Housing needs and desires in the Massachusetts autism community

2022 survey results

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Autism Housing Pathways
October 2022

About Autism Housing Pathways (AHP)

- 501(c)(3) non-profit organization founded in 2010.
- Its mission is to enable Massachusetts residents with developmental disabilities and their families to find or create sustainable, supported, self-directed housing that meets their needs and contributes to their quality of life.
- 5 core goals:
  - Building the capacity of families to find or create housing solutions for their family members with disabilities;
  - Building the capacity of individuals to maintain tenancy;
  - Improving the professional development of direct support staff;
  - Conducting research on the housing needs and resources of the Massachusetts autism community; and
  - Building the capacity of the housing sector to meet the residential needs of individuals with autism.

Survey rationale

- A national study, the 2009 “Opening Doors” report, called for market research into autism housing demand[1]
- The 2014 Massachusetts autism omnibus law called for study of the present, and anticipated future, statewide affordable supportive housing needs of people with Autism Spectrum Disorder (ASD)[2]
- The 2016 MA Housing Think Tank identified a small core of housing models that could be collectively adapted to the needs of a wide variety of people with autism, but did not quantify the percentages desired for each housing type[3]
- 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.”[4]
- There is a need to update the housing survey AHP conducted in 2011-2012[5]

[1] http://www.autismcenter.org/sites/default/files/files/openingdoors_print_042610_001.pdf
[2] https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter226
[3] http://mahousingthinktank.org/white-paper-and-recommendations/
[4] https://meridian.allenpress.com/inclusion/article-abstract/9/2/92/465612/Choosing-Home-The-Impact-of-Choosing-Where-to-Live?redirectedFrom=fulltext
[5] https://autismhousingpathways.org/wp-content/uploads/2022/02/AHP_Survey_results.pdf

Survey background

- Conducted in the fall of 2021 and winter of 2022 via SurveyMonkey
- Questions largely duplicated those in AHP's 2011-2012 survey
- Respondents were reached through a range of Facebook groups and email lists that primarily target families of teens and adults with developmental disabilities
- Cohort: answers had to be about an autistic Massachusetts resident who was 18 on or before October 1, 2021[1]
- After removing duplicates, ineligible responses, and responses that left all housing-related questions blank, there were 359 useable responses

[1] One respondent is currently out of state.

Survey limitations

- Since there are no solid data[1] on the total number of individuals with autism in Massachusetts, it is impossible to tell what the population size is or how representative the sample is
- Obvious bias includes skewing toward respondents that are "joiners", and participate in online support groups where outreach took place
- These limitations underscore the need for the state to improve data collection

[1] In 2016 we calculated a range of 75,000-100,000. http://mahousingthinktank.org/defining-the-need/#Demographics

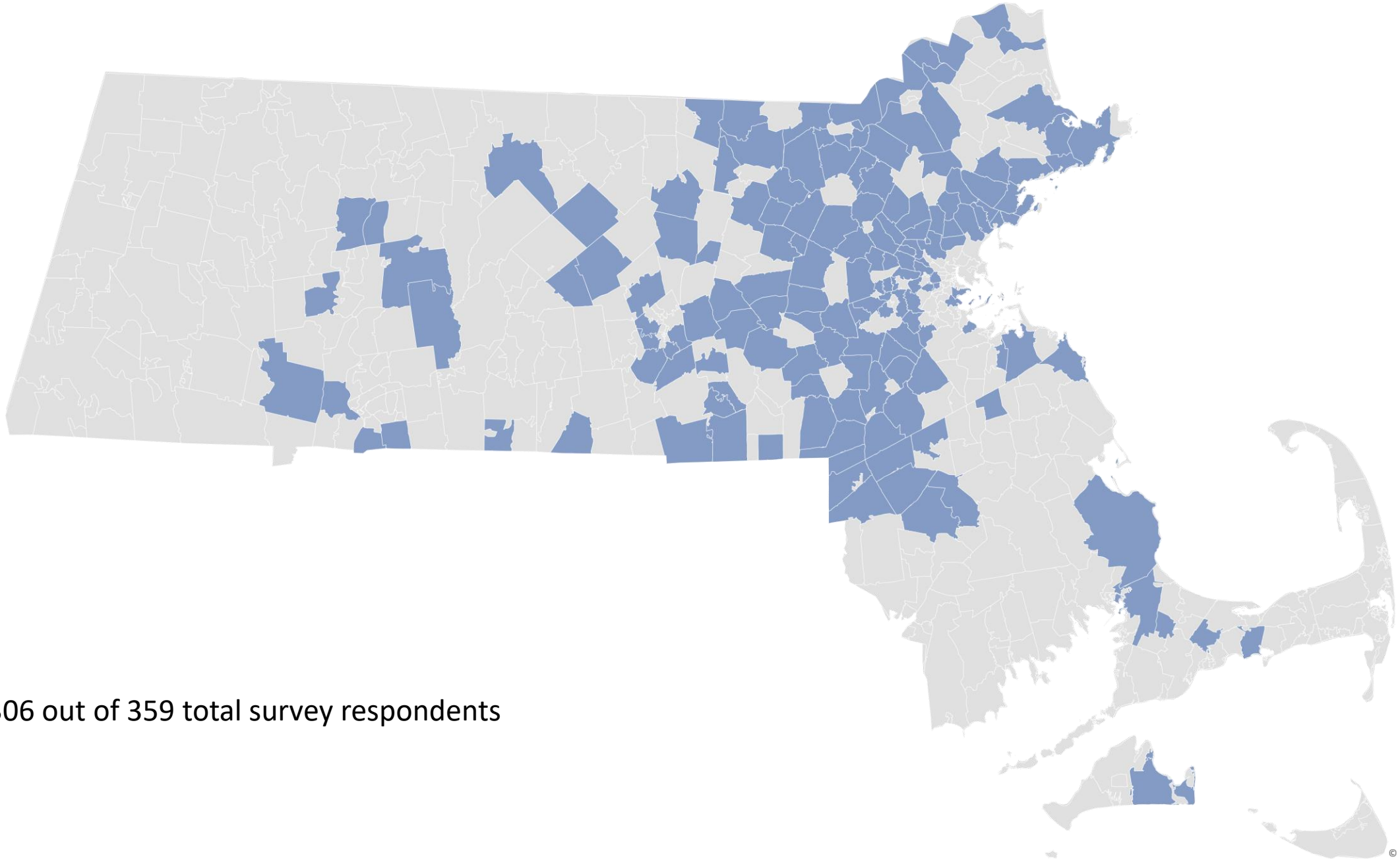
Survey design

- The survey was designed to determine:
  - The level and types of supportive services respondents needed
  - What existing services respondents might be eligible for, and their awareness of those services
  - Which respondents have needs that are not aligned with existing services
  - Preferred living situations and supports

Survey respondents

- 6.7% identified as the person with ASD.
- 83.1% identified as a parent or relative of the person with ASD.
- 9.6% identified as a legal guardian who did not also identify themselves as a relative.
- 0.6% identified as staff who did not identify themselves in any other category.

Distribution of respondents who provided zip codes



N=306 out of 359 total survey respondents

Cohort characteristics

- Age: ranged from 18-64, with an average age of 24
- Gender:
  - Male 79%
  - Female 19%
  - Other 2%
- Level of autism:

ASD-1	ASD-2	ASD-3	Other
160	82	84	32
44.7%	22.9%	23.5%	8.9%

"Other" mostly picked up diagnoses used prior to the division of ASD into the 3 levels used in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), although there were also a few genetic disorders.

Cohort characteristics, continued

- 96.7% listed a secondary diagnosis. Most prominently listed were:

Diagnosis	%
Anxiety or panic disorder	53.3%
Intellectual disability	44.7%
ADD or ADHD	37.5%
Learning disability	32.6%
Sensory processing disorder	21.3%
Depression	21.0%

Group definitions

- Each cohort member was assigned to one of five groups
  - Group 1: identified a need for 3:5 staffing or even more intensive
  - 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 breakdown

Group 1	Group 2	Group 3	Group 4	Group 5
54	117	144	40	4*
15.04%	32.59%	40.11%	11.14%	1.11%

* 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 outreach took place. In our 2012 survey, 2% of adults fell into Group 5. The 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.

Groups as analogs[1]

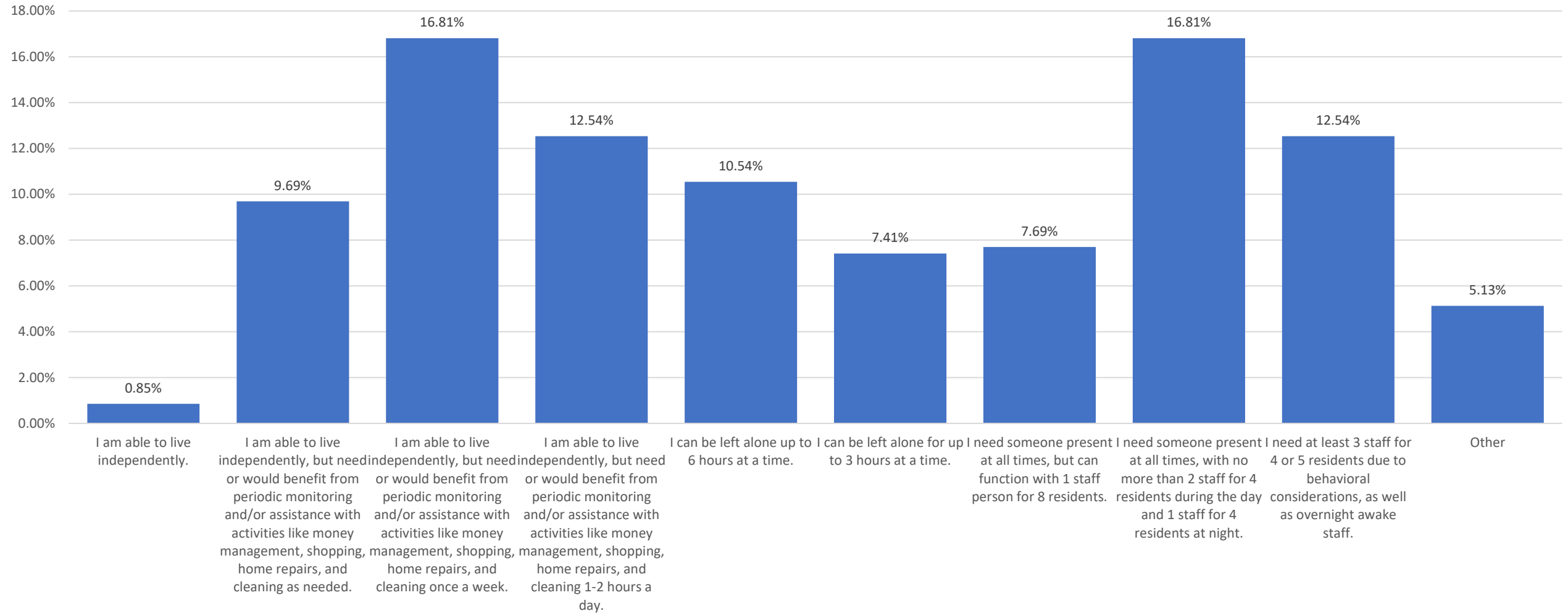
- Group 1 is considered an analog for Priority 1 for a group home provided by the Department of Developmental Services (DDS)
- Group 2 is an analog for any one of: DDS Shared Living; a less-intensively staffed group home through DDS; Priority 2 for residential through DDS; or for Adult Family Care, Adult Foster Care, or Group Adult Foster Care state plan services through MassHealth
- Groups 3 and 4 correspond to individuals who might be eligible for drop-in support hours through DDS
- Group 5 is an analog for independent living

[1] These groups are similar but not identical to the groups identified in our 2012 survey, as those with ASD but no ID were not eligible for DDS services at that time.

