

# Autism Housing Pathways 2022 Housing Survey

## Executive Summary

The survey was conducted in the fall of 2021 and the winter of 2022. It updates the results of Autism Housing Pathways' 2012 housing survey. Responses pertained to a Massachusetts adult with a diagnosis of ASD.<sup>1</sup> There were 359 useable responses. Most completing the survey did so on behalf of a family member with ASD.

### Cohort characteristics

- 18-64, with an average age of 24.
- 79% male, 19% female, 2% other
- 97% had a secondary diagnosis, including 53% with a panic or anxiety disorder and 45% with an intellectual disability
- Level of autism as defined in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5):
  - ASD 1: 44.7%
  - ASD 2: 22.9%
  - ASD 3: 23.5%
  - Other: 8.9% (this picked up a combination of those diagnosed under older versions of the DSM, as well as a few genetic disorders with autism as a secondary diagnosis)

### Supports needed

Each cohort member was assigned to one of five groups:

- Group 1: identified a need for 3:5 staffing or even more intensive support
- Group 2: indicated a need for prompting for at least one Activity of Daily Living (ADLs) or have BOTH an Intellectual Disability (ID) and a need for 2:4 staffing; not in Group 1
- Group 3: indicated they were independent in ADLs, need assistance with Instrumental Activities of Daily Living (IADLs); not in Groups 1 or 2
- Group 4: indicated they were independent in ADLs and needed some quality control with IADLs; not in Groups 1, 2, or 3
- Group 5: independent in ADLs and IADLs OR indicated they can live independently; not in Groups 1, 2, 3, 4

Group 1	Group 2	Group 3	Group 4	Group 5
54	117	144	40	4 <sup>2</sup>
15.04%	32.59%	40.11%	11.14%	1.11%

<sup>1</sup> One response pertained to an individual currently out of state.

<sup>2</sup> This group is undoubtedly underrepresented in this survey. It is likely that those able to live independently and their family members are less likely to participate in the online support groups where survey outreach took place. In our 2012 survey, 2% of adults fell into Group 5. A national study, the 2009 Opening Doors report cited a 2008 study that found 4% of autistic adults living independently; another 2% lived with a spouse, partner, or a family member who was not a parent or guardian.

Despite having the same need for intensive staffing as those who are Priority 1 for a Department of Developmental Services (DDS) group home, 26% of Group 1 does not have an ID, which would normally be required to be prioritized for housing by DDS. Additionally, 18.5% of Group 1 needs even more intensive staffing than a 3:5 ratio. Of this subgroup, 60% indicate a need for 1:1 supports, and another 20% constitutes those needing intensive medical support. While a small percent of the total survey cohort, this subset is highly vulnerable.

Almost 50% of Group 2 would benefit from a MassHealth service that provides drop-in services for prompting through activities of daily living regardless of housing type. (While MassHealth's Group Adult Foster Care service covers such drop-in services, it has historically restricted the setting to assisted living facilities or housing with a site-based subsidy; this requirement has been waived during Covid.)

Groups 3 and 4 collectively make up more than half of respondents, but do not meet criteria for either Adult Foster Care (AFC) or Personal Care Attendant (PCA) services through MassHealth. Almost 60% of Group 3 needs some contact daily. While assistive technology can help, staffing shortages present a challenge to meeting the needs of this subset when they cannot live with family.

73.4% have a lot of living skills but have difficulty initiating tasks or freeze when something goes wrong. This is an even bigger problem than it appears. 71% of Group 1 answered "no" to this question, not because they can't initiate, but because they don't HAVE the living skills. In Groups 3 and 4, about 90% of each group has difficulty with initiating or freezes.

Over 85% need assistance with money, appointment, and paperwork management. These are the most important skills for acquiring benefits. This is a population at high risk of losing benefits even if they can obtain them. Over 50% need schedules, medication management, a structured day, assistance with transitions, and choices.

In addition to the supports needed by the larger cohort, those in Group 1 need highly specialized supports. Over 70% need communication systems, positive behavioral supports, first/then directions, and visual supports. (Almost 50% of those in Group 2 also need visual supports.) Group home direct support professionals and DDS Shared Living providers need adequate training in the full range of these specialized skills.

