is a strain for family members. Having an environment to share openly about the frustrations and roadblocks experienced offers a place where families can find support and a listening ear. As families explore different options, many of the meetings involve brainstorming and sharing of ideas and successes.

As a response to the growing role that families play in providing support and care for individuals with I/DD, a group of national and state leaders in the disability field gathered to develop long-term policy solutions. In 2011, this group formed to develop an initiative that supported families nationwide; this initiative aims to gather consensus around policies and practices that advance family supports.

The national Community of Practice initiative's aims are not merely in the policy realm, but offer a transformational approach that works to shift the way policies are designed to support people with I/DD. The initiative creates an emphasis on supporting individuals and their families through their lifetime by providing a framework that stresses the development of a circle of supports around a person and their family. The shifting of attention toward the community for supports for people with I/DD is underpinned by the limitations of a service system that focuses on Medicaid reimbursable supports. While paid supports are often necessary, systems facing increased demand and shrinking budgets are becoming unsustainable and cannot guarantee lifelong support for an individual. Shifting this ideology toward an emphasis on community and system-wide reform that looks for long-term community-based supports that begin in early-intervention helps to balance paid services with free or low-cost community options that are much more sustainable.

Shifting the emphasis of supports being provided through multiple avenues transforms the traditional approach of utilizing paid supports exclusively—a relic of the institutional era. Figure 1 demonstrates this transition. In the first circle, the supports wrap around an individual and can create a barrier from the individual receiving supports from their family and the community. The stars in the second circle represent supports that are integrated in the community and through the family that are available to the individual. The Community of Practice posits that this alternative model is more sustainable and creates creative opportunities to support individuals with I/DD in the community.

The Community of Practice initiative was piloted in six states in 2013, including Washington. The Washington Community of Practice is staffed by the state Developmental Disabilities Council (DD Council).

PROJECT GOAL

To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.
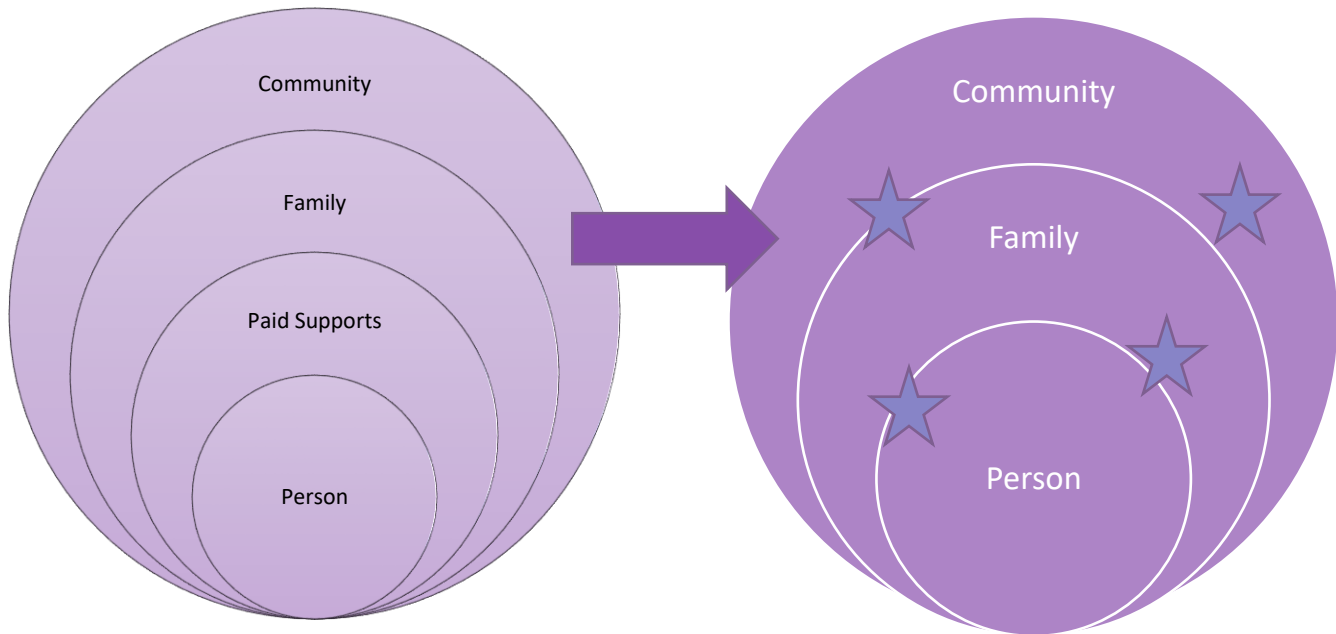
Through the DD Council, Washington has identified statewide priorities[33] for their Community of Practice initiative, including the following:

1. Adult Siblings who have and will assume support and care giving roles
2. Senior Caregivers with sons and daughters over forty living at home
3. Supporting Individuals with I/DD who are parents
4. Improving the "front door" experience of the DD system
5. Supporting Adults with I/DD living at home exercising decision-making, self-determination and autonomy

One of the ways that Washington is operationalizing these goals is through the work of Family Coordinators. These paid positions work locally throughout the state as a resource and education hub. The Family Coordinator works to connect families to available resources, trainings, and providers of services in their area. There are currently six Family Coordinators in the state located in eastern Washington, Jefferson, and King Counties.