Relationship of the safety net to need

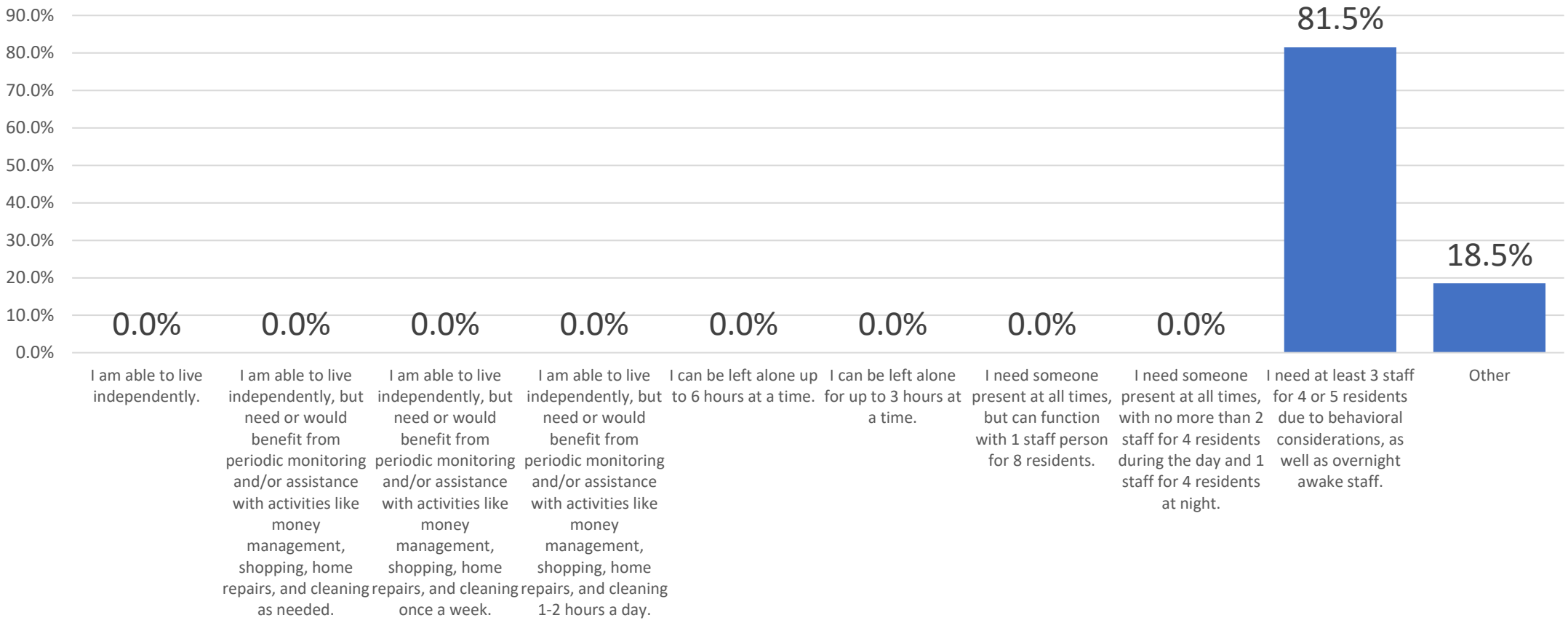
- Despite having the same need for intensive staffing as those who are Priority 1 for a DDS group home, 26% of Group 1 does not have an ID, which would normally be required to be prioritized for housing by DDS
- 51% of the cohort have too many skills to qualify for DDS residential or for MassHealth's state plan services, but lack the skills to live independently
  - This compares to 42% of adults in our 2012 survey
    - In part the difference reflects the fact that in the current survey both Groups 3 and 4 include people with intellectual disabilities (26% of those in the combined Groups 3 and 4)

Level of support believed needed



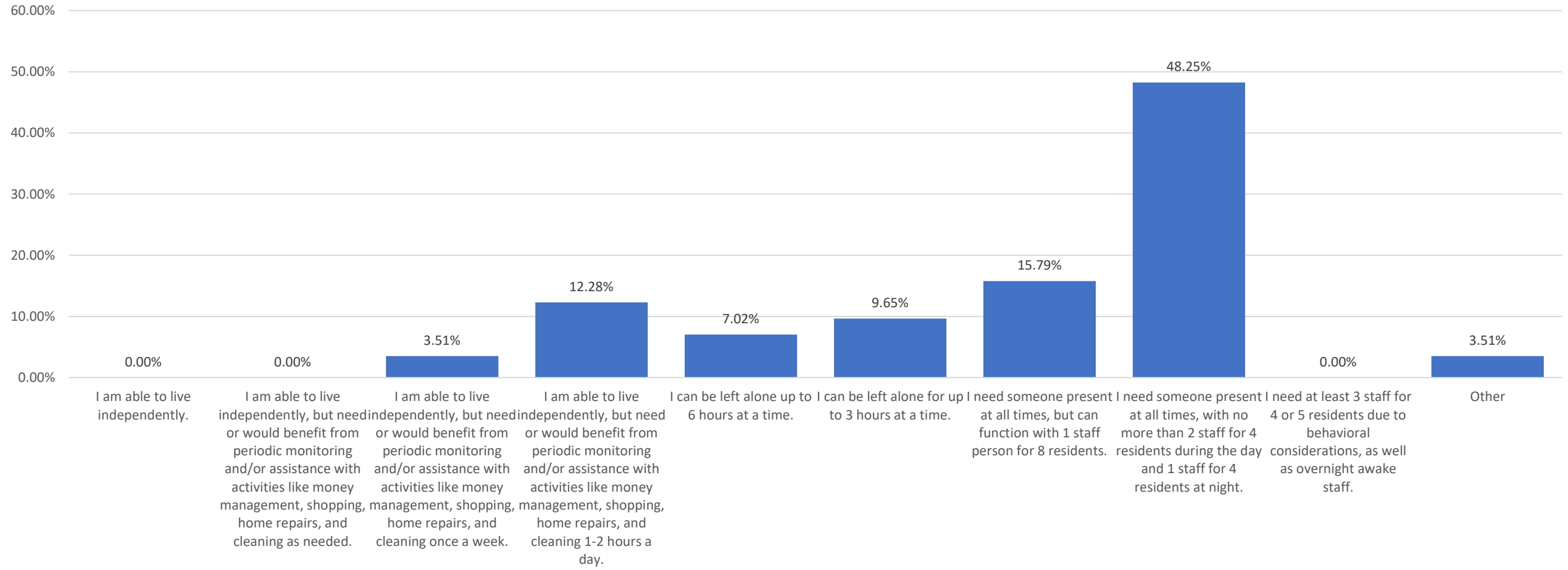
- There is a bimodal distribution with two peaks: people who need services once a week and those who need 2:4 staffing. These correspond to those who fit into existing life coaching services and group homes.
- However, breaking the data into the component groups can help to identify service gaps.

Group 1: Level of support believed needed



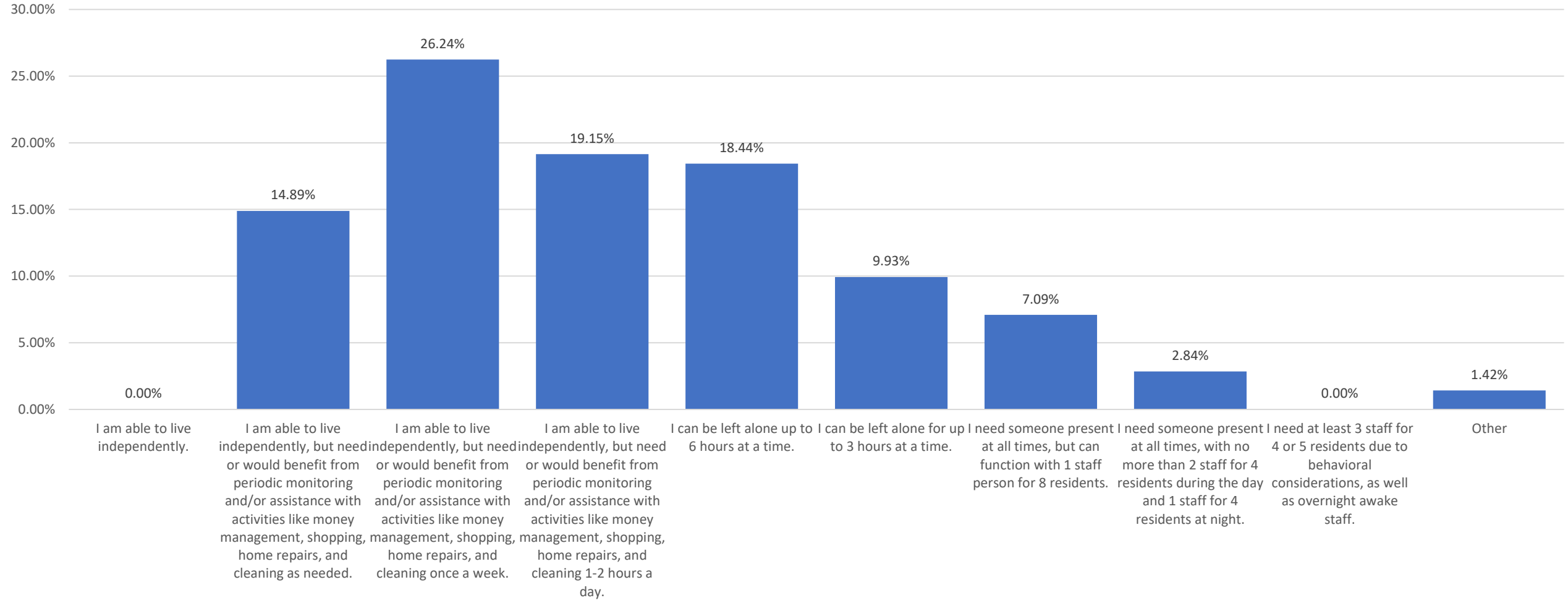
- “Other” comprises those needing even more intensive staffing: 60% indicate a need for 1:1 supports, and another 20% constitutes those needing intensive medical support. While a small percent of the total cohort, this subset is highly vulnerable.