### Living arrangements

54.3% either reported they are happy with their current living arrangement or listed their current situation as a preference. It is important to note almost half are not satisfied with their current arrangement, as a study published in 2021 found that "people with IDD [intellectual and/or developmental disabilities] who chose where and with whom to live had a 74% decrease in emergency department visits, regardless of their impairment severity."<sup>3</sup>

In Groups 1 and 2, a plurality of respondents indicated a preference for living with parents and/or siblings. Given the level of support needed by these groups, many of these might be candidates for living

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<sup>3</sup> <https://meridian.allenpress.com/inclusion/article-abstract/9/2/92/465612/Choosing-Home-The-Impact-of-Choosing-Where-to-Live?redirectedFrom=fulltext>

in an accessory dwelling unit attached to the family home, using Adult Foster Care or DDS Shared Living. Both programs pay a stipend to a provider who lives with the person.

Other groups are more likely to want to live alone or with a housemate. It is very important for those in these groups to get on waiting lists for affordable and subsidized housing early.

Only 15.5% wish to live with only people without a developmental disability; this would seem to indicate a desire for peers with disabilities to be present.

A significant plurality in Groups 1 and 2 (34% and 19%, respectively) favor a group home situation where the property is controlled by the families of the residents over a group home owned or leased by the state or a vendor. This is strikingly similar to the 2012 survey, when the figures were 33% and 21%.

Among adults happy with their living situation, the majority are in a private home or condo. The majority of Groups 3 and 4 prefer a private home, a condo, or an apartment. About 7% of the overall cohort are interested in intentional communities, with the highest percentage (almost 13%) in Group 1

#### Housing models from the 2016 Housing Think Tank

In 2016, the Massachusetts Housing Think Tank identified 6 housing models that could collectively meet the needs of most people with ASD. Survey respondents were asked to select the model from the think tank that would best meet their needs.

<b>Models from the 2016 Think Tank</b>	<b>%</b>
Individual apartments or condos in the community, located close enough to one another to permit socialization. A facilitator and a neighbor are both paid to facilitate connections and provide support.	35.3%
Shared living in a single-family home owned or leased by a family, individual, or a 3rd party not providing the services. It could involve substantially separate space, with a shared kitchen.	16.3%
Co-housing in which people with and without disabilities choose to live in community, while having their own living spaces.	17.2%
Inclusive, small footprint units, resulting in lower housing costs, with trained management and/or support providers (e.g., micro-units or single room occupancy units).	15.6%
Transitional housing that trains residents in the skills they need to live independently.	7.2
Licensed congregate living for people with intensive medical/behavioral needs.	8.4

#### Environmental modifications

Sound insulation is actually very important for all groups. Loud vocal self-stimulation (“stimming”), especially at night, can put tenancy at risk. It is not uncommon for people engaging in vocal stimming to be unaware of it.

Group 1 needs many more environmental modifications than other groups. Over 50% need a land buffer, sound insulation, unbreakable glass, durable construction, a fenced-in yard, and a sidewalk. Almost 50% need floor drains in bathrooms and a separate pantry. Absent units with these modifications, families in rental housing are at high risk of eviction.

### Preferred locations

For all groups, a town in walking distance to shops is the preferred location. Access to public transit is most important for those in Groups 3 and 4.

### Awareness of benefits

Over 30% of respondents report they do not know what the following benefits are: CommonHealth (53%), Adult Family Care (40%), Adult Foster Care or Group Adult Foster Care (38%), Personal Care Attendant Services (PCA) (31%), SafeLink (60%), Low Income Home Energy Assistance Program (LIHEAP) (50%).

### Awareness of housing programs

Less than 50% of respondents have applied to any single housing program. Over 50% do not know what the following programs are: the Alternative Housing Voucher Program, private subsidized housing, and single room occupancy. Over 30% do not know what public housing is. Less than 10% are participating in a housing program. Section 8 has more name recognition than any other program, but only about 45% have applied for a Section 8 voucher.

While there is no internal evidence in the survey related to eligibility, past conversations indicate that many families don't understand that it is the income of the adult with autism that determines eligibility for housing programs, not family income

### Financial preparedness

Special needs trusts allow funds to be saved for the benefit of a person with a disability while preserving eligibility for certain government benefits. 52% of individuals are beneficiaries of special needs trusts, as opposed to 37.5% in our 2012 survey.