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[33] Washington DD Council website. http://informingfamilies.org/topic/community-of-practice/ Accessed February 13, 2017.

There are a multitude of programs and interventions in Clark County that aim to prevent the experience of homelessness and find housing for those in crisis. Funding comes to the county through federal programs, statewide programs, and local funding. Through the work of the Clark County Department of Community Services (DCS) approximately $6.7 million of funding was spent in fiscal year 2016, and approximately $7.5 million in fiscal year 2017.[34] Local housing efforts aim to prevent and respond to homelessness through more than just emergency shelters. Interventions include transitional housing, permanent supportive housing, rapid re-housing and homelessness prevention.[35] DCS funding goes towards four main categories of programs: 1) Programs aimed to prevent or get out of homelessness; 2) Veterans housing assistance; 3) Acquisition, construction, rehabilitation of affordable housing; and 4) Housing support for individuals with behavioral health needs.

"The most effective way to prevent homelessness – access to affordable housing, physical and behavioral health services, and living wage jobs – are outside the control of the homelessness system. However, active partnership in these broader advocacy efforts is required so that the policies and strategies are inclusive of the needs of people who are homeless or at-risk of homelessness." [36]

The Department of Community Service's homeless crisis response system utilizes multiple programs. A significant portion of the funding goes towards programs that aim to address prevention including: outreach, permanent supportive housing, term-limited rental assistance, case management, system planning and coordination. A smaller portion of the funds is spent on assistance for veterans and the rehabilitation of affordable housing. Specific programs focused on behavioral health needs include: staffed housing programs, outreach, term-limited rental assistance, and capital investments. The work being done in the county addresses homeless prevention and response to the immediate needs of individuals faced with homelessness. With funding coming from multiple sources, there are opportunities to address homelessness through varied approaches. There is collaborative opportunity for crisis response and I/DD services to interact on developing sustainable solutions for people with I/DD who experience homelessness or the threat of homelessness.

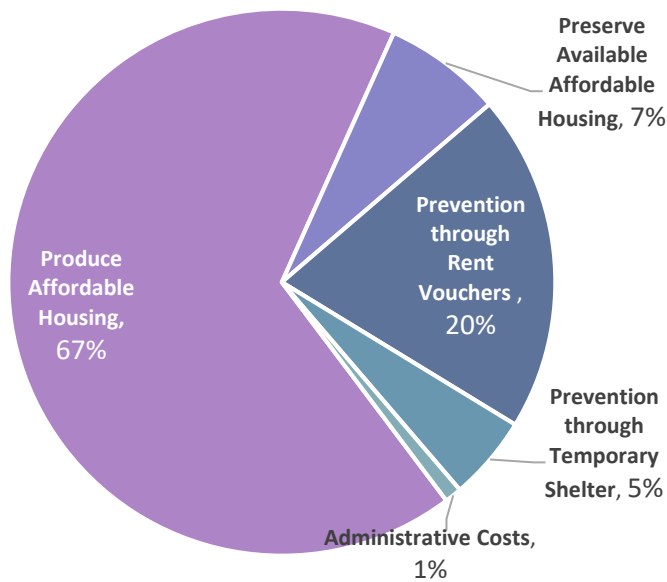[34] Department of Community Services, Clark County. Program Funding information report.

[35] Silver, A. Clark County's Scorecard in Washington's Goal to Reduce Homelessness. Street Roots News. May 14, 2014.

[36] Clark County Homeless System Presentation. https://www.clark.wa.gov/sites/default/files/dept/files/the-grid/021517WS_HomelessnessR.pdf. Accessed April 6, 2018.

In 2016, the Vancouver City Council responded to the community wide need for affordable housing with the approval of a property tax levy that would bring in up to $0.36 per $1,000 of assessed home value[37] to invest back into affordable housing. The approved property tax will bring in approximately $6 million in funding for seven-years beginning in January of 2017. At the end of the six-year period voters can renew the property tax or discontinue the program. The increased property tax does have exemptions for seniors 61 years and older and people with disabilities who earn less than $40,000 a year.

