

IDENTIFYING HOUSING NEEDS AND PREFERENCES of Adults with Intellectual and Developmental Disabilities and their caregivers in the Triangle and Triad of North Carolina





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Acronyms

ADLs Activities of daily living
ASD Autism Spectrum Disorder
CAP/DA Community Alternative Program for Disabled Adults DSP
Direct Support Professional
I/DD Intellectual and Developmental Disability

Executive Summary

There is a growing need for more housing options for adults with I/DD, particularly as caregivers age. Examining the preferences of both caregivers and adults with I/DD is crucial to ensure that as housing options and communities are developed, they will meet the needs and desires of the community they are serving. By including caregivers and adults with I/DD, we promote the freedom of choice for individuals to live in their desired house with access to needed supports and services.

In this project, both caregivers of adults with I/DD and the adults themselves were asked about their current housing situations, service needs, and future housing preferences. Data from caregiver survey responses and adult interview responses are presented. We received 207 surveys from caregivers and interviewed 31 adults with I/DD. Caregivers and adults with I/DD lived across North Carolina. Most lived in the Triangle region representing Orange, Durham, Wake, Chatham, Granville, Johnston, Nash, and Person counties. The adults with I/DD had a range of high school, college, and employment experiences. Although a majority did not attend a postsecondary education program after high school, a majority did currently have paid employment. 81% of respondents currently lived with parents or other family members. Participants reported varied services from receiving the Innovations Waiver, state-funded services, or they have yet to be received. A majority of caregivers said that adults with I/DD need total support in financial management, followed by medication/health. Caregivers reported some comprehensive support needed for cooking/meal planning, cleaning and home maintenance, community activities, safety, hygiene, and self-care. Parents were typically the source of unpaid support, whereas Direct Support Professionals were the primary source of paid support.

Caregivers and adults with I/DD reported a range of housing preferences. Collectively, there is a strong preference for a supportive community, shared outdoor spaces like walking trails, and easy access to community features like transportation, grocery stores, and restaurants. Houses, townhomes, and houses with separate suites or units with their own kitchens were the top three preferences for type of housing. Approximately half would not want a roommate. Most wanted to live in a suburban area with an intergenerational mix of ages. Caregivers reported that their most significant housing needs were transportation, being near family, having a community, needing support, and the desire for a full range of choices. Most adults with I/DD shared that they wanted to live in a community with houses close together, and a majority did not want to live in a rural area. A majority preferred living in a house or apartment.

Interview themes included housing features, structure, layout, cleanliness, possessions, and community accessibility. The top future housing priorities of adults with I/DD included three overarching themes: (1) Feeling safe: Many participants reported that the most essential aspect of their future housing is feeling safe in their home and community. This theme included responses related to living in a secure builcing and being in a "safe area of town." (2) Live in an accepting community: Some participants expressed a desire to live in an inclusive housing community for adults with I/DD that included activities and access to public transportation. Several participants also mentioned wanting to live in a society that accepts their intersectional identities. (3) Have a separate space to decompress: Regardless of whether adults with I/DD wanted to live with a roommate or alone, most participants wanted a separate, customizable space.

Housing preferences are critical to incorporate when developing inclusive housing initiatives. Surveys and interviews with caregivers and adults with I/DD highlight the desire for a housing community that includes options and provides adequate transportation, support needs, and access to community and social activities.

We need a full continuum of housing options from institutional to owning one's home

Caregiver Quotes

We need help! The only homes available are oriented for kids who are far less functional and not social. Please HELP!!!

Background

There is a growing crisis as many caretakers of adults with intellectual and developmental disabilities(I/DD) are aging. In the United States, most parents and family members serving as the primary caregivers of adults with I/DD are 60 or older (Braddock et al., 2015;2017). Caregivers report that their greatest concern about adults with I/DD is their future residence (Anderson et al., 2018). In a national survey of people with I/DD and family members, 62% reported that their dream was to live in their own homes or apartments (Friedman, 2019). HOPE (Housing Options for People with Exceptionalities) NC aims to create inclusive communities where people of all abilities and ages experience a sense of belonging. HOPE NC aimed to identify the needs and preferences of individuals with lived experience to create an inclusive, affordable community, one in which the housing and social needs of residents of different ages, abilities, and incomes are met with the engagement of neighbors providing social and natural supports.

The National Core Indicators - Intellectual and Developmental Disabilities (NC-IDD) program In-Person Survey was conducted in 2020-2021 to identify the experiences of adults receiving services from the state developmental disability services. In North Carolina, 428 adults with I/DD or their proxy respondents answered questions regarding their experiences, including housing options and life experiences. Of those adults, 50% lived with a parent or relative, 13% lived in group homes, 13% lived in specialized institutional settings, and 24% lived in other home settings. Of those who lived outside the family home, 61% had an input in choosing where they lived(NCI, 2021).

There is theoretically a broad range of housing and neighborhood options available to adults with disabilities, including group homes, segregated, private communities, and provider-controlled settings offering intensive, 24/7 care. But the reality, particularly in the Triangle area, is that there are few, if any, housing options available for adults with disabilities that are affordable and designed to be inclusive and supportive of independence, ongoing social interactions, and the overall well-being of their residents. The goal of the needs assessment is to identify the priorities for HOPE NC to address the critical need for housing options for people with disabilities by creating safe, affordable, inclusive communities where people of all abilities and ages experience a sense of belonging.

Aims

This study has two aims.

- 1. To identify future housing preferences of families of adults with I/DD to inform the creation of inclusive housing communities in the Triangle region of North Carolina.
- 2. To identify the housing preferences of individuals with I/DD to incorporate their lived experience into creating inclusive housing communities.

This report will answer the following questions:

- What are the characteristics and current housing and service situations of individuals with I/DD in the Triangle region of North Carolina?
- What do caregivers of individuals with I/DD hope for the future housing of the individual?
- What do individuals with I/DD want in their future living situation?



Methods

The survey was developed through an iterative process between the UNC team and the HOPE team to ensure questions most valid to the Triangle area of North Carolina were asked. Respondents were asked to complete a comprehensive online survey with 54 items, including demographics of the adult with I/DD, current living situation and service usage, and desires for a living situation for the adult with I/DD. The survey was deployed to the families in the Triangle area through two means: the HOPE newsletter listserv and the UNC Research Participant Registry. These databases comprise individuals with I/DD, their caregivers, and other stakeholders in the community. The process with both recruitment sources included sharing a message from the UNC and HOPE team inviting participants and a link to an online survey for anyone interested in participating. As a thank you for completing such a comprehensive survey, respondents received \$25.

Caregivers who participated in the survey and selected that they would like to be re-contacted about future studies related to housing needs received a follow-up email from a member of the UNC team (n = 169). Caregivers were asked to share information in the email with the adult with I/DD whom they care for.

Adults with I/DD who were interested in participating were asked to contact the UNC team to schedule a 1-hour interview. The following accommodations were offered to participants: sending interview questions in advance, providing the option to participate in person or via Zoom, encouraging a support person to accompany the adult with I/DD if desired, and offering various response options. Semi-structured interviews were conducted with adults with I/DD to capture perceptions of their current living situation and future housing needs. The interview consisted of 19 questions with follow-up prompts presented as a PowerPoint for the participants. Participants received a \$50 gift card electronically for completing the interview. Interview responses were analyzed using Braun & Clarke's (2006) inductive thematic analysis framework.



Section 1: Survey Responses

Respondent and Adult with I/DD Characteristics

We collected 207 surveys about unique individuals with I/DD. Age of the individuals with I/DD ranged from 16 to 65, with a mean age of 26 and 70% of the sample were under the age of 30.

The majority of responses were collected from parents of individuals with I/DD, with a high response rate from mothers.

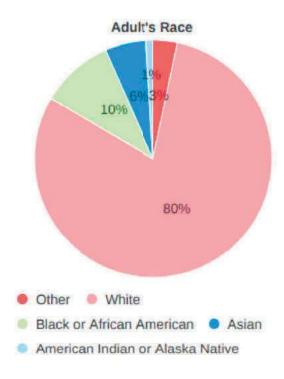
Survey Respondent Relationship to Adult with Intellectual and Developmental Disability

Mother	172
Father	22
Other	7
Direct Support Professional/Personal Assistant	3
Sibling	3

Individuals with I/DD were majority male, not Hispanic, and White. This particular sample is a lower percentage Black than expected based on the current demographic makeup of North Carolina.

Adult's Biological Sex at Birth

Male	155
Female	52
Adult's Ethnicity	
Hispanic or Latino	C
Not Hispanic or Latino	190

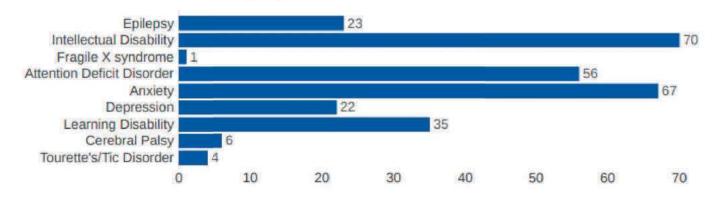


Many individuals with I/DD had more than one diagnosis, with autism and intellectual disability being the most prevealent diagnoses in this sample.