ABLE accounts are another (and relatively new) way to save for the benefit of a person with a disability while preserving eligibility for certain government benefits. They resemble 529 college savings accounts. The relatively poor uptake (28%) implies ABLE accounts are gaining ground slowly, despite not having as many barriers to admission as a special needs trust and having a degree of flexibility special needs trusts do not.

Overall, 75.3% cannot pay over \$1,000/month for rent and services on a sustainable basis. About half would struggle to fund a security deposit. However, there are a significant number of people who can afford a down payment of over \$35,000, indicating there may be the potential for mixed income housing, where those who can afford more might serve as patient capital. Their motive would be finding sufficient housemates to make a house practicable.

93% do not know their credit score. It is illegal for a landlord to refuse to rent to a voucher holder simply because they are a voucher holder. However, it is perfectly legal to refuse to rent to someone with either a poor credit score or NO credit score. It is important to carefully build good credit if someone is to use a voucher. While landlords can use alternative means of establishing ability to pay, such as requesting bank statements, many do not do so.

## Discussion

The data shine a light on gaps in the current menu of services, including:

- Half have too many skills to qualify for 24/7 residential supports from the Department of Developmental Services (DDS) or for MassHealth's state plan services but lack the skills to live independently.
- There is no housing pipeline for individuals with intensive support needs who lack an intellectual disability.
- Residential staff need training to work with individuals with intensive support needs.
- Drop-in services for prompting through daily living activities are not available in most housing situations.
- Workforce shortages impact the ability of individuals to live with support in the community.
- Innovative approaches are needed to support those who have difficulty with initiating skills or who freeze when something goes wrong.
- Without adequate support for appointment, paperwork, and money management, individuals risk falling through the safety net.
- A lack of environmental modifications in rental housing puts individuals and families at risk of eviction.
- People lack awareness of existing benefits, and especially of affordable housing programs.

What do people want?

- Almost half would prefer a different housing arrangement; research indicates the current situation puts them at higher risk of costly ED visits.
- Most do not want to live alone.
- Many of those with who need more support want to be with family; but to access DDS Shared Living, MassHealth Adult Foster Care, or to rent from family with a voucher, the person needs to be in a separate unit.
- Most of those who prefer not to live with family would like at least some peers with a disability present.
- For those with intensive support needs, almost twice as many would prefer a group home controlled by families to one controlled by the state or a vendor agency.

Possible strategies to improve the situation include:

- Workforce development:
  - Create vocational high school programs that allow students to graduate as both a Registered Behavior Technician and a Certified Nursing Assistant; training should also cover the use of communication systems and visual supports.

- Provide 2 free years of community college to those who have worked for 2 years in human services with adults.
- Create a pipeline of Shared Living providers for reverse Shared Living (where the housing is a permanent home for the individual), possibly by working with college programs in human services or nursing, where participants only commit to being a provider for a year.
- Modify the MassHealth Personal Care Attendant program to cover drop-in services for prompting through activities of daily living.
- Make accessory dwelling units created to provide housing for persons with disabilities exempt from local zoning.
- Require a percentage of units in new multi-family rental housing to include the most commonly needed environmental modifications.
- Create a specialized group home model serving the most vulnerable individuals with complex medical and behavioral needs using highly trained staff; some ideas are discussed at: <https://autismhousingpathways.org/co-provision-of-medical-and-behavioral-supports/>.
- Require that a percentage of housing funded through the Qualified Allocation Plan and/or the Facilities Consolidation Fund serve DDS clients who do not require an institutional level of care.
- Direct the Department of Housing and Community Development to disseminate information to local housing authorities about prioritizing persons with disabilities for Section 8 vouchers as a best practice.
- Include training about the full range of affordable and subsidized housing programs as part of the curriculum for the Department of Elementary and Secondary Education (DESE) Transition Specialist Endorsement. Teachers have more contact with individuals and parents than anyone else in the process of transition to adulthood; they are best positioned to share critical information with families.
  - The Transition Specialist Endorsement should also include training in lesser-known benefits, such as Adult Foster Care, Adult Family Care, and the Personal Care Attendant program; and should cover ABLE accounts and the importance of having a good credit score to be able to utilize a housing voucher.
- Provide training about autism to Options and Shine Counselors in Aging Service Access Points and Councils on Aging, as well as to staff at Housing Consumer Education Centers.