The estimated cost of the property tax is inconsequential for most homeowners. For a home that is valued at $250,000, the tax is an additional $7.50 a month or $90 a year. Although the property tax has a minimal impact on an individual basis, the creation of the Affordable Housing Fund creates great opportunity for individuals and families in need in the Vancouver area.

FIGURE 2: AFFORDABLE HOUSING FUND ALLOCATIONS

Preserve Available Affordable Housing, 7%

Prevention through Rent Vouchers, 20%

Produce Affordable Housing, 67%

Prevention through Temporary Shelter, 5%

Administrative Costs, 1%

To administer the $6 million in funding, the City of Vancouver invited project proposal requests for organizations that aimed to use a portion of the funding to address issues related to affordable housing. The 2017 applications were reviewed by a committee of community leaders and evaluated project proposals based on pre-determined spending priorities. The identified priorities aim to prevent, preserve, and produce affordable opportunities in Vancouver. As Figure 2[38] shows, the largest amount of spending (67% of the funding, or approximately $4 million) will go to the development of new construction projects. Seven projects were selected that create 237 new multifamily rental units, with 80 of these units earmarked for low-income individuals with rental agreements through the Affordable Housing Fund.

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[37] City of Vancouver Washington. Affordable Housing Fund. https://www.cityofvancouver.us/ced/page/affordable-housing-fund Accessed February 23, 2017.
[38] Vancouver Affordable Housing Fund. 2017 Allocation Plan. October 2, 2017.

Approximately 7% of the 6 million in funding ($400,000) will be awarded to three proposed multi-family rehabilitation projects, with an opportunity for additional projects to be identified throughout the funding cycle. The three identified projects are required to meet fair housing standards, prevailing wage, and eligibility expense requirements. Roughly 25% (approximately $1.5 million) of the allotted funding will be used on homeless prevention projects. Prevention is addressed through two different approaches: first, through housing assistance that may include rental costs, security deposits, and financing for utility or rent assistance. The second prevention priority is to address homelessness by investing in shelter space for single women. Funding will address necessary improvements to existing shelters that may increase capacity for single women, or the creation of new transitional shelters. The final 1% of the Affordable Housing Fund is budgeted for implementation and administrative costs.

The Affordable Housing Fund develops needed infrastructure in Clark County around addressing access to affordable and equitable housing. Moving forward, there is opportunity for the fund to collaborate with diverse underserved populations to be included in planning and development. The findings of the proposed research from this project can provide meaningful data and recommendations to the City Council in earmarking funds for people with disabilities in the future.

FUTURE COLLABORATION

The HOME meeting group, Community of Practice initiative, the work of Clark County's Department of Community Service, and Affordable Housing Fund are examples of resources and projects addressing housing needs in Clark County. With each project taking a different approach, the need for collaboration is evident among these projects and others. The HOME meeting group offers a wealth of resources and can connect family members to innovative ideas and support. The Community of Practice initiative offers statewide and national backing to transform the approach to seeking services and supports for individuals with I/DD and their families. Through the Department of Community Services in Clark County, several strategic interventions and programs are in place to address the prevention of homelessness county wide. And finally, the Affordable Housing Fund's investments in multiple housing projects, and different prongs of homelessness prevention, create local opportunities to address the housing crisis. In subsequent research and reports, PEACE will work to collaborate with funders on recommendations for including people with disabilities and their families in upcoming projects.

FINDINGS AND RECOMMENDATIONS

As evidenced through the history and background sections of this report, there is ample information available that addresses housing issues in two silos: the overall affordable housing crisis in the state and in Clark County, and the complex factors related to finding housing for people with I/DD specifically. There is little research, however, on how these two topics interact with one another, and the policy implications that occur due to these intersections.

To explore this further, PEACE proposed conducting a qualitative study and analysis on the barriers that people with I/DD experience to finding housing. The following section summarizes the research findings and next steps of this research by detailing:

1. Research methodology and analysis – the methods of data collection, participant consent and data security, sampling and participant recruitment, and the protocol used during data collection
2. Research findings – a summary of research findings that were developed from the qualitative analysis process
3. Recommendations and next steps – the recommendations based on findings, next steps, and considerations

METHODOLOGY

The assessment was conducted through qualitative interviews and focus groups. Semi-structured interviews provided the opportunity for the PEACE research team to navigate conversations with pre-determined questions while also being flexible to let the conversation shift according to respondent's feedback. Because interviews were done with people who have various abilities, picture cards for each question were created along with a step-by-step visual aid of the interview process. The researchers determined when the use of these materials was needed. Each focus group and interview session were audio recorded using AudioNote software, transcribed using ExpressScribe software to play the audio. The researchers then used Dedoose software to organize and code the qualitative data. Notes were kept during the focus groups and interviews to highlight non-verbal cues, observations, and identify themes that developed through the conversations.