Group 2: Level of support believed needed



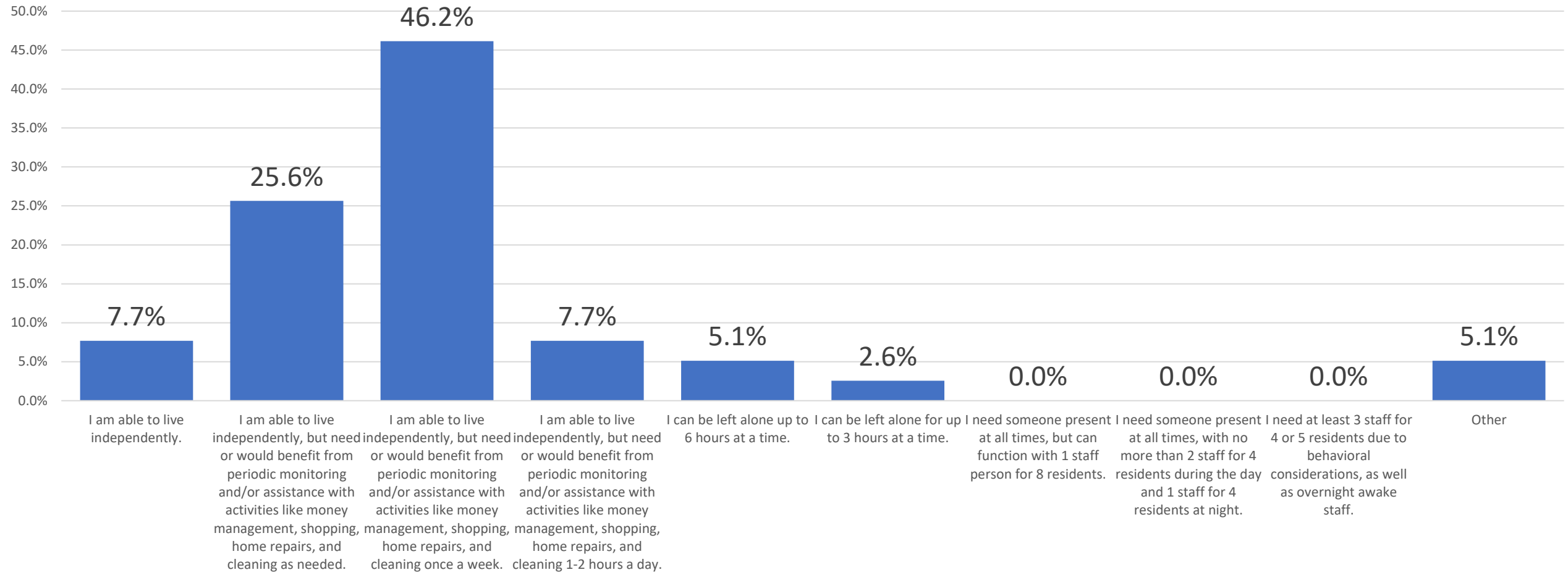
- By virtue of the group definition, anyone in this group needing less than 2:4 staffing needs prompting with at least one ADL. This would indicate almost 50% would benefit from a MassHealth service that provides drop-in services for cueing regardless of the housing type. (Group Adult Foster Care allows drop-in services for cueing, but generally restricts the setting to assisted living facilities or housing with a site-based subsidy [as opposed to a portable voucher].)

Group 3: Level of support believed needed



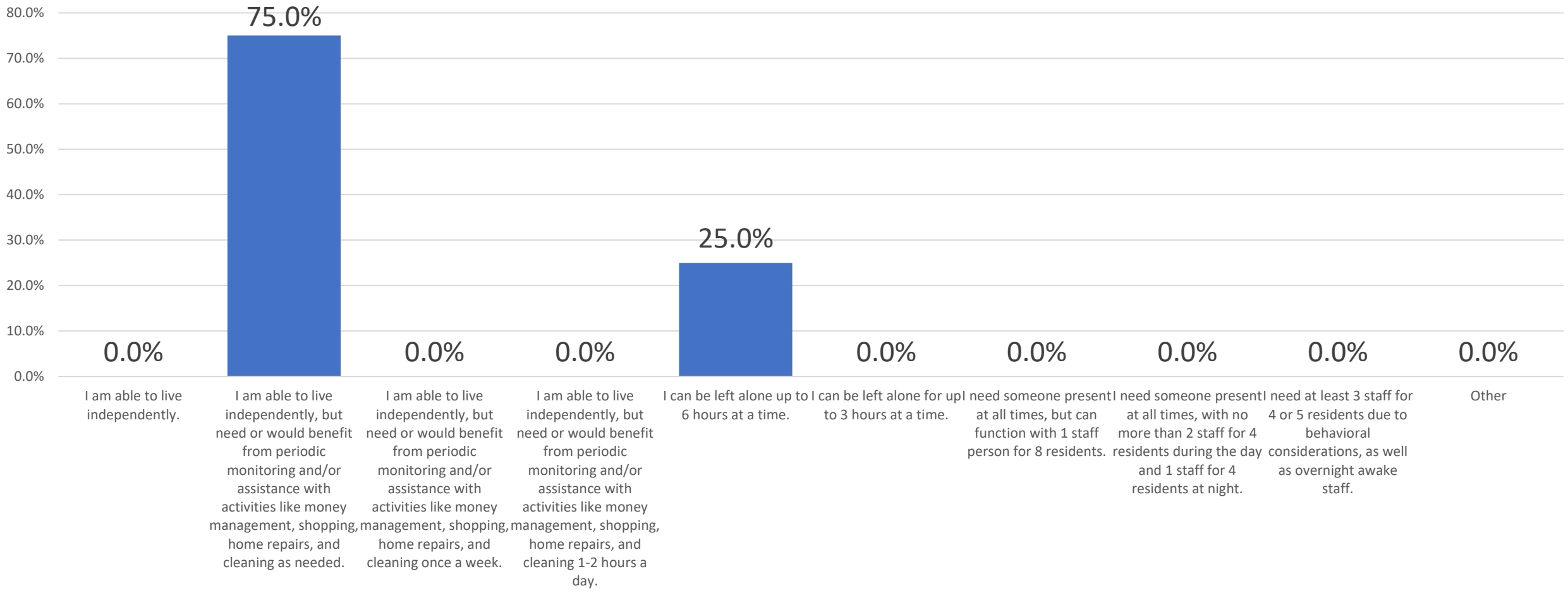
- About 40% of this group is likely to be well-served by life coaching. The remainder need at least some contact daily, but do not qualify for Adult Foster Care or Group Adult Foster Care. While technology can help, staffing shortages present a challenge to meeting the needs of this subset when they cannot live with family.

Group 4: Level of support believed needed



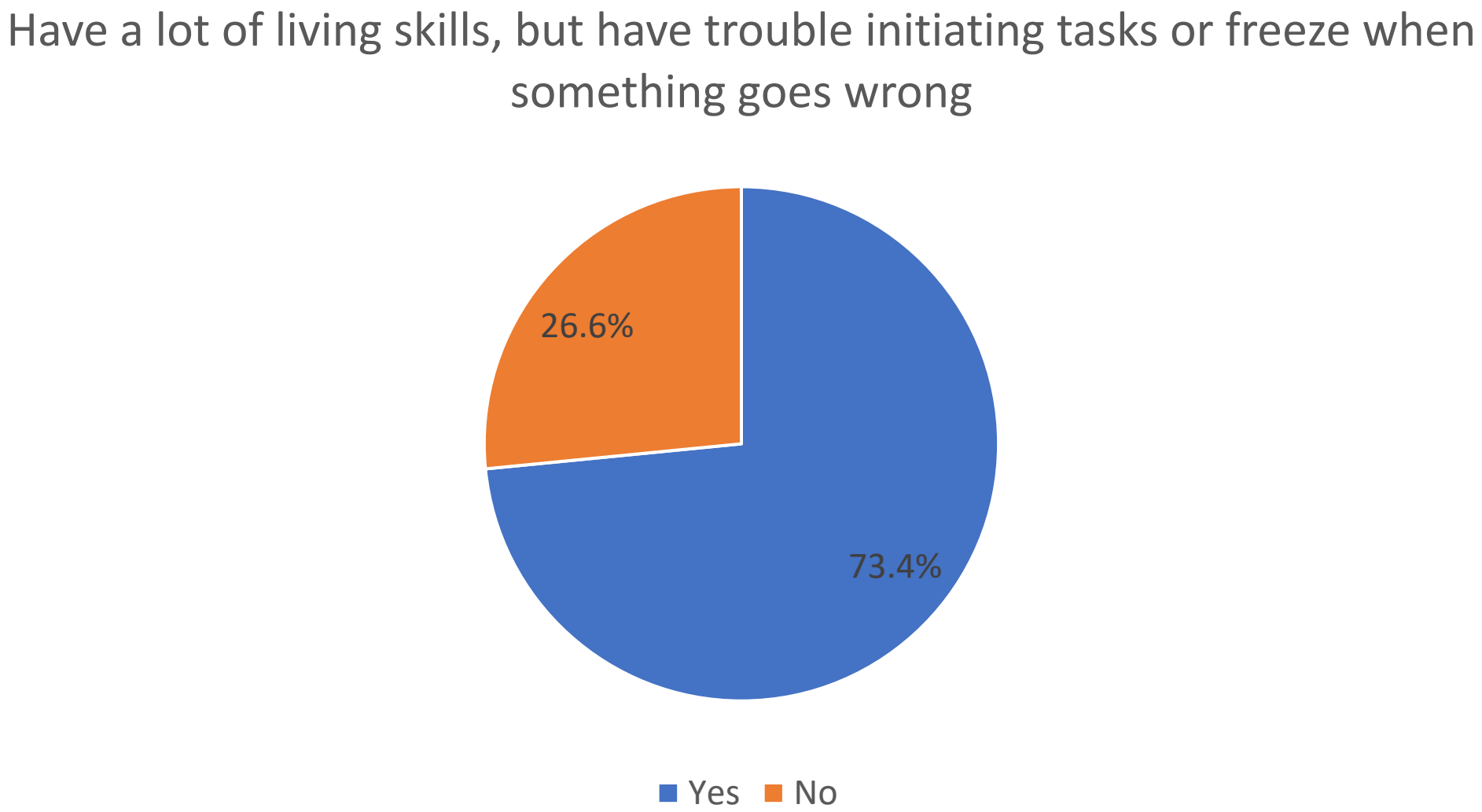
- Life coaching would appear to be the most crucial support needed by this group.