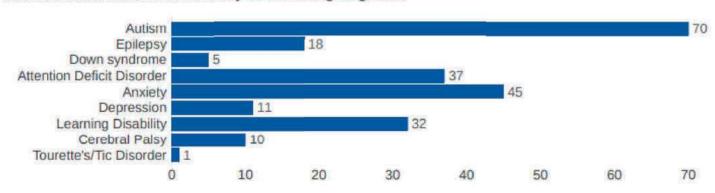
Adult's Diagnoses

Autism	78.26% 162
Epilepsy	13.53% 28
Intellectual Disability	49.76% 103
Fragile X syndrome	0.48% 1
Down syndrome	4.83% 10
Attention Deficit Disorder	31.40% 65
Anxiety	39.13% 81
Depression	13.53% 28
Learning Disability	24.64% 51
Cerebral Palsy	6.28% 13
Tourette's/Tic Disorder	1.93% 4
Other (please specify):	16.91% 35
Total	207

Individuals with Autism Co-Occurring Diagnoses



Individuals with Intellectual Disability Co-Occurring Diagnoses



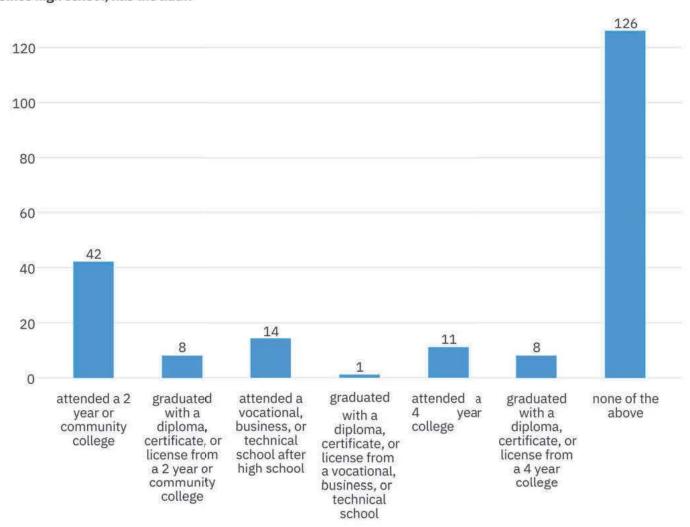
High School Diploma and Employment

Respondents were asked to report on whether the individual with I/DD completed high school, attended community college or university, and the current employment situation.

When the adult left high school, did they



Since high school, has the adult



Does the adult have a paid job now?



Current Housing

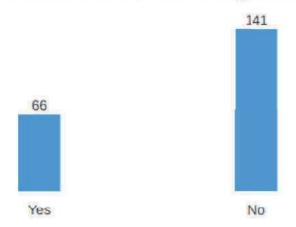
Respondents were asked to report on the current residence of the individual with I/DD. 81% of those who responded reported that the individual lived with parents, another relative, or a guardian. Of note, only 9% live alone or with a spouse or partner.

Adult's Current Residence

Independently (alone)	11
Independently (with spouse/partner or roommate)	6
Supervised apartment	3
With parent(s)	157
With another relative/guardian other than a spouse or parent	2
Group home (less than 6 beds)	14
Intermediate Care Facility (6 or more beds)	4

Respondents were asked to report if the individual with I/DD lived anywhere else since leaving high school, with less than half having had a different living situation.

Has the adult lived anywhere other than their current residence since high school?



Some of the places adults lived since high school include parents home, group homes, and college dorms.

Services and Support Needs

While many of the respondents noted that one or more services are currently being received, 35% are not receiving any services. The vast majority of those not receiving services live at home with parents; only 5 individuals not receiving services live independently or at a college dorm.

Current Services Being Received

Yes, receiving NC Innovations Waiver	42.29%	85
Yes, receiving Community Alternative Program for Disabled Adults (CAP/DA)	5.97%	12
Yes, receiving home health services such as home health aide, skilled nursing services, medical supplies, and specialized therapies	2.49%	5
Yes, receiving state-funded services	13.43%	27
Yes, receiving other types of services (Please specify:)	17.91%	36
No, services are not currently being received	35.32%	71
Total		201

For the individuals receiving Innovations Waiver, 78% are receiving services for Community Living and Support, with the next highest service being respite services (40%).

Other resources reported include employment support, such as Vocational Rehabilitation.

Rate How Much Support the Adult Needs

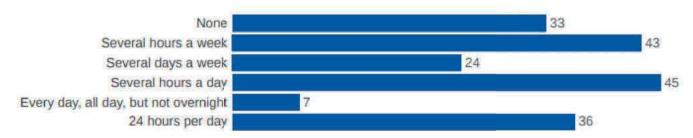
	No extra support	Some support	Total support	Total
Hygiene and self-care	81	89	17	187
Social and recreational activities	21	113	53	187
Keeping self safe	26	100	61	187
Community activities	24	102	63	189
Cleaning and home maintenance	16	106	67	189
Cooking/meal planning	17	98	73	188
Medication/health related needs	23	87	78	188
Financial management	5	56	126	187

Respondents also reported needing transportation support and supervision to help the adult with I/DD complete activities independently.

Invisible Supports

While many adults with I/DD receive support services directed at activities of daily living (ADLs) such as hygiene, cooking, and health needs, adults with I/DD also need "invisible supports", or the behind the scenes work that caregivers provide for the adult with I/DD. Examples of invisible supports may include coaching an individual through activities, (e.g. providing visual supports or teaching routine activities), providing advocacy (e.g. advocating at medical appointments), and being a lifeline (e.g. emergency response to an illness) (Bagatell, Lamarche, and Klinger 2023).

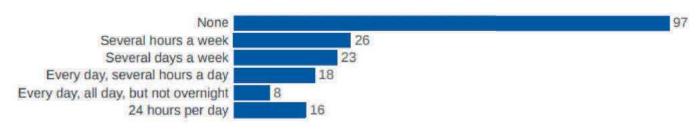
How much unpaid supervision does the adult receive in their living situation?



What are the sources of unpaid support?

Parent(s)/Guardians	169
Family members (such as siblings)	65
Unrelated individuals	16
Other	11

How much paid supervision does the adult receive in their living situation?



What are the sources of paid support?

Direct Support Professional/Personal Assistant	66
Respite Care	26
In-Home Aide	5
Other	45

Housing Preferences

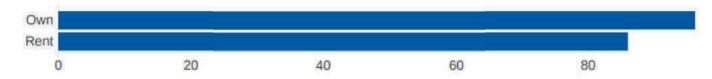
The following data relates to the housing preferences share by the survey respondents.

What type of housing would you prefer for the adult?

Single-family detached house	23.56% 45
Single-family attached (such as a townhome/duplex/condominium)	22,51% 43
House with separate suite or unit with own kitchen	21.99% 42
Low-rise multifamily apartment building (less than 4 floors)	15.18% 29
High-rise multifamily apartment (5 floors or more)	2.09% 4
Other, please specify:	14.66% 28
Total	191

Other types of housing identified include group home, supported living with roommates, co-housing or communal living, and townhouse/condo/duplex.

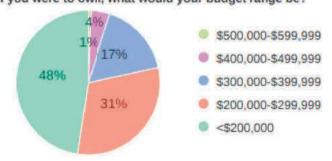
Would you prefer to own or rent the adult's residence?



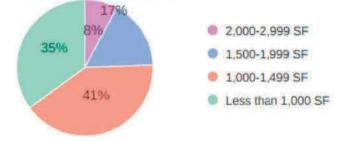


18% \$1,501-\$2,500 \$1,001-\$1,500 \$500-\$1,000

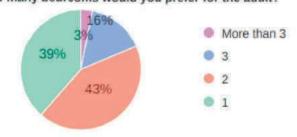
If you were to own, what would your budget range be?



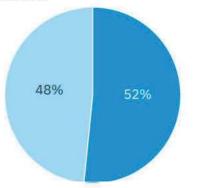
What would your preferred home size be for the adult?



How many bedrooms would you prefer for the adult?







For adults who DO want a roommate, why?



For adults who DO NOT want a roommate, why?



No

Yes

What is your preferred location?

Suburban area with a mix of houses, shops, and businesses (Such as Cary or Apex)	89
Suburban area with mostly residential uses (Such as Holly Springs)	8
City in a mostly residential neighborhood (Such as neighborhoods in Durham or Raleigh)	46
Rural area (Such as in areas within Granville, Harnett, Lee, Moore Counties)	6
Small Town (Such as Butner, Saxapahaw, Swepsonville)	11
Other, please specify:	27
Total	187

Other locations identified as preferred locations include walkable neighborhoods with access to shops a businesses, places with free transportation, or unlisted towns like Chapel Hill, and Hillsborough.

What range of ages would you want the adult to live near in the neighborhood?