Protecting research participants from potential harm is an essential part of conducting interviews. Research participants were given a consent form, demographic form, and ground rules of the session (all materials included in the appendix). These materials helped ensure that participants were aware of potential risks, pertinent data was collected, and a general understanding of the format and process of participation. Demographic forms and consent forms have been stored

securely in PEACE's office in a locked cabinet to ensure the privacy of all research participants. PEACE utilizes a secure server with only key staff being able to access research folders.

PARTICIPANT SAMPLING

Recruitment flyers and information for research participation were disseminated through PEACE's expansive network. The information provided detailed the research purpose, aims, and details of participation. The sampling methodology relied on a theoretical sampling approach. This approach was aimed to recruit participants with various experiences of searching for housing and services for themselves or family member with I/DD. Qualitative methods rely on saturation to complete the sampling process. Saturation occurs when a topic or theme has been addressed by multiple participants and indicates to the researcher that the repetition repeated among interviews indicates that sampling and further participation is complete.[39]

Through gathering a diverse range of experiences, the researchers were able to explore various dimensions of the problems and barriers identified. The research team conducted focus groups that consisted of family members, providers, and case managers along with interviews with individuals with I/DD. Altogether there was a total of 21 participants who participated in the study. The interviews from these participants gave a diverse and rich account of the barriers and needs in Clark County used for this analysis.

FOCUS GROUP AND INTERVIEW PROTOCOL

While the qualitative process is conversational and dynamic, it is an empirical process grounded in systematic data collection. To ensure that data is being sought after in an empirical way, each focus group and interview conducted used the same format. The researchers guided these processes through the methods detailed in Figure 3 (a full research protocol can be found in Appendix). These processes and methods were determined after time was spent ensuring that protocols aligned with best practices in both qualitative methodology and disability research.

ANALYSIS

The data collected through interviews was transcribed verbatim by the researchers, along with notes taken during the interviews. The data was coded to identify potential themes, categories, and a framework. The coding process is iterative and interpretative. In the first phase of coding, the researchers assign units of meaning to the raw transcribed interviews. Pulling out meaning from the

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[39] Glaser, B.G., Strauss, A.L.: The Discovery of Grounded Theory: Strategies for Qualitative Research. Aldine, Chicago (1967)

transcription allows the researchers to begin to code for patterns and organize similar themes across the interviews. The researchers use initial coding to examine, compare, and conceptualize[40] the raw data by creating coded shortcuts for referencing.
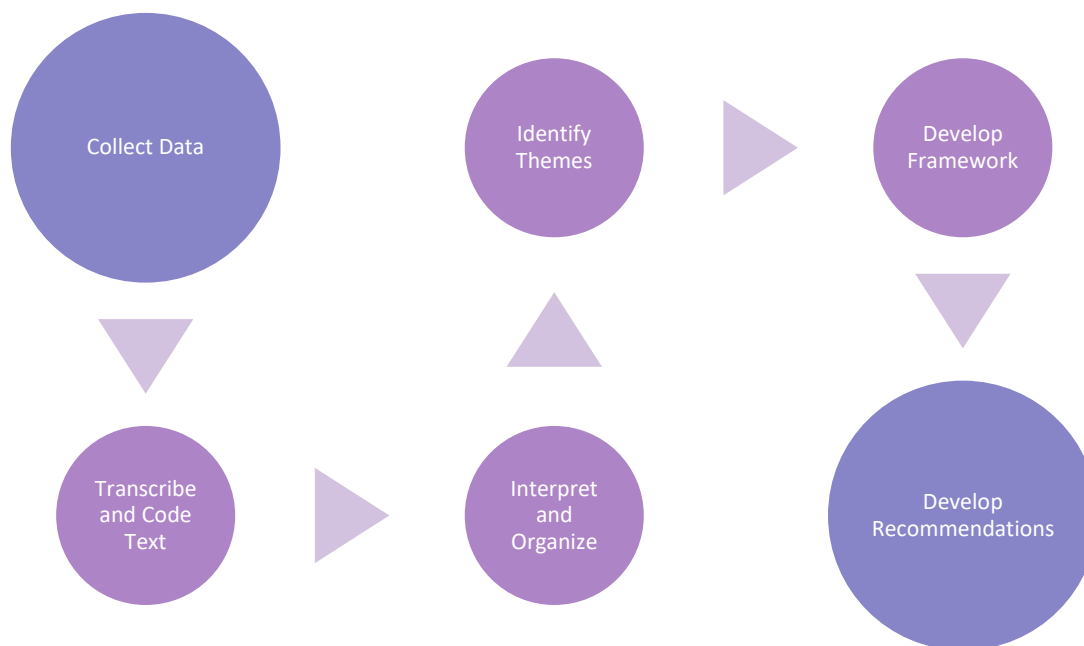
FINDINGS

Participants in both focus groups and interviews were asked to reflect on the barriers they've experienced in finding long-term housing for people with disabilities in Clark County. Participants reflected on singular incidences and long-term barriers that they have experienced. These experiences were coded for researchers to be able to group and understand in context of subsequent interviews and focus groups.