Group 5: Level of support believed needed

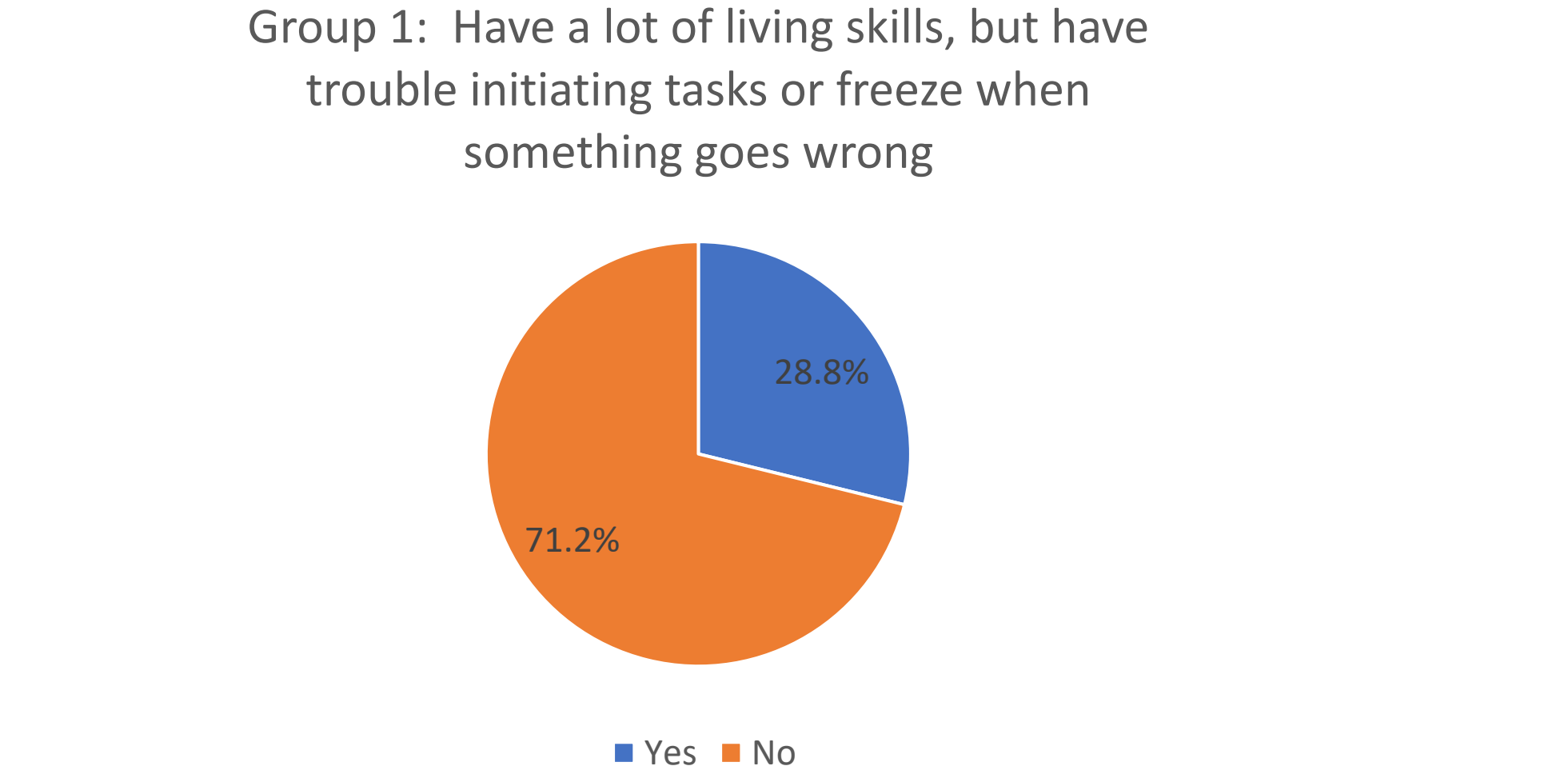


- Life coaching would appear to be the most crucial support needed by this group.

Accessing skills is a problem . . .



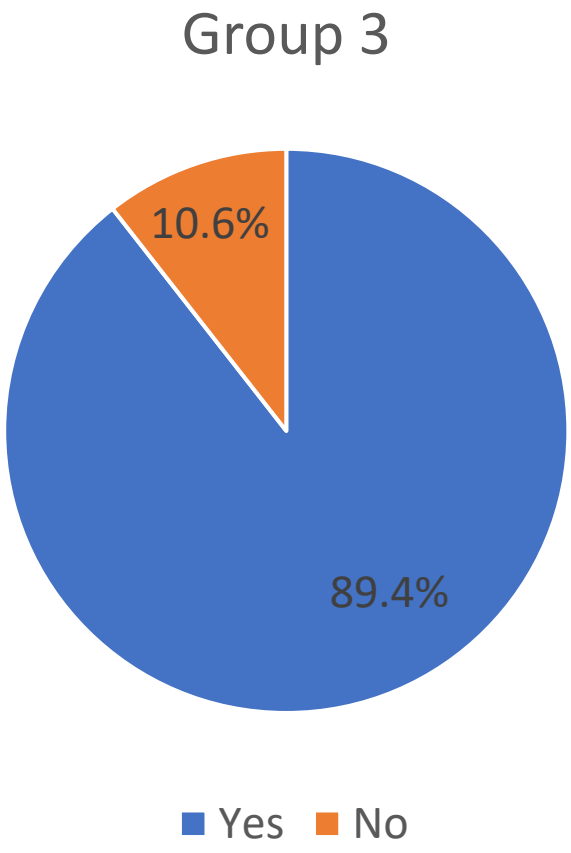
. . . And it’s even worse than it seems

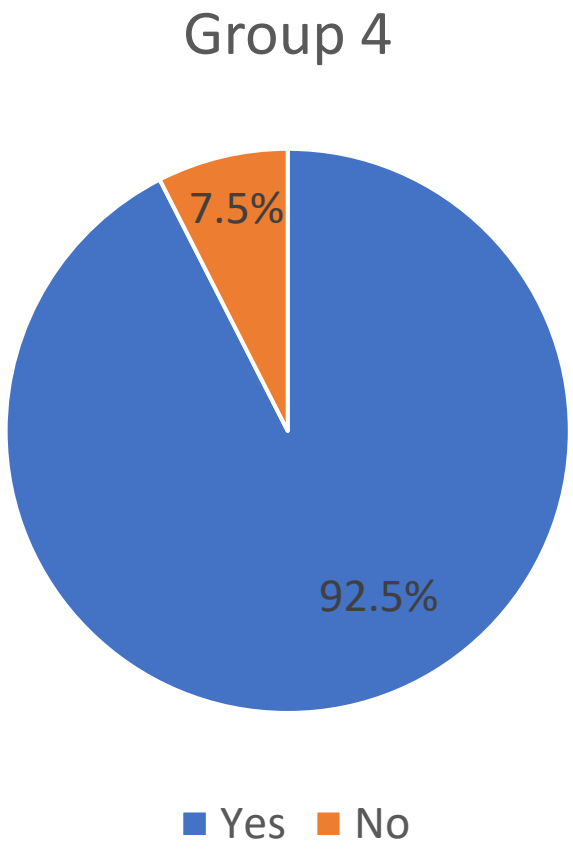


Because some of those who answered “no” did so not because they can initiate, but because they don’t HAVE the living skills.

Groups 3 and 4 are most affected

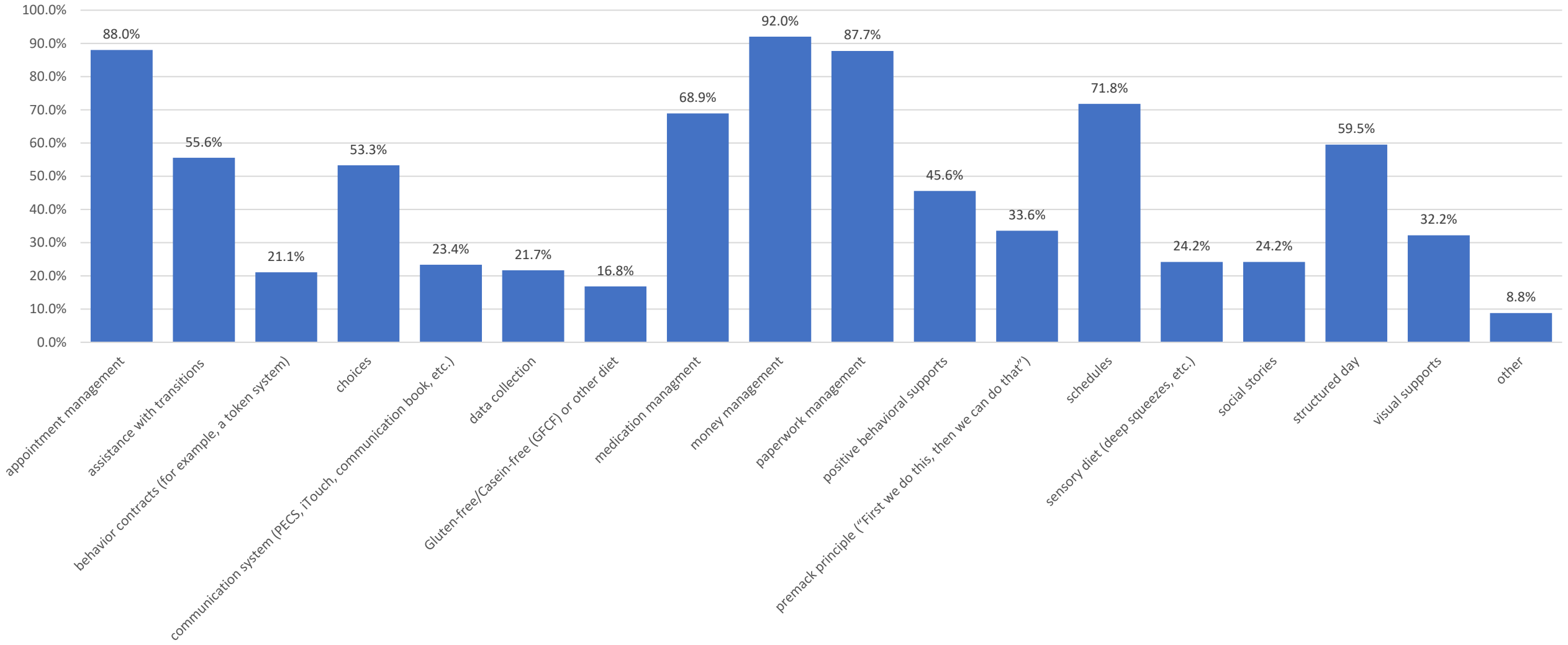
Have a lot of living skills, but have trouble initiating tasks or freeze when something goes wrong.