17% 32
21% 39
26% 48
35% 65
70% 132
188

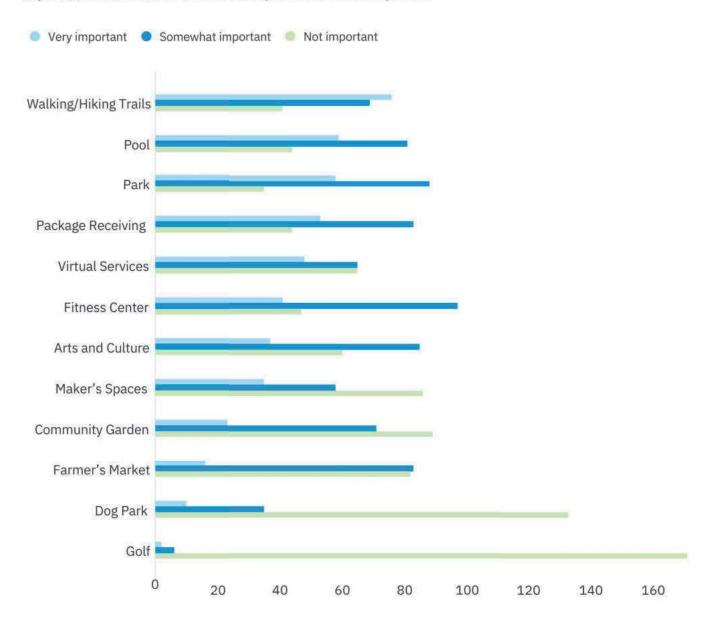
Intergenerational Living

Multigenerational or intergenerational living is a purposeful mix different ages in a community to provide opportunities for generations to mix and support one another. There is a current movement to improve health for older adults by providing more intergenerational living options. Research shows benefits to older adults living in intergenerational programs such as reduction of loneliness, social isolation, and depression. Family members and caregivers felt less burnout due to the support network of intergenerational programming. Younger individuals living in intergenerational communities also see benefits such as enhanced empathy, reduction of anxiety, and an improved sense of self-worth (Suleman and Bhatia, 2021).

This model of intergenerational living could provide the same benefits for the I/DD community. A mix of families, older adults, and adults with I/DD would provide a built in network for community and support for all individuals in the community.



Importance of Amenities from Most Important to Least Important

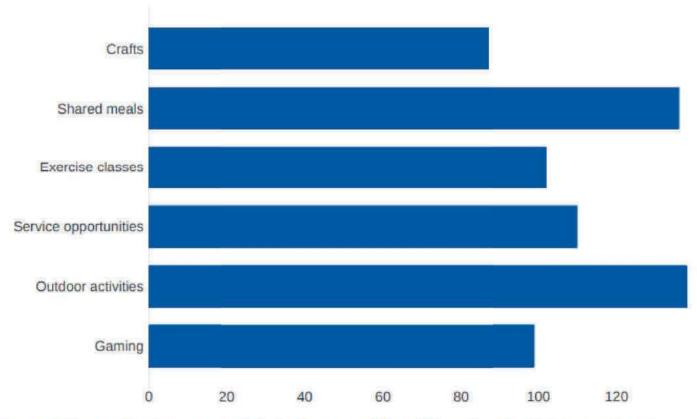


The most important amenities identified were outdoor and recreational spaces (wa.king/hiking trails, pool, park, fitness center). Practical services such as package receiving and virtual services were also deemed important amenities for adults with I/DD.

The importance of nature and outdoor spaces

Research has found that spending time in nature has cognitive benefits such as better attention and improved working memory. Just viewing a green natural space can help cognition and the sounds of nature can improve performance on demanding cognitive tasks. Access to outdoor space also improves mental health--it reduces stress, increases happiness, and leads to more positive social interactions. Just two hours a week in nature is enough to significantly improve health and well-being (APA, 2020).

What types of social activities would the adult be interested in participating in?



Respondents were also given an opportunity to share any additional information about housing needs and preferences. The table below highlights common themes from the responses and specific quotes from the respondents.

Open Ended Responses

Transportation	"Close to public transportation."
	"Walking distance to grocery shopping, pizza place/casual dining is important."
Family	"I would really like him to always be near family." "He needs to stay in [city]his brother who help him out from time to time live in [city]."
Community	"He likes being out in the community—would be unhappy if not going out most/all days of the week."
	"Her own space but opportunities/expectations of socializing" "Get together for meals, social, etc"
	"With community services available such as socialization, special Olympics, bowling, etc. Interaction with peers and typical peers."
Support	"She'll never live on her own so a group home is our choice." "Needs help with shopping, cleaning, and some cooking supervision."
	"We would like a 24 hour resource to handle emergency situations as well as help resolve daily life dilemmas."
	"Can function mostly independently but needs someone to check in periodically to help manage medications, supervise diet, assure house is kept clean, and manage finances."
Choice	"We have to advocate for CHOICES." "We need a full continuum of housing options from institutional to owning one's own home."

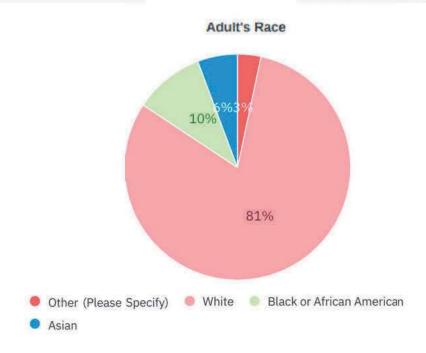
Section 2: Interview Responses

Adult Characteristics

We interviewed 31 adults with I/DD to learn directly from those with lived experience what their preferences are. Adults ranged in age from 18 to 65, with a mean age of 27 and 60% of the sample under the age of 30. This closely matches the survey makeup that adults were recruited from.

The interviewees were predominantly white, not Hispanic, and male, though the interview sample had a slightly higher percentage of females than the original survey sample.

Adult's Biological Sex at Birth		Adult's Ethnicity	
Male	21	Hispanic or Latino	2
Female	10	Not Hispanic or Latino	29



Interviewees had a range of diagnoses, including ASD, I/DD, and mood disorders. The interview sample included the majority of diagnoses captured in the survey response.

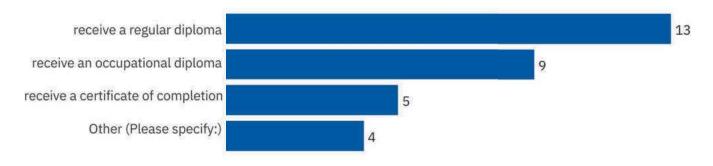
Adult's Diagnoses

Autism	74%	23
Epilepsy and/or seizures	3%	1
Intellectual Disability	29%	9
Down syndrome	13%	4
Attention Deficit Disorder	39%	12
Anxiety	32%	10
Depression	16%	5
Learning Disability	23%	7
Cerebral Palsy	3%	1
Other (please specify):	26%	8
Total		31

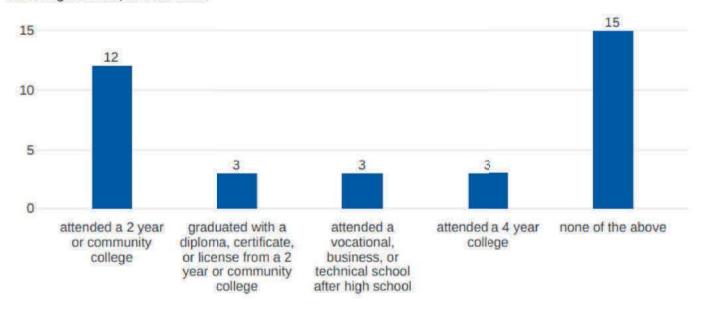
High School Diploma and Employment

42% of interviewees had received a regular diploma upon leaving high school and 48% had no post-secondary education. In regards to employment, 58% of adults interviewed were currently employed.

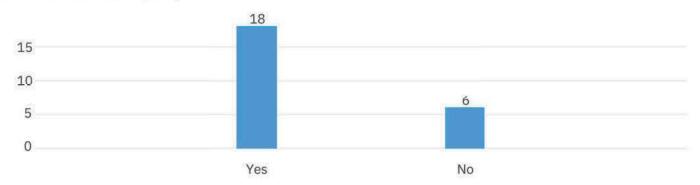
When the adult left high school, did they



Since high school, has the adult



Does the adult have a paid job now?



Current Housing

Like the survey, most adults interviewed lived with their parents (80%). Other living situations included living independently or with roommates, living in a college dorm, and living in a group home. Please see the Appendix to learn more about the housing features adults with I/DD reported currently having.

Adult Current Residence

Independently (alone)	2
Independently (with spouse/partner or roommate)	1
With parent(s)	25
Group home (less than 6 beds)	1
Other (please specify):	2

Services and Support Needs

Like respondents to the survey, the adults with I/DD whom we interviewed had a range of services currently being received and included a number of adults who were not receiving any services.

Current Services Being Received

Yes, receiving NC Innovations Waiver	7
Yes, receiving Community Alternative Program for Disabled Adults (CAP/DA)	3
Yes, receiving home health services such as home health aide, skilled nursing services, medical supplies, and specialized therapies	2
Yes, receiving state-funded services	4
Yes, receiving other types of services (Please specify:)	8
No, services are not currently being received	12
Total	31

Of the individuals receiving the Innovations Waiver, 71% are receiving services for Community Living and Support. Other services received included employment support, respite care, and clinical services. Overall, interviewee characteristics closely match the features of the adults in the survey sample. Thus, the adults who were interviewed are representative of the overall survey sample.

Housing Preferences

Through closed-ended questions (see Appendix) and follow-up interview questions, adults with I/DD reported their preferences related to housing.

Like the survey responses, adults liked walking trails, parks, and other recreational spaces (garden, pool, fitness center). They reported enjoying visiting various community spaces such as movie theaters, grocery stores, and restaurants.