By developing codes, the researchers translated the codes into themes and categories. From the data collection process, 510 initial codes were created. The 510 codes were reassembled through the axial coding process and grouped based on their similar relationship identified in other interviews. In this stage of coding, the data is looked at collectively to provide meaning and identified similar themes or phenomena occurring in more than one interview. As themes emerged in the data, the researchers grouped themes to develop a framework that helps to organize the detailed codes into similar groupings. This framework is organized into three overarching

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[40] Strauss, A. and Corbin, J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Sage Publications. September 22, 1998.

categories: 1) the barriers to housing that are related to state level policy or services; 2) the barriers to housing that are related to local policy or services; and 3) the barriers that overlap among both state and local policy or services.

Looking at the findings through this framework shows how the findings overlap and intersect. A common theme when examining the data that emerged was that many of the barriers are not singular experiences. Rather, each barrier is multi-faceted and connects to other barriers. An example, finding an affordable option intersects with choice, which intersections with income, and transportation to work, and social connections, and so on. Understanding that the barriers overlap in this way means that one solution or recommendation will not solve the problem. It is important, however, to look at how the data interacts with policy on local and statewide levels and to understand the experiences of people with I/DD in attempting to find and sustain housing in Clark County.

FIGURE 4: BARRIERS IDENTIFIED BY RESEARCH PARTICIPANT

	Families	Individuals with Disabilities	Providers	DDA
State Level				
Services/ Supports	✔	✔	✔	✔
Providers (capacity, quality)	✔	✔	✔	
Reliance on Families	✔		✔	✔
Choice/ Independence	✔	✔	✔	✔
Innovation	✔	✔		
Local Level				
Transportation	✔	✔		✔
Roommates	✔	✔		✔
Safety	✔	✔	✔	✔
Landlord/Lease	✔	✔		✔
Resources and Information	✔	✔	✔	✔
Independent Living Skills	✔	✔	✔	✔
Physical Space/ Comfortability		✔		
State and Local				
Community/ Social	✔	✔	✔	✔
Accessibility	✔	✔		
Income	✔	✔		

Research participants identified multiple barriers to finding and attaining housing. While the physical space of a home (rent, location, accessibility, etc.) were discussed, a significant portion of the conversations centered around barriers relevant to services and supports available to people with disabilities. All 6 focus groups (with family members, providers, and DDA staff) and interviews with people with disabilities commented on the barriers to finding and sustaining housing related to the limitations of DDA services available. The conversations touched on the trade-offs that family members and people with disabilities must make to have access to services. Many of the findings intersect with one another, with themes and categories overlapping. A summary of themes that arose in these conversations are shown in Figure 4.

THE NEED FOR FAMILY SUPPORT

One topic that was addressed by parents was the limitations they experienced in support available when navigating waivers and residential options. Families commented on the need for continued support of their family member with I/DD even when that person lives in a 24/7 residential setting. When an individual receives supports in the family home, some of this strain is mitigated through respite services. However, families noted the loss of respite support when the individual moves out of the home even though families may be providing just as much support to keep their family member supported in a 24/7 residential placement. The move out of the home does not decrease reliance on family support, but the funding and services for respite are no longer available.

> *"We lose all our respite dollars that wouldn't come back to us in other services and we probably still need respite hours if we were managing his care outside of home" – Parent*

> *"A lot of the families are not willing to have their kids move out. Because one, it's twice as much work, in some cases it's impossible to do. Most of us work and take care of our child um so the obstacles are more non-tangible" - Parent*

This trade-off for family members was noted not only by families, but by providers, DDA staff, and people with disabilities. Policies and available services should honor the natural supports needed to make a housing placement successful; this success includes the social support of the family and community.

ON THE IMPORTANCE OF CHOICE

Research participants identified the need for honoring choice and preference when looking for housing. Participants alluded to the lack of choices available not only in affordable housing, but in

options that were sustainable and creative. With a shortage of housing, and limitations of supports available, persons with I/DD have little to choose from, and decisions are made not based on preference, but what is currently available. The implication made by research participants indicates the need for choices to be honored and prioritized in residential services for people with disabilities.