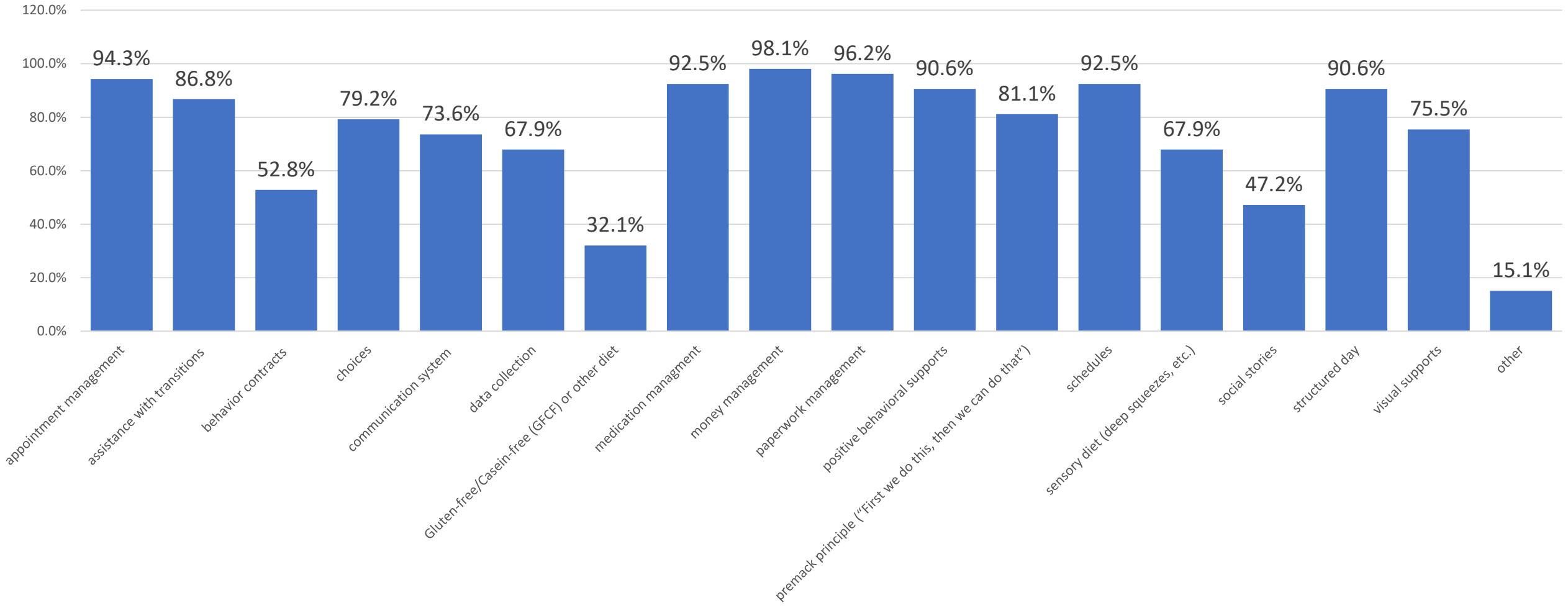
These groups do not qualify for prompting services through MassHealth.

I need the following supports to be successful



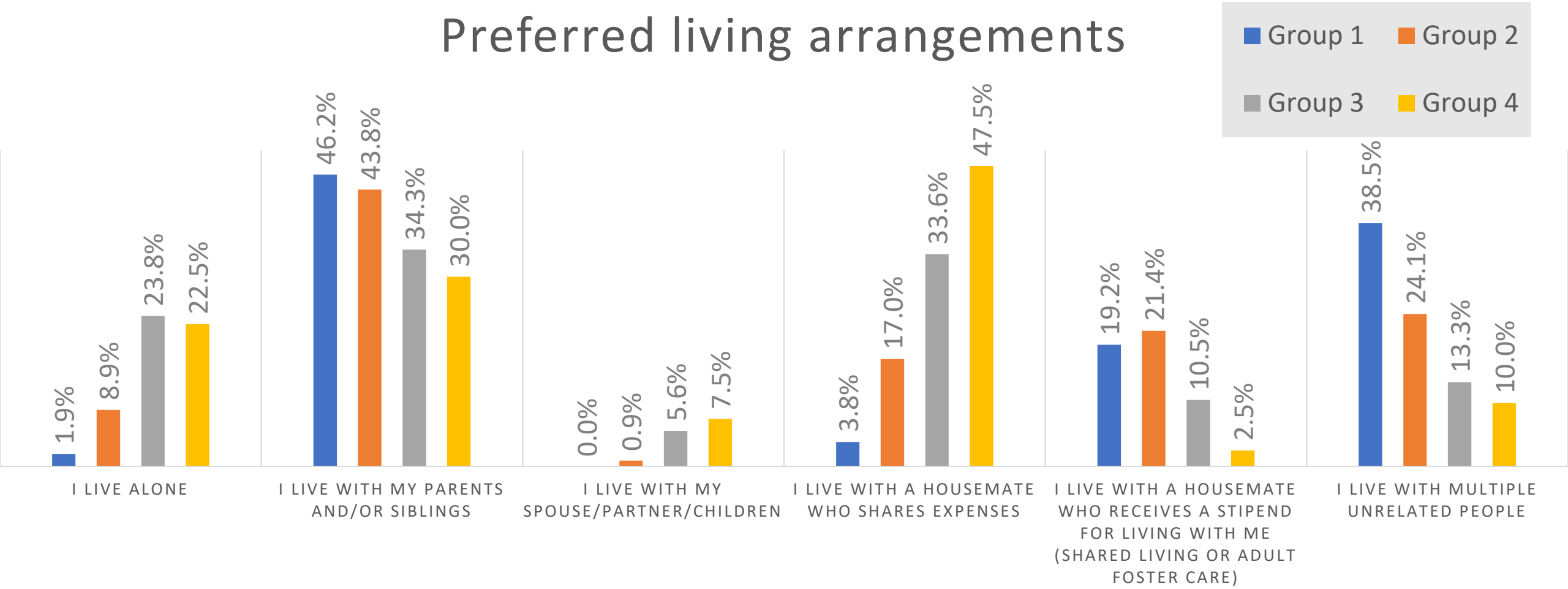
- Over 85% need assistance with money, appointment, and paperwork management. These are the most important skills for acquiring benefits. **This is a population at high risk of losing benefits even if they can obtain them.**
- Over 50% need schedules, medication management, a structured day, assistance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

Group 1: I need the following supports to be successful



- 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 need adequate training in the full range of these specialized skills.**