Most report a preference for a city or a community over a rural area and a preference for a house with features like a yard, porch, or deck. Adults with I/DD report a preference for living with other people and having a pet, such as a cat or dog. Walking trails are a preferred feature of the community, as are parks, pools, grocery stores, and restaurants. Interviewees would like to do social activities, volunteering or work activities, and fitness and outdoor activities. Many adults reported needing help with household tasks, transportation, and scheduling their day.

Section 3- Interview Themes

During the first half of the interview, adults with IDD described where they lived at the time that the interview was being conducted. Interviewees talked about what they liked and did not like about their housing and community. During the second half of the interview, adults with IDD described their ideal living situation. Interviewees talked about the type of housing that they would like to live in, whether they would like to live with or near other people and the activities that they would like to have within the community where they reside. Below, we'd like to highlight themes that were generated from participant responses.

Housing Structure and Layout

Physical structure of house

When asked what the adults with IDD like best about their current housing, several individuals indicated that they were happy with the layout of their current house. For example, one participant liked having bedrooms in a separate section of the house from other living spaces.

When considering their *future housing*, some participants mentioned minimal space is important because it limits the needed upkeep. For example, one participant wanted to live in a townhome or apartment because they preferred less space. When asked why that type of housing is desired, they stated, *"It's not a lot to clean."* Age 24

"It's got a good, like, layout, so like... where things are makes sense, and there's kind of a clear division of like, alright, these are the bedrooms [that] are all on one side, the communal space is in this place, and the flowing through it makes sense. Things like that." Age 23

Airflow

When asked what they don't like about their current home, two adults with IDD mentioned the airflow in the house makes it an uncomfortable living environment. "In the summer, it gets really hot upstairs and it's much, much cooler in the lower [part of the house]." Age 31

Separate space within the home

When asked what they like most about their home or what makes them feel happy in their home, most of the adults with IDD mentioned that they like having a separate space that they can go to and decompress.

"I think having a private space to myself within - Like, if I'm living with others, I need a room where I can just be like, alright, nobody, no humans other than me. Cats are fine... I'd say that's kind of like the most important thing." Age 23 "But again, stressing I'm sorry, [interviewer]. Excuse me, just to... that he would... for him to have his own room, as he said in the beginning of the interview. He likes having his own room."; Caregiver of Age 31

→"I like having my own space" Age 28

"It's my space... that makes me feel really happy in my house" Age 27

"The space to get away from people" Age 26

Some adults further described how they enjoyed being able to customize their room based upon their interests.



""...My space. I love my bedroom and my bathroom. I decorated my bedroom. My parents even painted the walls." Age 27

Outdoor space surrounding the house a priority

For some adults, having an outdoor space surrounding the house was what they liked best about their home. Three adults with IDD mentioned wanting a deck or yard so that they could have a dedicated space for family and friends to enjoy when they come over.

"It's nice to be able to go sit somewhere outside." Age 34

"I like our yard... and our outdoor fire pit and our outdoor porch." Age 31



sometimes!

Other adults with IDD who were interviewed indicated that outdoor spaces such as a porch or a deck are not a priority for their future housing.

"I think if I had to have an outdoor space at all, I would want it to be not really out--it would be like, a like, kind of walled and like windowed in like patio thing because I don't like heat and I don't like bugs." Age 18

"I think when it comes to finding a group home or making [a] group home, I think outdoor space is less priority among people looking for group homes... You know, for front yard and backyard isn't high priority for those looking for group homes as well as me and my friends... never thought of it as a high priority." Age 25

"Yeah. Although I wouldn't want to actually have a space where I have would have to mow a lawn..." Age 38

Amenities in the living space

One participant reflected on prior living situations when they did not have access to their own washer and dryer. They expressed a preference to have such amenities in their living space.



Cleanliness of Home



Bug infestation

Two participants mentioned that they have cockroaches in their living space, an aspect of their living situation that they dislike.

"It's kind of a recent thing, but we've more frequently been getting cockroaches in the house more frequently. It didn't happen as frequently before. Maybe a year ago it wasn't this bad, but seems to be getting worse." Age 18

Desire for a clean living space

Several of the adults with IDD indicated that they feel sad when living spaces are dirty or disorganized. For one interviewee, this was the result of having roommate that did not clean up after themselves.



"It's just more space taken up and, you know, learning a roommate's like dirty habits is never fun... because then it's like, well, you have to live with that person and you have to live with, you know, dirty dishes everywhere and other, you know, a mess... so yeah, I'd rather be by myself." Age 31

Material Possessions as a Source of Comfort

Several adults with IDD identified that having specific material possessions in their home provides them with comfort and security.

"Cabbage Patch Kids are like... it's like a security thing for me, and I really don't go anywhere without them." Age 21

"I collect sports stuff, sports memorabilia, animals. Star Wars figures." Age 22 "My floof brigade, which is the army of plushies that I have, my fluffy pillows, my like little random like nooks and crannies, and like in the family room and in my bedroom." Age 18

Affordability



"Hopefully a house that's, like, affordable and not like overtly and crazily expensive, since everything is like expensive, and getting more expensive." Age 31

"Affordability... Yeah, I would much rather live somewhere not ideal, but that I'm not going to have constant financial stress over, than, you know, dream home but..." Age 23

"I just kind of stopped doing bowling during COVID because, well, obvious reasons and then it just kind of was like, eh it's expensive..." Age 18

Affordable Housing

At the end of the interview, participants were asked if there was anything that was not touched upon that they think is important about their future housing. Two of the adults with IDD brought up the desire for affordable housing, one of which mentioned that they would sacrifice location and their dream home if it meant being secure financially.

Cost as a barrier to recreation

Participants indicated that the cost of activities is a barrier to engaging in recreational activities.

"Yeah, the nearest swimming pool from my house is like about two miles from my house. And it's an, it's a club works gym. And you have to go with somebody that's a member over there. You also have to pay \$10." Age 34

Accessibility

Accessible Housing

Participants described the importance of having accessible housing and community spaces. One wheelchair user mentioned that the best part of her home is that it is "ADA accessible" Age 31

Accessible Community Spaces

Several participants described being limited in the types of outdoor community activities they can engage in due to them being inaccessible. For example, going to gardens, parks, and walking trails can be challenging unless they are paved.

"So I like looking at flowers, trees and stuff, but unless it's paved, it's difficult for me to go by myself just out of like an abundance of caution" Age 27



Another participant enjoyed spending time at coffee shops in the community, with the caveat that they have to be quieter, given the individual's sensitivity to noise.

"I have a lot of, I have issues with like noise... and being in crowded environments. So sometimes, you know certain like coffee shops, if like I've never been there before, like you don't know how loud or like popular they're going to be. So sometimes it's a bit of a hit or miss, but usually like hate to say it but like Starbucks is typically good. But the Barnes and Noble 'cause they like, serve coffee. And that's what kind of a generally quiet place." Age 27

Geographically accessible housing

When participants were asked what they like best about their current housing, several mentioned that being within walking distance to amenities, stores, and other recreational activities is convenient.



"Well, it's easily convenient to all the grocery stores and fast food restaurants, and there's several grocery stores in my area... Very convenient walking distance within, like a mile, mile and a half." Age 34

Other participants identified that their current housing is too isolated from activities and stores, which is a barrier for them due to the lack of transportation.

"I find it too isolated that it's, like I said, there's no nothing within walkable distance. And there's no public transit that I can access here, and I have to drive everywhere, and I don't like driving." Age 28

Transportation

Transportation dependent on caregivers

A majority of the adults with IDD indicated that they rely on caregivers or other family members to get them to and from soial activities, appointments, and work.



"Someone drives me because I can't drive myself. I don't drive. Never going to drive and don't plan to." Age 38 "Yeah, I mean, I don't have my driver's license yet, but my grandmother, or my mom, or her boyfriend, drive me." Age 26

Use of public transportation



Some adults with IDD described using public transportation such as GoRaleigh or Uber to get to various places. However, these individuals often used public transportation out of necessity.

"I usually get there like, on the bus or a taxi. Or my mom, or house staff." Age unknown

Barriers to using public transportation

Several adults with IDD mentioned that they were unable to use public transportation because the transportation where they lived was either not well-maintained, non-existent in their community, unreliable, or expensive. This impacted their ability to get groceries, socialize, engage in recreational activities, and get to work or appointments.

"Uh so. That they that they pick."
And so you know, there, there are things like, if I if I go out like to Barnes and Noble, or to a coffee shop or whatever then like. Then I'll use, you know. GoRaleigh and pay the taxi, you know? Uhm, but, for example, for doctor visits, I don't trust them." Age 27

"...public transit in North
Carolina sucks...It is nonexistent. Pretty much. Like,
yeah, you can say that you
have it. Okay. Technically we
have public transportation.
Okay? But like it's, for
example, I live in Raleigh. So
I use GoRaleigh, right? My
parents live in Cary. Most of
my doctors are in Cary.
Because it's GoRaleigh, if it's
a Cary address they can't
take me there." Age 27

"If I ever have the opportunity, I do. It's just [that] transportation is hard." Age 34

Safety

Desire to have a safe home and community

When participants were asked what the most important aspect of their future housing is, many of them indicated that they want to feel safe in their home and community.