"I think a lot of times decisions get made for us especially when it comes to this community a lot of decisions get made that people think we need or you know but they don't necessarily ask us. They look at us as a whole and assume everyone needs this the way it is. No, it doesn't work that way with housing, with employment, with anything." – Person with a disability

"There isn't anything else, so they're [people with disabilities] put in environments that maybe aren't the best. And sometimes it isn't that people want to but that's all there is." – Provider

PROVIDER QUALITY AND CAPACITY

Another identified barrier to keeping a successful residential placement that was identified is the quality and capacity of providers of care. Residential providers handle critical support in the lives of people with disabilities. They attend to personal care, health and safety concerns, and general house duties. The importance of well-trained, qualified, and knowledgeable staff was emphasized by families, people with disabilities and providers themselves. Families acknowledged the need for better pay and benefits to ensure that quality staff are retained and trustworthy.

"I know what I've been upset about with the quality of care or the lack of care or the attention or all of these other things and I'm like well what's going on for these other people and whose checking on them. I mean the case manager once a year? That's not adequate and I don't, it gets treacherous to go to this space here, but these people I'm sure I trust are doing their level best but what I see is a complete lack of process of structure for the provider and their staff. I hear constantly from the staff they are not treated well" - Parent

In a conversation with providers, they echoed the statement of lack of competitive pay, poor management and low morale. This can lead to poor service delivery and affect the quality of care that people with I/DD are receiving.

"I've just been treated horrible. I am a huge advocate, in our meetings I do not stay quiet I stand up for what is right and then I get in trouble for it. Because it's, it's a lot of work. We have come a long way, but we're not there yet. And I see the potential of what we could do and what my clients deserve but I'm just told 'shh' just swept under the rug" - Provider

An emphasized need on family support, with the fear of losing valuable services, the need for real choices for people with disabilities, and quality care in providers point to larger policy problems. These high-level findings address the need for systems level change that are beyond the scope of

this project. However, next steps and recommendations will be provided in the subsequent section to address some of these needs.

LOCAL LEVEL BARRIERS

Research participants helped to identify barriers that were related to local level services or specific to living in Clark County. While some of the themes identified as "local" overlap with statewide barriers, the following themes identify challenges to acquiring housing in Clark County.

RESOURCES

Parents, persons with disabilities, providers and DDA made comments of the need for access to resources in finding houses. Participants reflected on the difficulty they have had navigating systems and knowing what options are available in the area. Parents especially remarked on all the dimensions that go into making a successful residential situation for their loved one. The coordination of this work requires knowledge of many moving parts, and parents often found themselves missing the critical information that they needed.

> *"You're building everything from scratch there's really no help finding the apartment finding the roommates finding all the supports you need teaching them what they need to know"* - Parent

> *"Um I guess I would ideally like to see a list of options on paper available to me as you know having a client of the county you know, that you know everybody asks the housing question they would say this is what we have, what we aware what's available all the way from Stephen's Place to you know uh county funded group home or something like that"* - Parent

ROOMMATES

Another important element to a successful living situation is the dynamic experienced in looking for and keeping a roommate. Both parents and people with I/DD along with DDA staff commented on the necessity of finding a roommate to offset costs. In addition to cost saving, a good fit for social reasons was noted as very important. Many participants commented on the desire to find roommates outside of DDA services and emphasized the importance of maintaining social connections with people who do not experience disabilities.

> *"…I think if we were to find something where he had other young people, a roommate kind of thing, I frankly think a frat house would be like a perfect spot for him because he loves playing games and hanging out with people and all those guy things, right? I think he would love that. Um, but that's not an option so um…"* – Parent

> *"If it would lower the cost…I can't have one here but if I could find one in another place that's bigger and I could lower the costs of living maybe I'd consider having one or two roommates"* - Person with a disability

Several focus groups commented on the barrier they experienced in working with local landlords and filling out rental applications and navigating leases. The lack of knowledge around accommodations, experiences, and the needs of people with disabilities was apparent and a tangible barrier. Families experienced discrimination and the need for education and advocacy in ensuring that people with I/DD had equal access to securing and keeping housing.

> *"…landlords don't necessarily understand the, uh, the relationship of, of a person who is…needs that kind of support. And so, when you are calling for…you know they want to run your rental history, you don't have one. They want to run a credit report, maybe you don't have one. Um, well you've got a parent that's trying to help you or a supported living agency…"* – DDA Staff

> *"I had this one [landlord], and this is a year ago in Fall, that we were telling, you know, it was for my son and his roommate at the time and he was like 'and how retarded are these people?'"* - Parent

> *"I think also landlords can be a barrier or condo boards, you know. Um, I heard a story from a parent who was trying to rent a unit, actually I think I've heard this a couple of times; One specifically was trying to rent a unit in a condo building, I'm thinking and you know just having to explain, 'okay well this is the person that's going to be living there but I am the representative payee and the guardian and I will be paying for it.' And the kind of interworking's of that dynamic um you know was difficult…a challenge to explain"* – DDA Staff

INDEPENDENT LIVING SKILLS

Another notable theme was the lack of transition or independent living skills trainings that are available in the area. Participants commented on the need for training and programs that provide practical life experience to make one successful in living independently or away from home. Parents remarked on the need for independent skills to be taught and valued. And DDA staff mentioned the importance of the skills being attained through employment to be transferable to being able to successfully live independently.