Preferred living arrangements

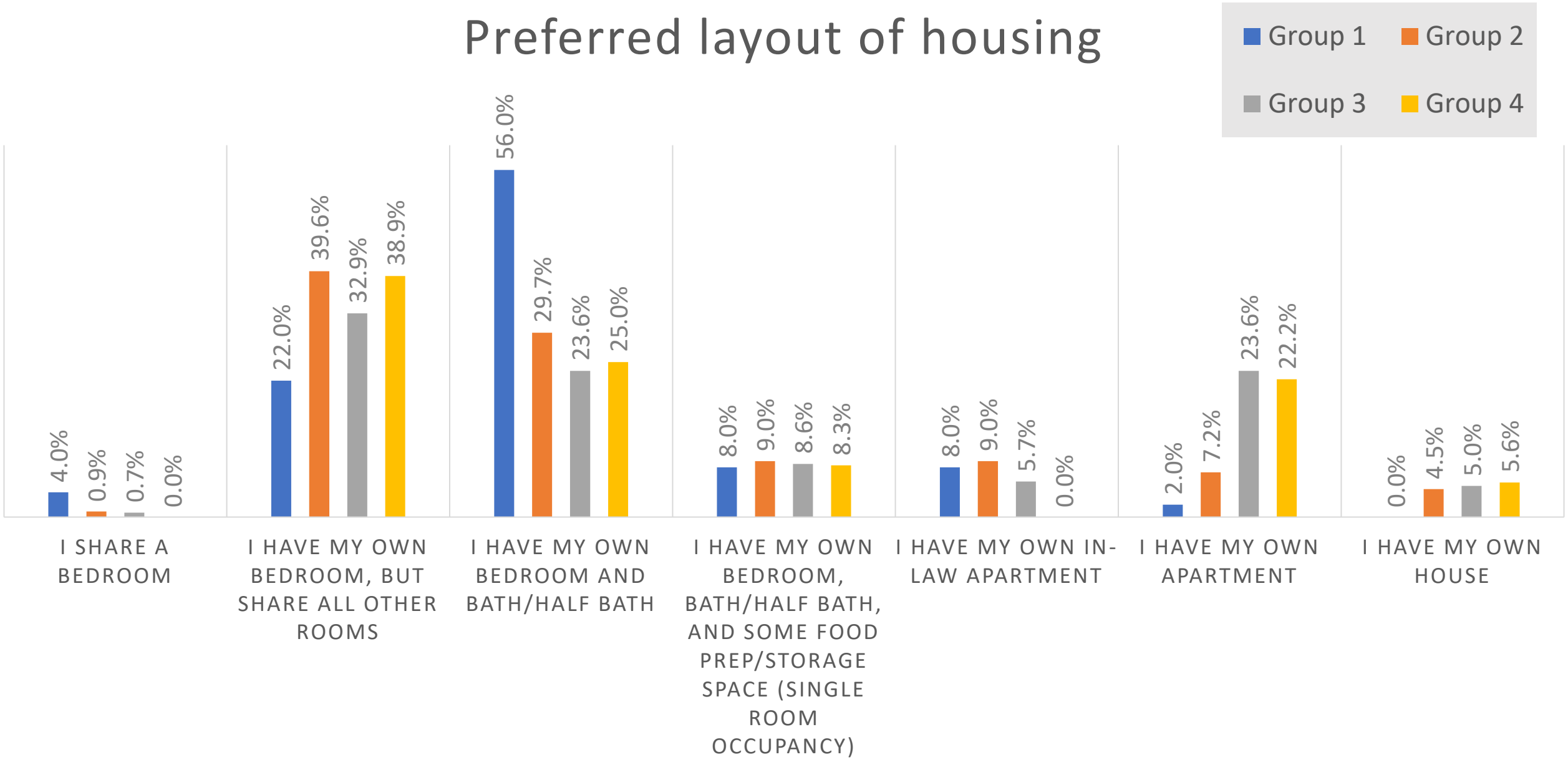


- Overall, 54.3% of people either reported they are happy with their current living arrangement or listed their current situation as a preference.
- In Groups 1 and 2, a plurality of respondents indicated a preference for living with parents and/or siblings. Given the level of support needed by these groups, many of these might be candidates for living 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.
- Notes: Percentages total more than 100%, as respondents could select multiple options. Starting with this graph, Group 5 is no longer included in breakdowns by group, as only one person in Group 5 answered this and subsequent questions.

Who do people want to live with?

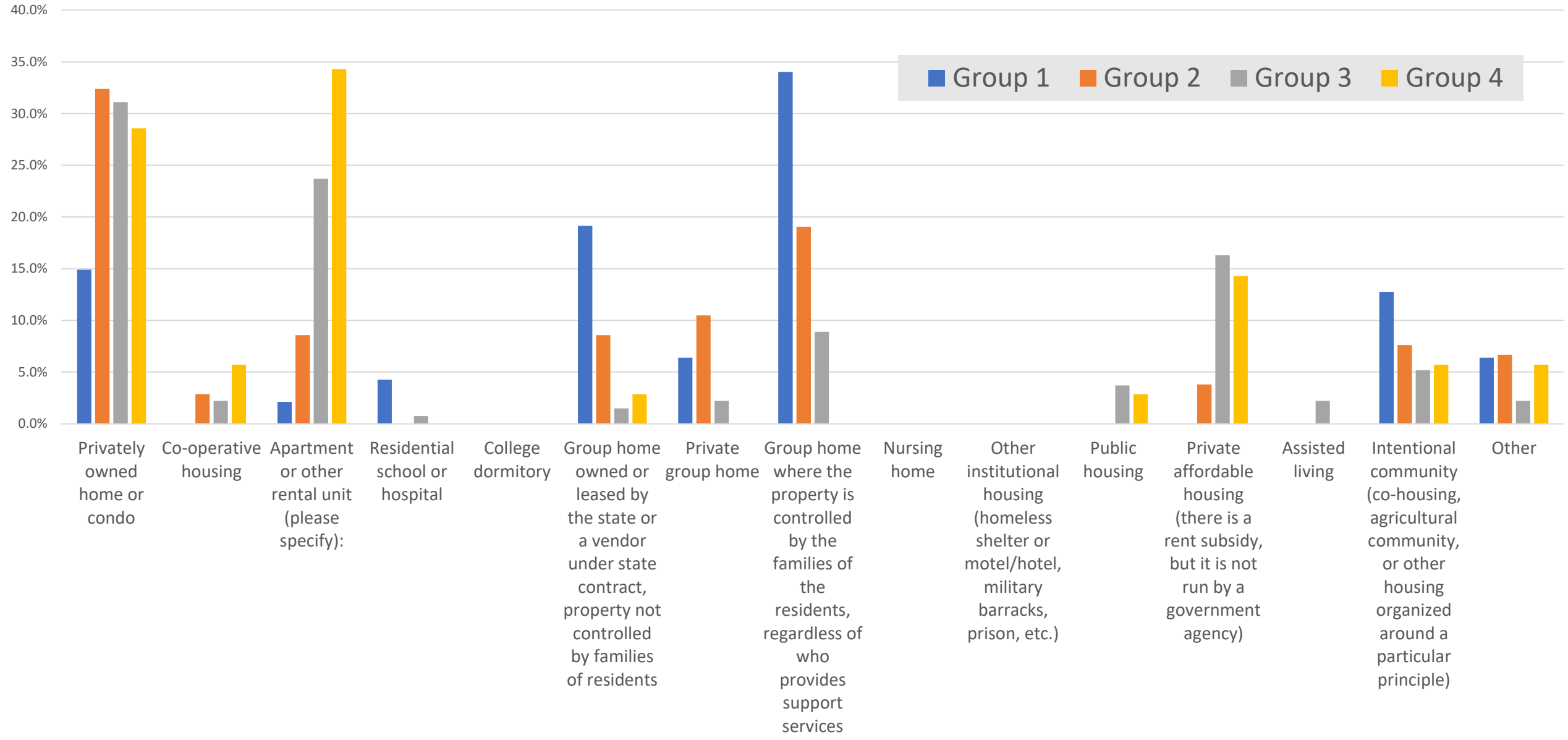
- 81% of those who prefer to live with multiple unrelated people would like there to be <5 people in the home
- 48.9% would like any housemates to be a mixture of people with/without developmental disabilities
  - In Group 4, this rises to 73.1%
  - In Group 1, this declines to 23.5%
- 20.8% would like any housemates to be a mix of people with an autism spectrum disorder and other developmental disabilities
  - In Group 1, this rises to 41.2%
- 23.5% of Group 1 respondents indicated a preference for housemates with ASD only
- Only 15.5% wish to live with only people without a developmental disability; this would seem to indicate a desire for peers to be present.

Preferred layout of housing



- Group 1 is more likely to prefer having their own bath.
- Groups 3 and 4 are more likely to prefer having their own apartment.

Preferred housing type



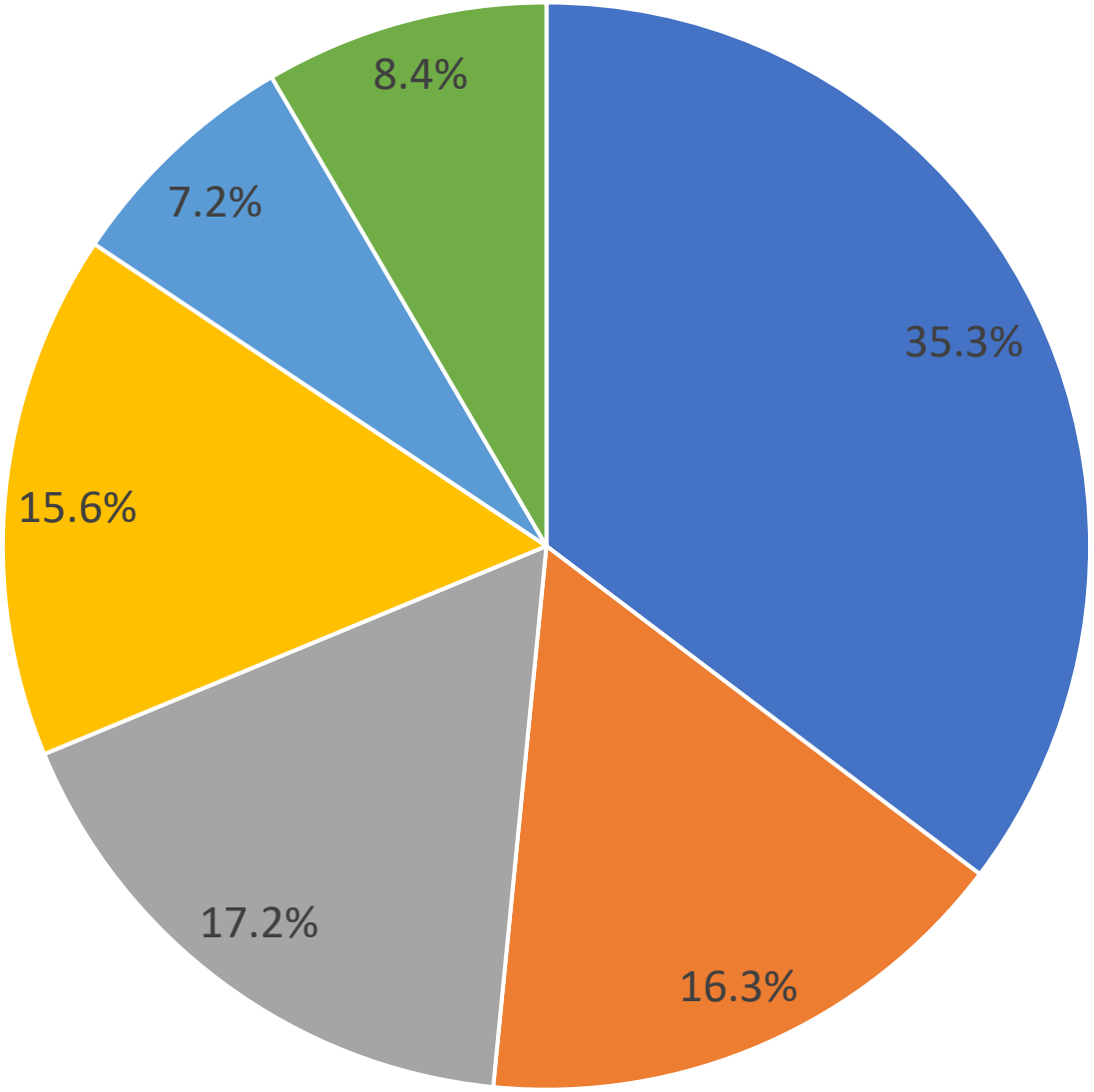
Housing type, continued

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

The 2016 Massachusetts 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.
- Models were:
  - 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.
  - 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.
  - Co-housing in which people with and without disabilities choose to live in community, while having their own living spaces.
  - 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).
  - Transitional housing that trains residents in the skills they need to live independently.
  - Licensed congregate living for people with intensive medical/behavioral needs.