"I just want to be safe in the community where I live." Age 31

"I want my future house to be safe." Age 33

Safety Concerns in the community

One interviewee and her caregiver discussed at length her experiences living in disability housing in an unsafe community. Her caregiver that was providing support during the interview indicated that "there's a Food Lion shopping center there. There are drugs and shootings every night. The largest homeless camp in [City in NC] is behind that shopping center". Age 33

The caregiver described receiving a call from her adult daughter with IDD who said, "Mom. They're shooting." The caregiver told her to "Get on the floor. Everybody needs to be on the floor." Because the area in which this adult with IDD lives is unsafe, she is unable to leave the house and take a walk down the road.

Measures to promote safety

Adults with IDD were asked to identify what makes them feel happy or safe within their current housing situation. For many participants, various technological devices fostered a sense of safety where they live. For example, participants described having motion lights that send alerts when there is activity outside, mobile devices with internet connection in the house, and alarm systems.

"So the new upgraded doorbell system has a camera, so we're even more safer than before, so we don't even have to turn on the lamp in the guest bedroom as well as the front door light. Well, we'll probably keep the front door light on to know who it is and stuff, but yeah, even more safer now." Age 25

Caregivers foster feelings of safety

Several adults with IDD indicated that their parents and the assistants who provide support with daily activities contribute to feelings of safety in the home.

"The fire alarms and the staff". Age Unknown

Interviewer: "What makes you fee safe in your house?

'My family, I have my family, my dog.' Age 22

> Interviewer: "Yeah. So the people in your house, [and] the animal? Great."



Support Within the Home

Feeling supported in one's home

"My favorite part to be at home is having fun with my family and friends..." Age 22 When adults with IDD were asked what they like best about their home, many of them described spending time with their family and feeling supported by the individuals who care for them.



"Being supported and listened to by my dad..."Age 28

Caregivers to assist with daily activities



When interviewees were asked to describe the types of activities that they needed help with throughout their day, several indicated that they needed assistance with cleaning their living spaces, laundry, cooking, and scheduling transportation arrangements.

One adult with IDD highlighted that they feel more comfortable engaging in daily activities (e.g., chores) when they have a support person that they can trust (Age 28).

Help with maintenance & upkeep

One participant mentioned feeling sad or afraid in their home when "something breaks... then I'd have to go and fix it" (Age 31). They further described how their new landlord does not regularly check in on the house, which is challenging. A different participant also indicated that their landlord does not prioritize the upkeep of the homes. Another participant stated they would like to live in an apartment (Age 31). Their caregiver provided additional context for why this housing choice would be ideal.



Caregiver: "If I could just interject, an apartment would be ideal in that, you know, there's not a lot to worry about. Hopefully, there would be a super or someone taking care of, you know..."

Interviewer: "The maintenance."





Caregiver: "Yeah, yeah. That type of thing. Someone to call if there were a problem with the plumbing..."

Independence

When asked what makes them feel happy in their home, two adults with IDD indicated that they enjoy having the independence to engage in preferred activities and routines. They also expressed a desire for independence in the future.

Interviewer: "Most important to you about your future housing?"

"Being able to be on my own, and being able to gain my independence fully back." Age 34

"So I have a lot more independence. I can go to bed when I want, I can wake up when I want. I can choose what to eat and when to eat it and stuff." Age 27



Shared Living Space

Roommates foster socialization

One adult with IDD indicated that the best part of their house is "I get to spend time with other people and friends and spend time with my roommates" (Age 33). For some, having people to live with increases opportunities for socialization. Other adults described their ideal future living situation and indicated that having a roommate is a priority for them. This included partners, friends, or other people who met a particular criteria and whom participants were compatible with.

"I think if I could find a roommate who would, like, meet my ambiguous criteria for friend material, that would be cool. Because then I would actually have social interaction without having to like set up, like, meetings and like schedule, just--this is hangout time, or whatnot, because I cannot do that." (Age 18)

One adult mentioned that "actually being able to choose" roommates is a priority (Age 33). 28

Roommates can also create a toxic living environment

"I am a generally a bit--I'm more independent than they are, and I do things like go out. And, for example, my Dungeons & Dragons sessions. They're from 7pm to 11pm at night, once or twice a week. And so it's, like, difficult with timing and letting them know hey, I'll be away, you know, I'll be here, but I'll be back, you know?" Age 27

Some adults with IDD discussed specific issues that they had with their roommates who did not have similar needs or routines. Living in such an environment created notable tension and stress for the individuals. For some, having these challenging interactions led them to want to live independently in the future.

Preference to live independently

Some adult participants expressed a desire to live alone due to the uncertainty of having roommates and shared living space.

Individuals were particularly concerned about not having their space and material possessions respected by roommates and living with another person whom they do not get along with.

"I'm more okay with living alone if I had my own apartment, because I'm not really sure about having roommates because I don't know what other roommates might do, you know?" Age 38

"That is just me. You know that I don't have a roommate. It's wonderful." Age 31

"...I'm fairly independent, and so in--with disability housing, you're going to be with someone, you're going to be with at least one other person, right? And you don't know if you're going to clash, or what. Or if, like, you're going to clash with their guardians, for example, like before." Age 27

Pets as a source of comfort and safety

For some adults with IDD, having a pet was comforting and made them happy in their living situation.

"I really love the people I live with, and the cats that I live with. They all make me happy." Age 23

"...Having pets I can take care of also helps." Age 28









Type of Community

A familiar community

Living in a community that is familiar was a priority for a few of the adults with IDD.



Communities for adults with disabilities

When asked the question, "If you could live anywhere where would it be?", some adults with IDD described living in a complex with people with disabilities.

"I would like to live in an apartment complex for adults with disabilities in an area where there's easy access to public transportation on the regular basis." Age 34

This sentiment was also expressed by several caregivers who were supporting the adult during the interview.

"I hear people are doing it for themselves, as far as... there are lots of families that have gone in on--OK, I've got a special needs child. You've got a special needs child... and set them up together in a condo and let them live independently. But then the various family members cross over in checking in to make sure that things are done and..." Caregiver of Age 26

Accepting communities

A few participants desired to live in a community that accommodated their disability and was accepting. Two additional participants also identified wanting to live in a place that accepted their intersectional identities but didn't think that the state of North Carolina could meet that requirement.

"Geographically, I think I just want... I think I'd prefer to be somewhere where the state is not trying to legislatively attack trans rights. That would, that's a big... that's kind of my biggest complaint about living in North Carolina." Age 23

"I would like to live in a place that is accepting of everyone, that is roomy, and that's accommodating to my physical impairment." Age 34

Community spaces designed for socialization

Several adults with IDD and their caregivers discussed wanting to live in a community that created spaces to foster socialization.

"Somewhere that's close to most areas of social gathering, and that has access to public transit, and has--it has safe walking and or cycling roads." Age 28

One caregiver in particular described the importance of the community having structured activities that would be available for their loved one. "But [they] would thrive the most, though, being around people with kind of programmed things to do and community spaces to be her... having a private space, but still having access to public spaces to be around folks." Caregiver of Age 21



Engagement in the Community

Community activities designed for individuals with IDD

Adults with IDD described a variety of community activities that they engage in with other individuals with disabilities. For example, adults described being involved in Special Olympics and Best Buddies. They also met other individuals with IDD at events hosted by the YMCA and the Autism Society, among other local organizations. When the interviewees were asked why they enjoy attending activities with other individuals with IDD, many described liking the opportunity to socialize with others.

Community activities NOT designed specificallyfor individuals with IDD

Adults with IDD described a variety of activities that they engage in within the community that are not specific to individuals with IDD. For example, several adults mentioned attending sporting events where they cheer on their favorite local sports teams.

Other participants enjoyed working out at the community gym or playing sports with friends in the neighborhood. Several adults mentioned having a community of individuals who meet up and play Dungeons & Dragons or other role-playing games.

When adults with IDD described going to various places within the community, many identified that they enjoyed going with family and friends, as it provided opportunities for socialization.

A few of the participants mentioned that they enjoy traveling or spending quality time with their family. For example, one participant described enjoying the weekends that her and her mom spend time at bookstores, coffee shops, and restaurants.

"Yeah, I mean, gardens are great. But I do like, I do like going to the ... Arboretum with some of my friends." Age 22



Barriers to engaging in community activities

Quite a few participants mentioned that they no longer participate in some activities that they engaged in prior to the pandemic. Reasons for not participating included no longer feeling comfortable being in confined spaces (e.g., movie theatres and restaurants) and the discontinuation of activities that they used to attend.

"He was very much involved with the acting. I mean, he is a trained actor. He's done independent films. He's been in theaters, and before COVID, he was pretty active with that, and he has a group of friends that they did a lot of the, you know, movies that were on YouTube and all that. Ever since the COVID hit, he's not... he's still involved, right? But he's not doing much at all with that." Caregiver of Age 31

For other adults, physical health was described as a barrier to engaging in community activities. For example, one participant indicated that she was a "like a social butterfly", but while receiving chemotherapy, she is required to isolate from friends.

Volunteering Opportunities

Many adults with IDD mentioned their involvement in volunteer work within the community. Interviewees volunteered at family churches, food pantries, community gardens, and as Special Olympics coaches, among other activities. Volunteering provided adults with IDD the opportunity to socialize with people in the

community.