> *"Yeah, their transition program is a house and the students that go there they learn how to grow plants, how to cook, how to log recipes, how to do laundry, how to make beds, I mean it's phenomenal. Um, because somebody has to be in a position to teach and assume that they're going to learn. And there's nothing like that, at least in our area that I know of"* - Parent

> *"…You are kind of teaching job skills and, you've got a business that runs to kind of support this community, and it's run by people with developmental disabilities. You know, if that's what they want, to have a job, then let's give them skills to be able to do that, and kind of pave their way to housing and then maybe that leads to a bigger and better job maybe"* – DDA staff

STATE AND LOCAL LEVEL BARRIERS

There were several themes that emerged in the interviews that require attention at both the local and state level of policy and services. Many of these needs focus on the importance of community, not just a neighborhood per se, but a circle of support that helps ensure that many of the barriers that people with I/DD have experienced are addressed. This theme was explored through conversation around the need for social activities, the need for innovation in residential settings, and the need for services that are flexible to truly meet the needs and preferences of the person.

"And I'm not saying it's not scary or there's nothing unknown about it, but I will tell you that ever since I opened the possibilities to [new job] I've met so many more people that relate to me better that are not in the disability community that are more part of my community than ever before. So, I think the more that my disability community can take the focus off their disability and just see who's out there…" – Person with a disability

"…if you went to any residential options you would lose all of your respite which is what we use to navigate the community. You would lose your um community guide services, you would lose everything that gets him [person with a disability] out in the community and helps him be a contributing member" – Parent

"a community that was dedicated to people with issues like these we would have more understanding neighbors we could be more supportive of each other without having any one of us be there full time. I just see it does take a village kind of thing and I want to create that village" - Parent

RECOMMENDATIONS

The intent of this report is to act as a working document. Any future policy recommendations and next steps are grounded in the data which was collected by people who experienced firsthand or helped support persons with I/DD. PEACE will work collaboratively with DCS to help implement the following recommendations as a next step to addressing the housing needs identified by people with I/DD.

1. **Continue work with state advocacy efforts** - The findings in this report emphasize the need for change beyond local policies and resources to make independent and integrated options available to individuals with I/DD. Collaboration with family advocates, self-advocates, and statewide decisionmakers can help change the services and supports, need for choice, and provider quality mentioned in the findings. Further work around innovation in housing options for individuals with I/DD is needed.
2. **Further study and exploration to understand the** problem – The strength of qualitative research is that it is exploratory in nature. Many themes were uncovered in this process.

However, to gain a deeper understanding of the problem and how it is experienced in diverse areas, further study is needed. Potential areas to focus on would be in rural areas of the county, with transition age specific individuals, and with persons experiencing multiple diagnoses.

3. **Development of housing resources** – The need for education materials, access to resources, networks and collaboration on housing was made transparent in the research. Next steps in this domain could be around researching what materials are available within and outside of disability services and creating an education campaign and website. Many research participants mentioned the collaborative resource available through the HOME group, funding and support of this group is recommended. Places of collaboration and learning could be valuable and a possible housing conference to discuss resources would be valuable to pursue.

4. **Pursue independent skill development programming** – The importance of independent decision-making and choice was brought forward in the findings. Next steps in this theme include exploring what programs and services work to teach independent life skills and target areas within Clark County that could benefit from developing such programming. Utilizing peer-to-peer education would be relevant to teaching successful models to living independently and gaining the skills required to manage the home. The use of technology in developing skills towards independence is recommended. The can be done through exploring current uses of technology in the disability field, researching vendors, and possibly creating a skills training or equipment share with tools that utilize technology to provide supports.

APPENDIX

Consent Form

Parents Empowered and Communities Enhanced (PEACE) is working with the Clark County Department of Community Services Center for Community Health (DCS) to brainstorm solutions for the housing crisis in Clark County for people with disabilities. To do this, we are listening to stories and experiences of people with disabilities, their family members, and providers. What you share will help create recommendations to address these needs. Today, we'll discuss issues that are important to you.

This session will take about an hour and fifteen minutes. Your participation is voluntary; if you choose not to participate, or want to discontinue participation at any time, this will not result in any negative consequences to you, and nobody from the Department of Community Services will know that you decided not to participate.