What model would best meet my needs



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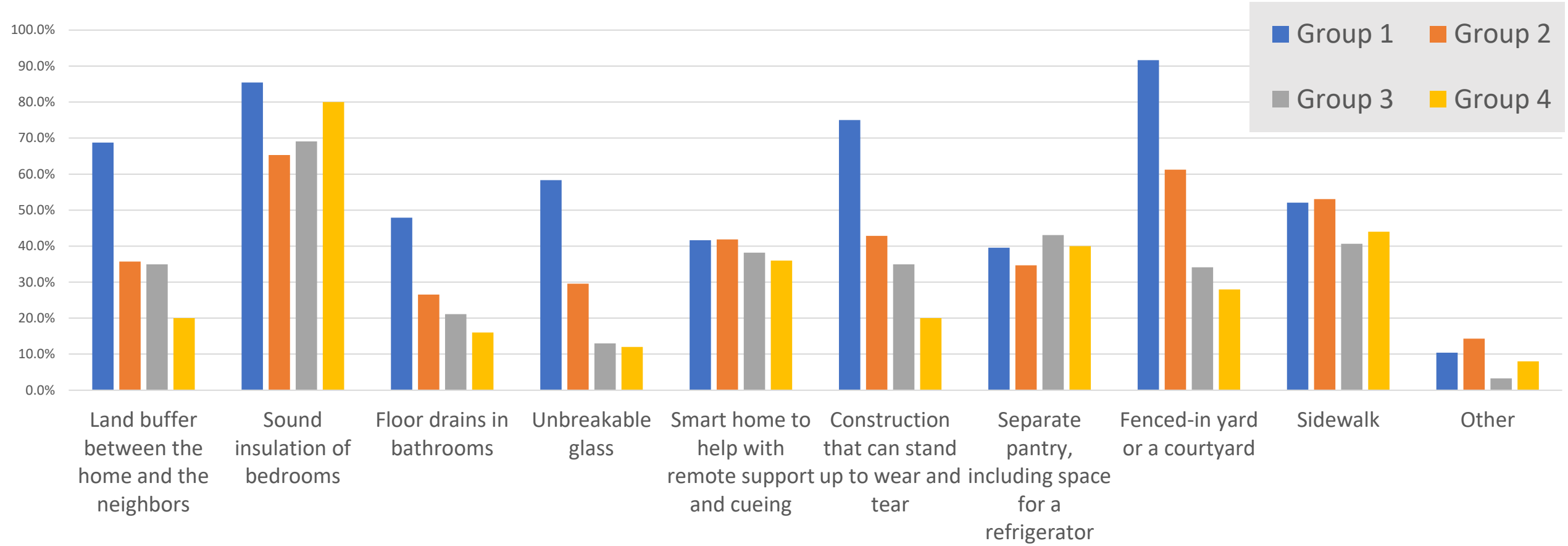
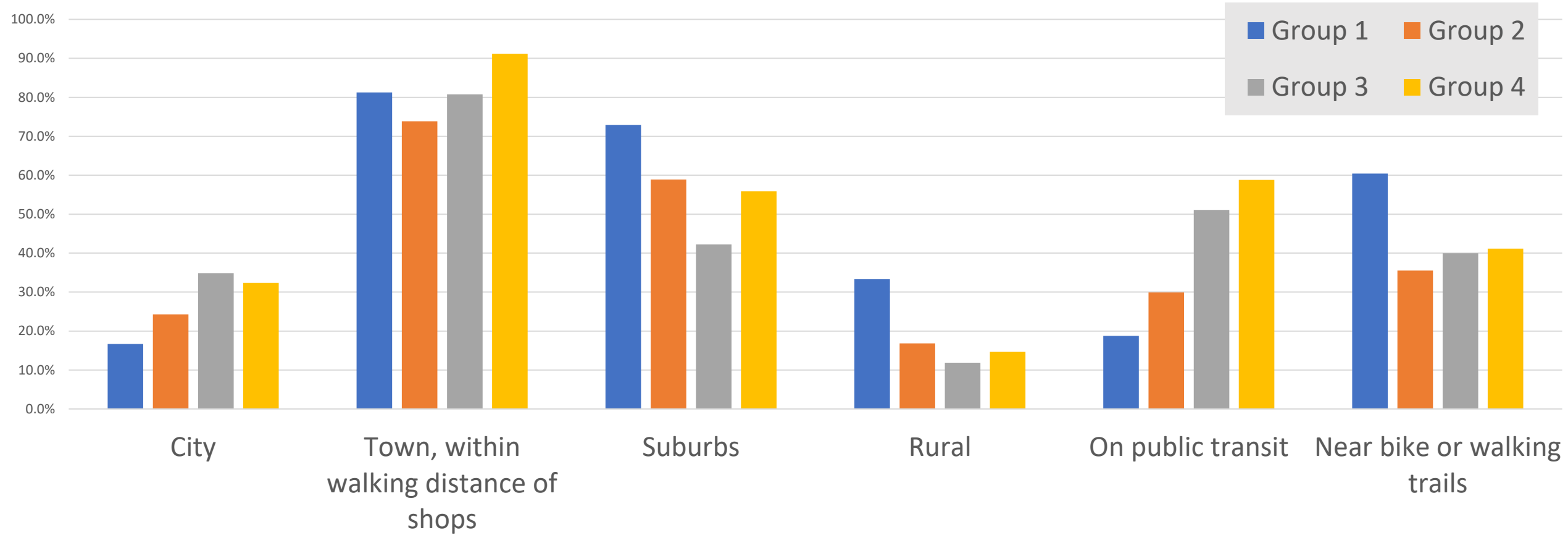
Design features/environmental modifications that contribute to success



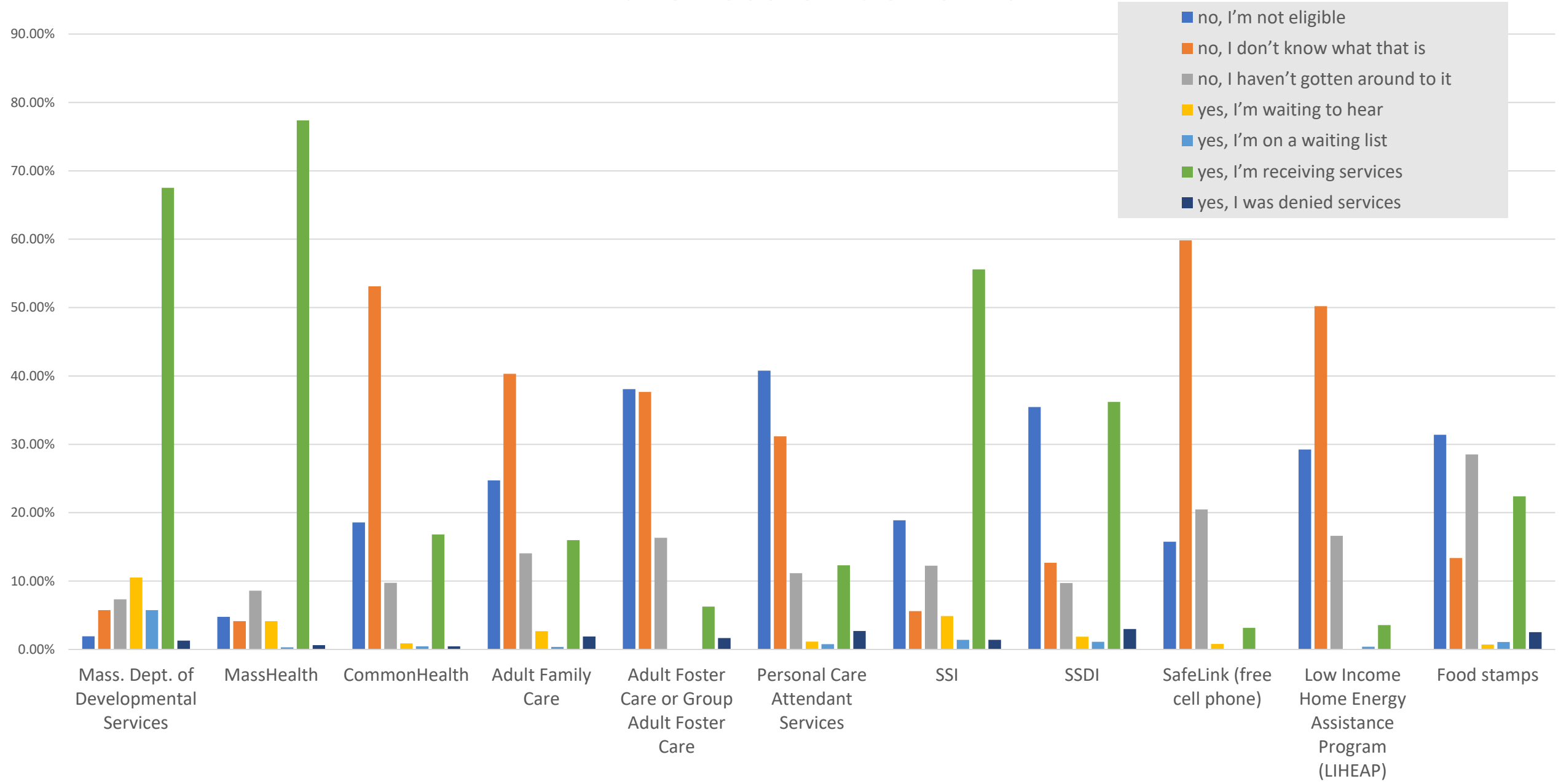
- Group 1 needs many more environmental modifications than other groups. Over 50% need a land buffer, sound insulation, unbreakable glass, durable construction, a fenced-in yard, and a sidewalk. Almost 50% need floor drains in bathrooms and a separate pantry. **Absent units with these modifications,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

Preferred locations and amenities



- For all groups, a town within walking distance of shops is the preferred location. Suburbs are in second place.
- Only in Group 1 is a substantial percentage interested in a rural location. The ability to access walking and biking trails is also most important for this group.
- Not surprisingly, the more likely individuals are to have to transport themselves, the more important public transit becomes.