I volunteer with the youth ministry for the middle school, and I'm a student leader, a speaker, and I volunteer on the banquet, our business team, which--that sets up the breakfast for the volunteers and lunch if we have certain events. And I volunteer on the connect team, which--those are the greeters, which welcome everyone into the church... I enjoy it because I'm a people person and I like to, you know, try to brighten up someone e's day." Age 34

"I've been working at a food pantry weekly, helping deliver food to people in need." Age 28



Paid Employment

In addition to volunteering opportunities, three adults with IDD highlighted their enjoyment of work opportunities, as this provided them with opportunities to socialize with friends, colleagues, and customers.

"I talked to customers who were there, and we served--I served them ice coffee. And we also had tea as well." Age 31

Engagement in Activities within the Home

In addition to adults with IDD engaging in activities within the community, most adults highlighted needing downtime to relax and engage in activities within the home that they enjoy. For example, adults mentioned putting puzzles together, playing video games, watching TV, listening to music, and exercising.



Conclusions

This report has highlighted the importance of housing for individuals with I/DD and their caregivers in North Carolina. Individuals and their families have many preferences for building an inclusive housing community. It will be critical to include affordable and accessible housing for families.

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Appendix I: Visualization of Interview Responses



1. Do you live in a house?

80.6%

Yes



19.4%

No





2. Do you live in a townhouse?

16.1%

Yes



83.9%

No





3. Do you live in an apartment?

6.45%

Yes

93.5%

No







4. Do you have a porch?

61.3%

Yes

29.0%

No



9.68%





5. Do you have a yard?

77.4%

Yes

19.4%

No



3.23%





6. Do you have a deck?

64.5%



16.1%

No



19.4%

I don't know/ Not asked





7. Do you have green communal space?

41.9%

25.8%

32.2%

Yes









8. Do you have a fitness center in your neighborhood?

16.1%

80.6%

3.2%

Yes



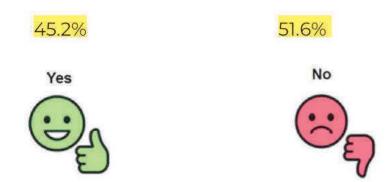
No

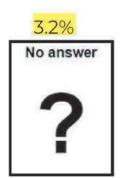






9. Do you have a pool in your neighborhood?





10. Do you have a place to play sports in your neighborhood?

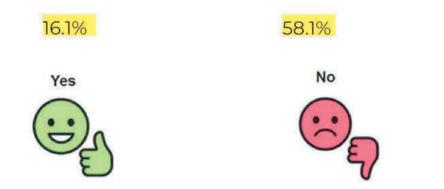








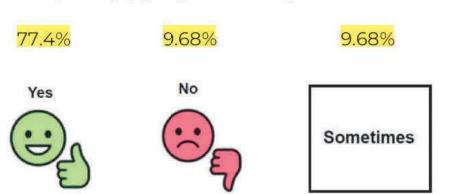
11. Do you have a dog park in your neighborhood?







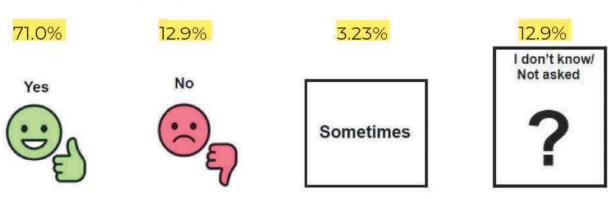
12. Do you enjoy going to a walking trail?





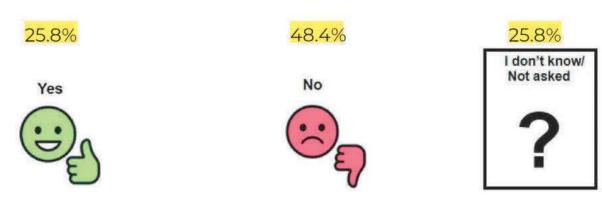


13. Do you enjoy going to a park?



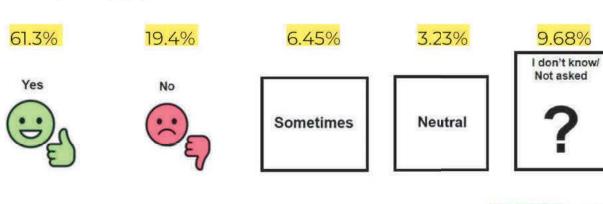


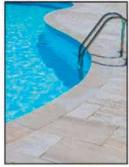
14. Do you enjoy going to a dog park?



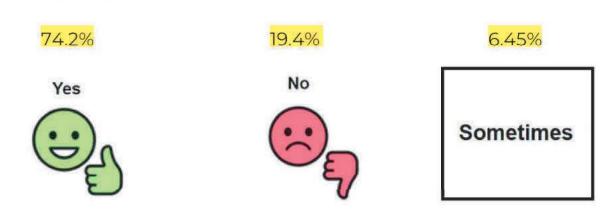


15. Do you enjoy going to a garden?





16. Do you enjoy going to a pool?





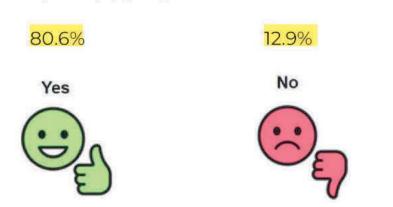
17. Do you enjoy going to a fitness center?



I don't know/ Not asked



18. Do you enjoy going to a movie theater?



Sometimes

6.45%



19. Do you enjoy going to a library?

61.3%

12.9%

12.9%

3.23%

9.68%

Yes



No E

Sometimes

Neutral



20. Do you enjoy going to a grocery store?



6.45%

12.9%

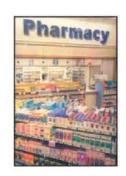
Yes



No



Neutral



21. Do you enjoy going to a pharmacy?

35.5%

32.3%

6.45%

12.9%

12.9%

I don't know/ Not asked

Yes



٩

Sometimes

Neutral

?



22. Do you enjoy using public transportation?

41.9%

41.9%

6.45%

6.45%

3.23%

I don't know/ Not asked

Yes



No



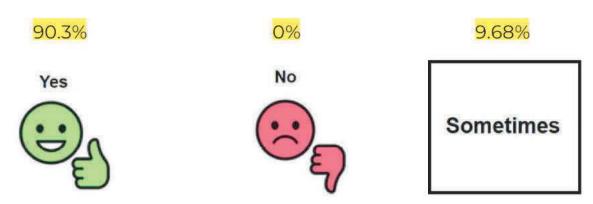
Sometimes

Neutral

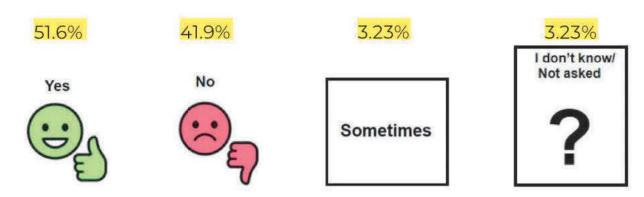
?



23. Do you enjoy going to restaurants?



24. Do you enjoy going to a place of worship?





25. Do you drive to any of those places?

96.8%

Yes



3.23%

No



方

26. Do you walk to any of those places?

45.2%

Yes



45.2%

No



9.68%





27. Do you ride a bike to any of those places?







28. Do you take a bus to any of those places?





29. Do you live alone?

6.45% Yes

93.5%

No



30. Do you live with other people?

93.5%

6.45%

No







31. Would you like to live in a city?

51.6%

Yes

32.3%



16.1%



(!) (

32. Would you like to live in a community with houses close together?



64.5%

3.23%

No

3.23%

29.0%

Yes



٥

Neutral

I don't know/ Not asked





33. Would you like to live in a rural area?

22.6%



16.1%

Yes



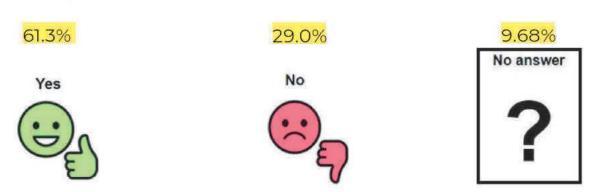
No



No answer

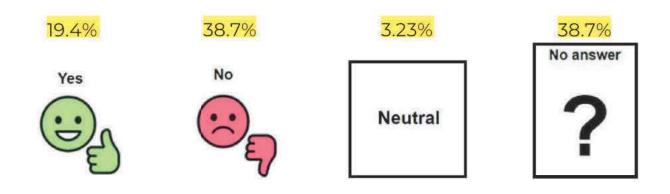


34. Would you like to live in a house?



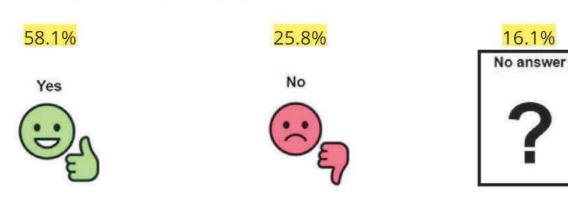


35. Would you like to live in a townhouse?





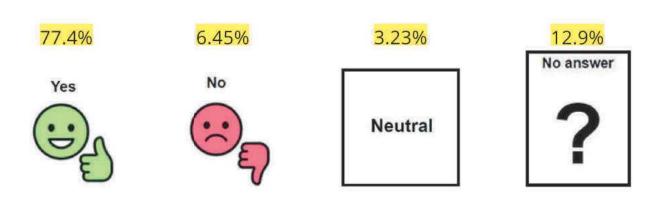
36. Would you like to live in an apartment?