We will audiotape the brainstorming session. We will also take notes. Only researchers from PEACE will listen to the recording or review the notes. We will reference the information you've provided in meetings, reports, and communications, but we will never mention you by name or in a way that could identify you.

- I agree to participate in the research on housing barriers for people with disabilities carried out by PEACE to aid with the research
- I am aware of the topics to be discussed in the focus group.
- I am fully aware that I will remain anonymous throughout data reported and that I have the right to leave the focus group at any point.
- I am fully aware that data collected will be stored securely, safely and in accordance with Data Collection Act (1998).
- I am fully aware that I am not obliged to answer any question, but that I do so at my own free will.
- I agree to have the interview audio recorded, so it can be transcribed after the interview is held. I am aware that I have the right to edit the transcript of the interview once it has been completed.
- I am aware that I can make any reasonable changes to this consent form.

_____   _____

Printed Name   Participant's Signature

_____   _____

Date   Researcher's Signature

Demographic Form

What is your home zip code? _____

What is your sex? (given at birth) □ Female   □ Male   □ Other

How old are you? □ 18-25 Years □ 26-49 Years □ 50-64 Years □ 65 and older

What is your race/ethnicity? (Check all that apply) □ Asian or Pacific Islander □ Black/African American   □ Hispanic/ Latino

□ White/ Caucasian   □ Native American/ Alaskan Indian

□ Other _____

What was your total household income last year? □ $0 - $ 25,999 □ $26,000 - $51,999   □ $52,000 - $74,999

□ more than $75,000   □ Don't know

What languages are spoken in your home? (Check all that apply) □ English   □ Spanish   □ Other _____

What relationship do you have with a person with a disability? (Check all that apply) □ Self   □ Family Member □ Service Provider □ Friend

□ Other _____

Housing status for your son or daughter with a disability? □ Own Home   □ Rent Home   □ Family Home

□ Rent a room   □ Other _____

Ground Rules

1. All participants will be treated with respect.

2. One person will speak at a time and everyone will get a turn.

3. You can share your first name with the group, or a nickname or name of your choosing.

4. We will not discuss private information outside of the brainstorming session.

5. There are no right or wrong answers

6. We will not judge or criticize each other's responses. Are there other ground rules anyone would like to add?

Focus Group Moderator's Guide

PEACE Families and Providers

April and May 2018

1.1. MODERATOR INTRODUCES SELF AND EXPLAINS PURPOSE OF FOCUS GROUP
- 1.1.1. Gets participants to share about the barriers they've experienced - Housing
- 1.1.2. Share feelings in confidence
- 1.1.3. Sheds light on some of the unseen but understood elements of housing for people with disabilities
- 1.1.4. Gives everyone opportunity to express themselves

1.2. Moderator Explains Procedure
- 1.2.1. Like a discussion. Most important get your feelings/beliefs. No right or wrong answers; only the truth, what you've really experienced
- 1.2.2. Everything is confidential. Only first names.
- 1.2.3. Session is recorded so can make sure we get your feelings/words right
- 1.2.4. Repeat and clarify and taking notes
- 1.2.5. Several questions for about 45-50 mins. Take a 10 min break. Come back, review, and have time for more questions.

1.3. Individual Introductions, even if some you know each other.
- 1.3.1. Name, relationship to disability

1.4. Discussion Topic for today Housing and barriers

2. Icebreaker – What your friends or acquaintances who do not support someone with a disability be surprised to learn about your life?
   2.1. Probe for shared or unique experiences
   2.2. Ask to share and explain their answers

3. Body of Focus Group
   3.1. What is a roadblock to finding long-term sustainable housing for your family member with a disability?
       3.1.1. Probe for shared or unique
   3.2. Suppose you could invest in one housing improvement for people with disabilities – what would it be?
   3.3. Share with us a time when you were looking recently looking for housing for your family member with a disability?
       3.3.1. Probe for tangible versus emotional experience
   3.4. If your loved one with a disability was to describe themselves and what they were looking for, what would they say?
       3.4.1. Do you think this is similar to what you'd also say? What would you add or change?
   3.5. Activity with notecards – Think of three needs related to housing for your family member with a disability. What are they? There's notecards with 1,2,3 on the back.

Order them from most important or critical and write the need and explanation. 1 being the most pressing, 3 being the least.

4. Break – 10 mins to snack and restroom
5. Wrap-Up Questions – Phase 2
   5.1. Review oral summary of the topics discussed and key terms
       5.1.1. Do you feel like this captures at a high level what we discussed today?
       5.1.2. Are there things we missed?
   5.2. Next Steps
6. Session wrap up – Thank you – Recruit more, send participant with flyers