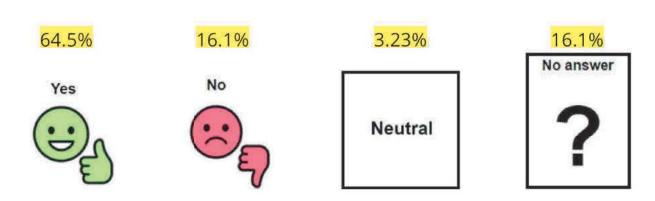


37. Would you like to have a porch?



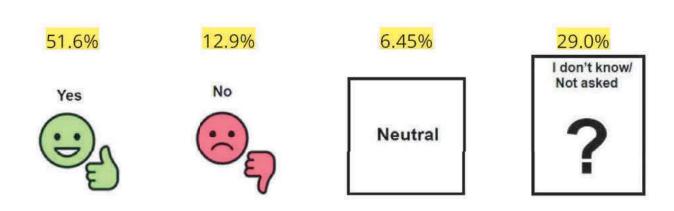


38. Would you like to have a yard?



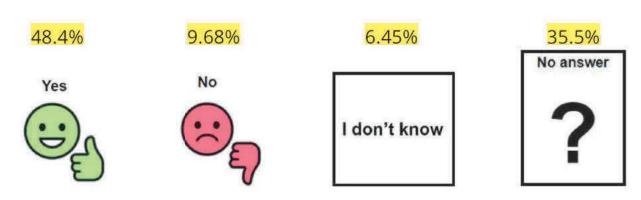


39. Would you like to have a deck?

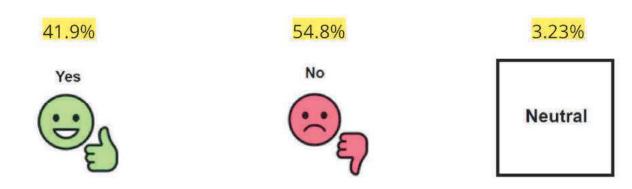


40. Would you like to have a green communal space?

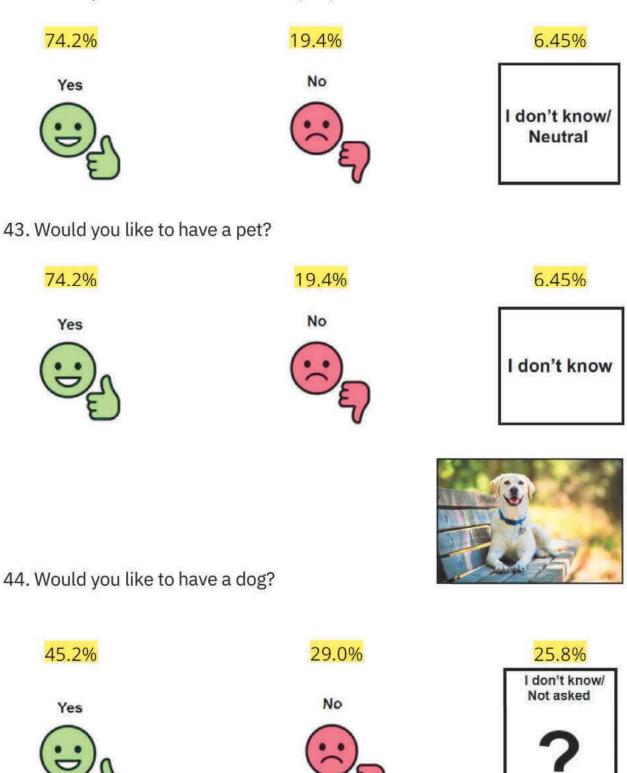




41. Would you like to live alone?

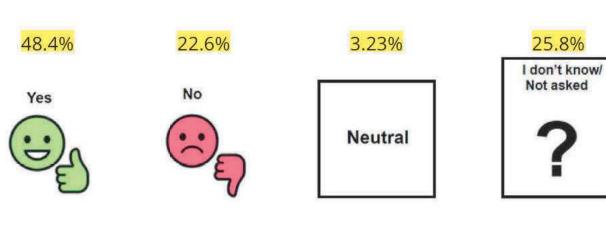


42. Would you like to live with other people?



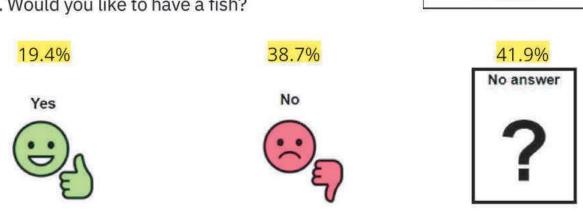


45. Would you like to have a cat?





46. Would you like to have a fish?





47. Would you like to have any other animals?

32.3%

35.5%

32.3%

Yes



No





48. Would you like to live near a walking trail?

74.2%

6.45%

19.4%

Vac



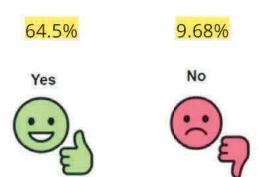
No







49. Would you like to live near a park?



9.68% Neutral





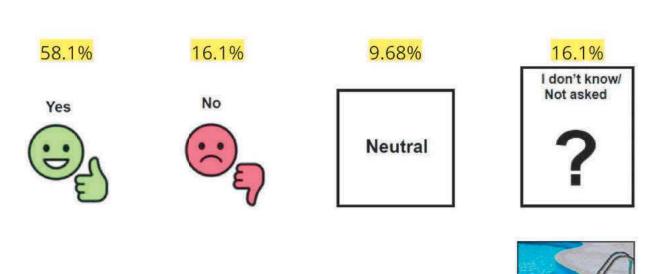
50. Would you like to live near a dog park?



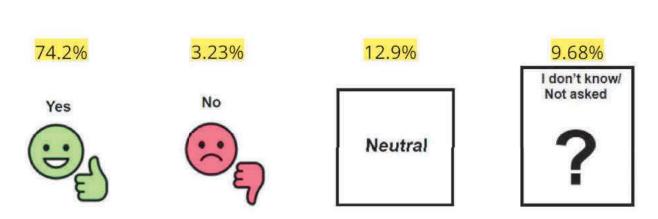




51. Would you like to live near a garden?

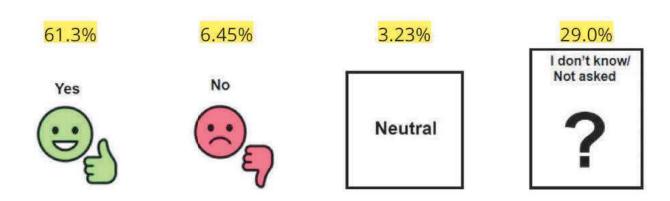


52. Would you like to live near a pool?



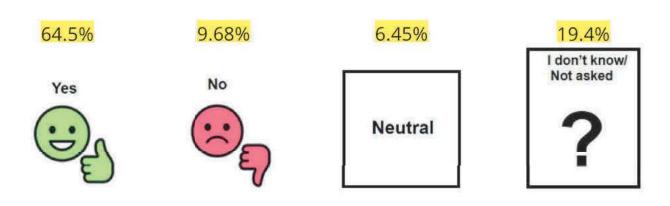


53. Would you like to live near a fitness center?



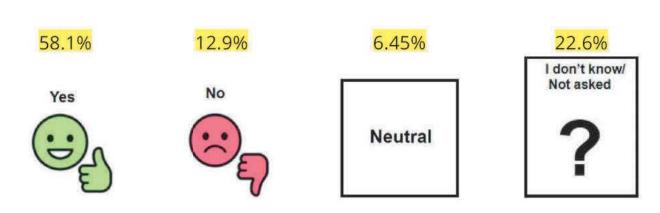
PÓFCÖRN

54. Would you like to live near a movie theater?

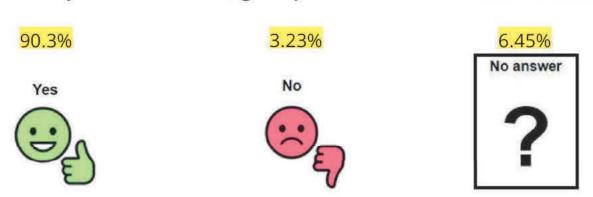


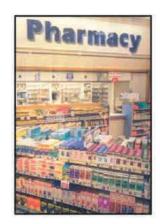


55. Would you like to live near a library?

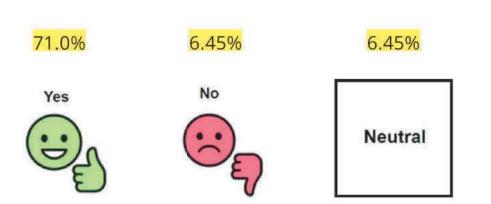


56. Would you like to live near a grocery store?





57. Would you like to live near a pharmacy?



16.1%
I don't know/
Not asked

58. Would you like to live near public transportation?

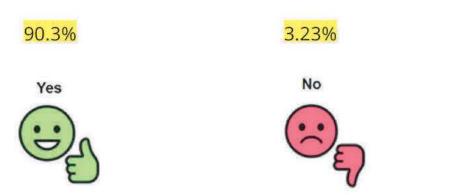






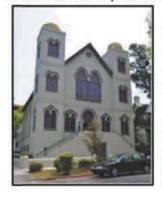


59. Would you like to live near a restaurant?

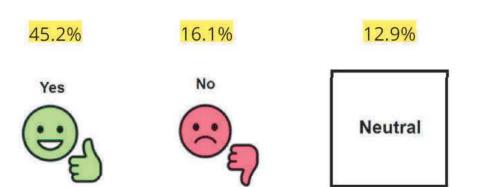


3.23%
I don't know/ Not asked

60. Would you like to live near a place of worship?









61. How often would you like to go to a walking trail?



19.4%

All the time

51.6%

Sometimes

29.0%

No answer

?

62. How often would you like to go to a park?

16.1%

All the time

54.8%

Sometimes

29.0%

No answer



63. How often would you like to go to a dog park?

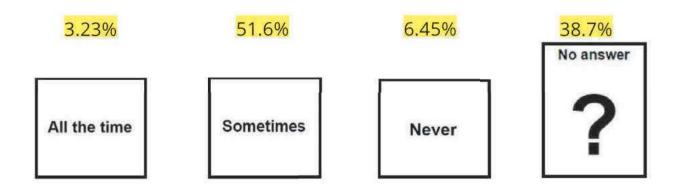


9.68% 16.1% 25.8% 48.4% No answer

All the time Sometimes Never



64. How often would you like to go to a garden?





65. How often would you like to go to a pool?

29.0%

41.9%

6.45%

22.6% No answer

All the time

Sometimes

Never

?



66. How often would you like to go to a pool?

22.6%

29.0%

12.9%

35.5%

All the time

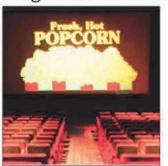
Sometimes

Never

?

No answer

67. How often would you like to go to a movie theater?



9.68%

54.8%

3.23%

32.3%

No answer

All the time

Sometimes

Never



68. How often would you like to go to a library?

3.23%

61.3%

3.23%

32.3%

All the time

Sometimes

Never

?

No answer

69. How often would you like to go to the grocery store?



38.7%

All the time

38.7%

Sometimes

22.6%

No answer

?

70. How often would you like to use public transportation?



22.6%

35.5%

12.9%

29.0%

No answer

All the time

Sometimes

Never

?



71. How often would you like to go to a pharmacy?

16.1%

48.4%

35.5% No answer

All the time

Sometimes

?

72. How often would you like to go to a place of worship?





16.1%

35.5%

6.45%

41.9%

No answer

All the time

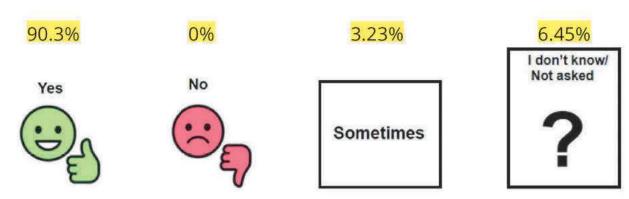
Sometimes

Never

?

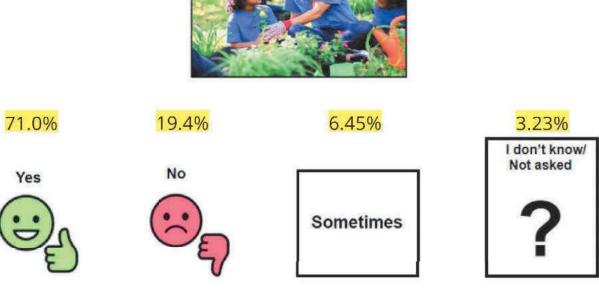


73. Do you like to do social activities?



74. Do you like to do volunteering or work activities?







75. Do you like to do fitness activities?

71.0%

12.9%

3.23%

12.9%

I don't know/ Not asked



Yes





Sometimes



74.2%

9.68%

6.45%

9.68%

I don't know/ Not asked







Sometimes

77. Do you need help with household chores?





9,68%

Yes

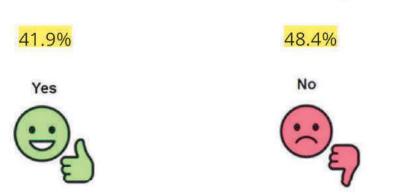
No

Point of the state of the st

78. Do you need help with self-care?











79. Do you need help with transportation?

87.1%

9.68%

3.23%

Yes







80. Do you need help with scheduling?

71.0%

16.1%

12.9%

Yes







81. Are there any other activities that you need help with during the day?



48.4%

Yes



32.3%

VO



19.4%



Appendix II: Visualization of Interviewees Hopes for the Future





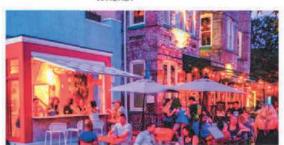
WHO?



WHAT?



WHERE?



WHO?



WHAT?



This Photo by Unknown Author is licensed under CC 89-5A-AC

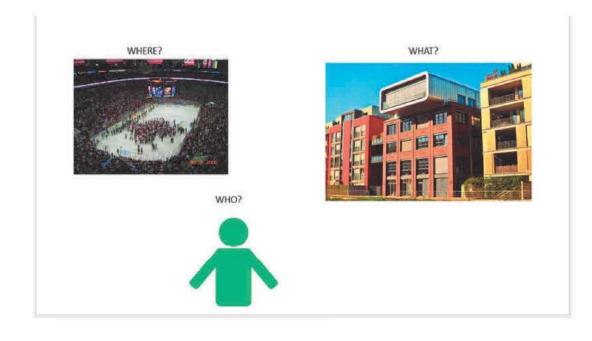
WHERE?



WHO?







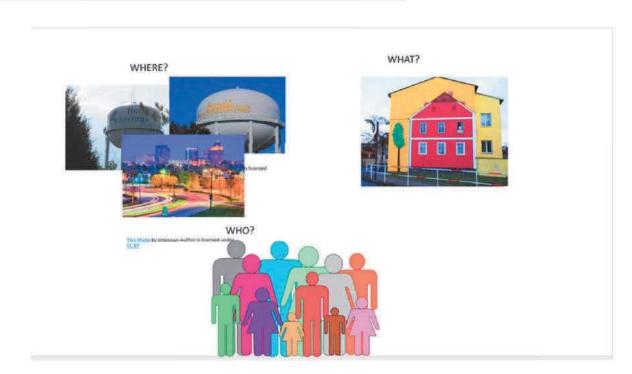




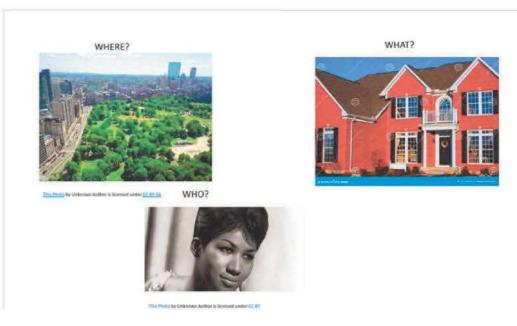


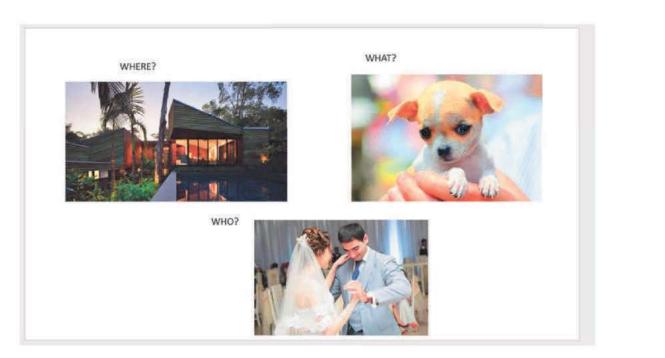












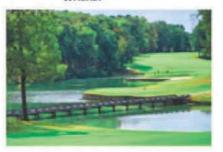
WHERE? WHAT?



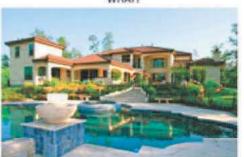
Pink Apartment



WHERE?



WHAT?



WHO?



WHERE?

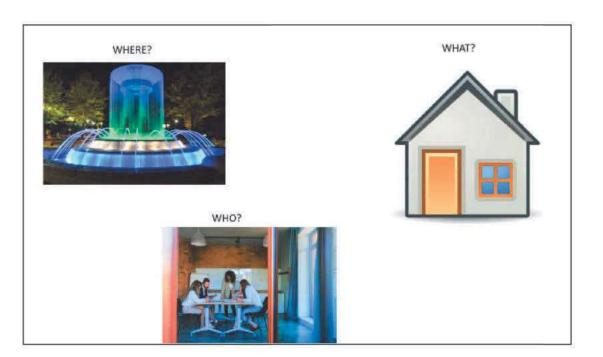


WHAT?



WHO?





WHERE?



WHAT?



WHO?



WHERE?



WHAT?



WHO?



WHERE? WHAT?







WHERE?



WHAT?



WHO?



WHERE?



WHO?



WHAT?