Awareness of benefits

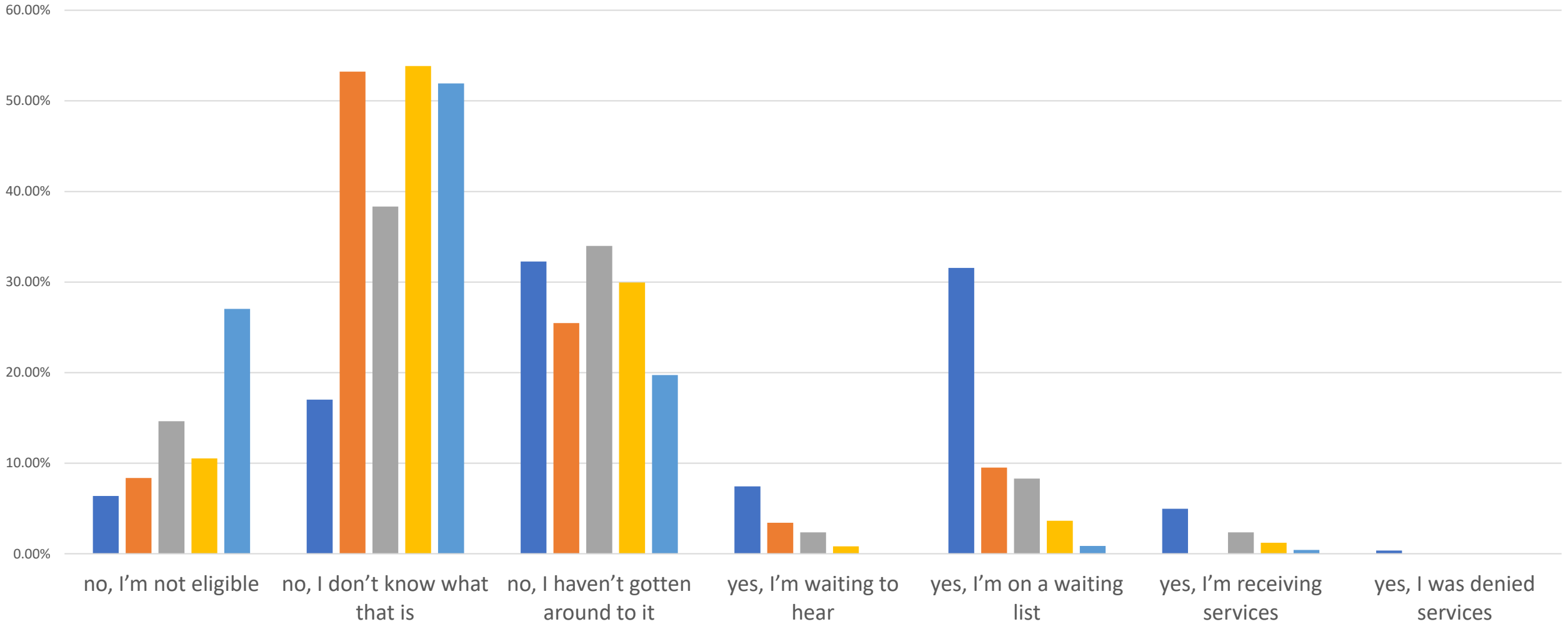


Awareness of benefits, continued*

- Over 50% of respondents have accessed benefits from DDS, MassHealth, and SSI. There is also good awareness of SSDI and SNAP.
- 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%).
  - **Educating special education transition staff about programs may help to increase awareness of individuals and family members.**

* Note that possible responses were standardized across programs. In some instances, respondent may have reported they were on a waiting list for programs that do not have waiting lists.

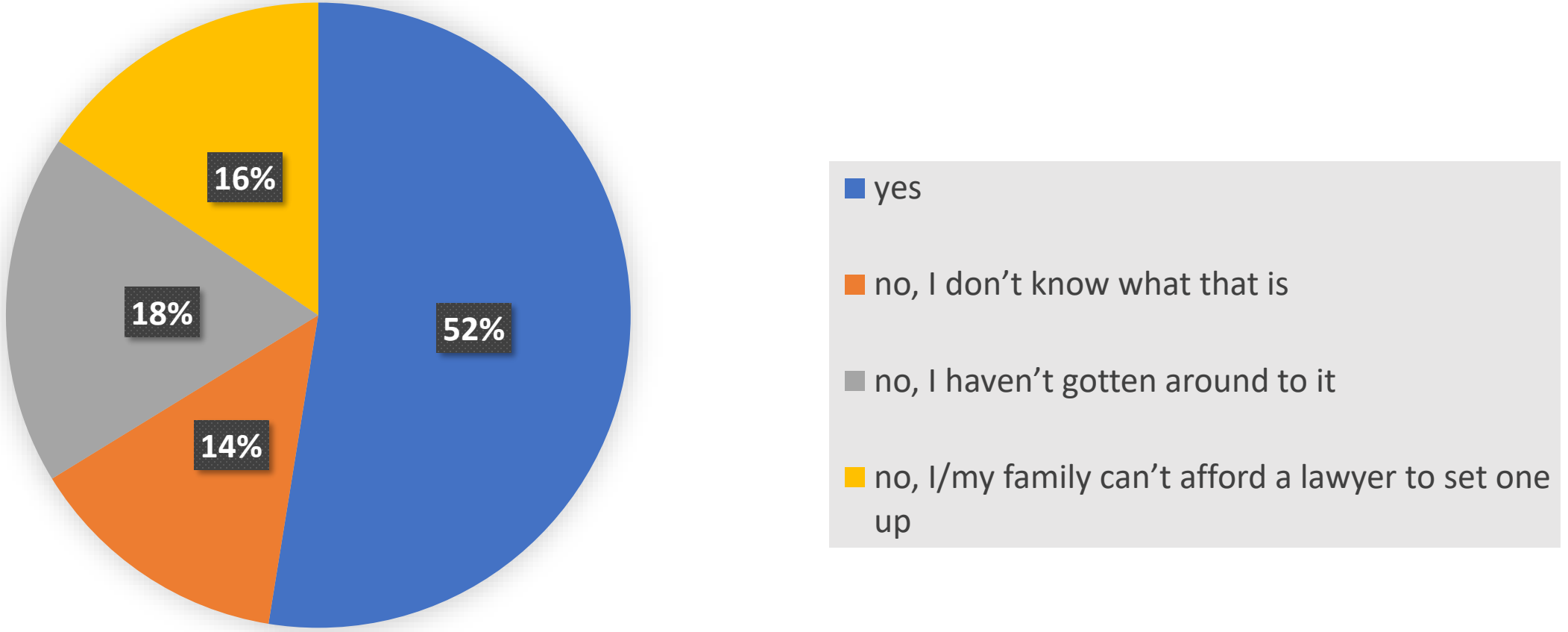
Awareness of housing programs



Awareness of housing programs, continued

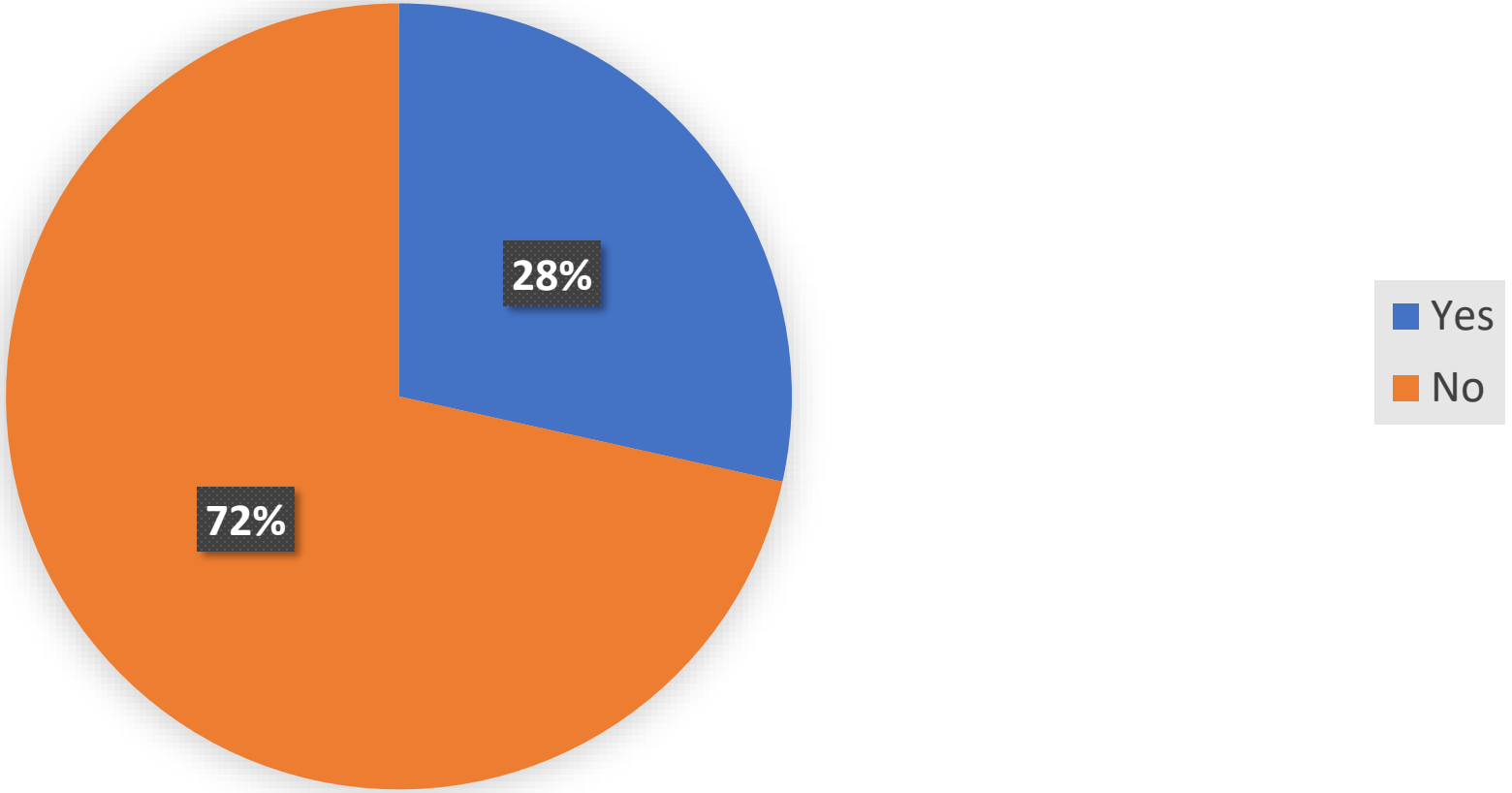
- **Less than 50% of respondents have applied to any single housing program.**
- Over 50% do not know what the following programs are: the Alternative Housing Voucher Program, private subsidized housing, single room occupancy.
  - Over 30% do not know what public housing is.
- Less than 10% are participating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

Are you the beneficiary of a special needs trust?

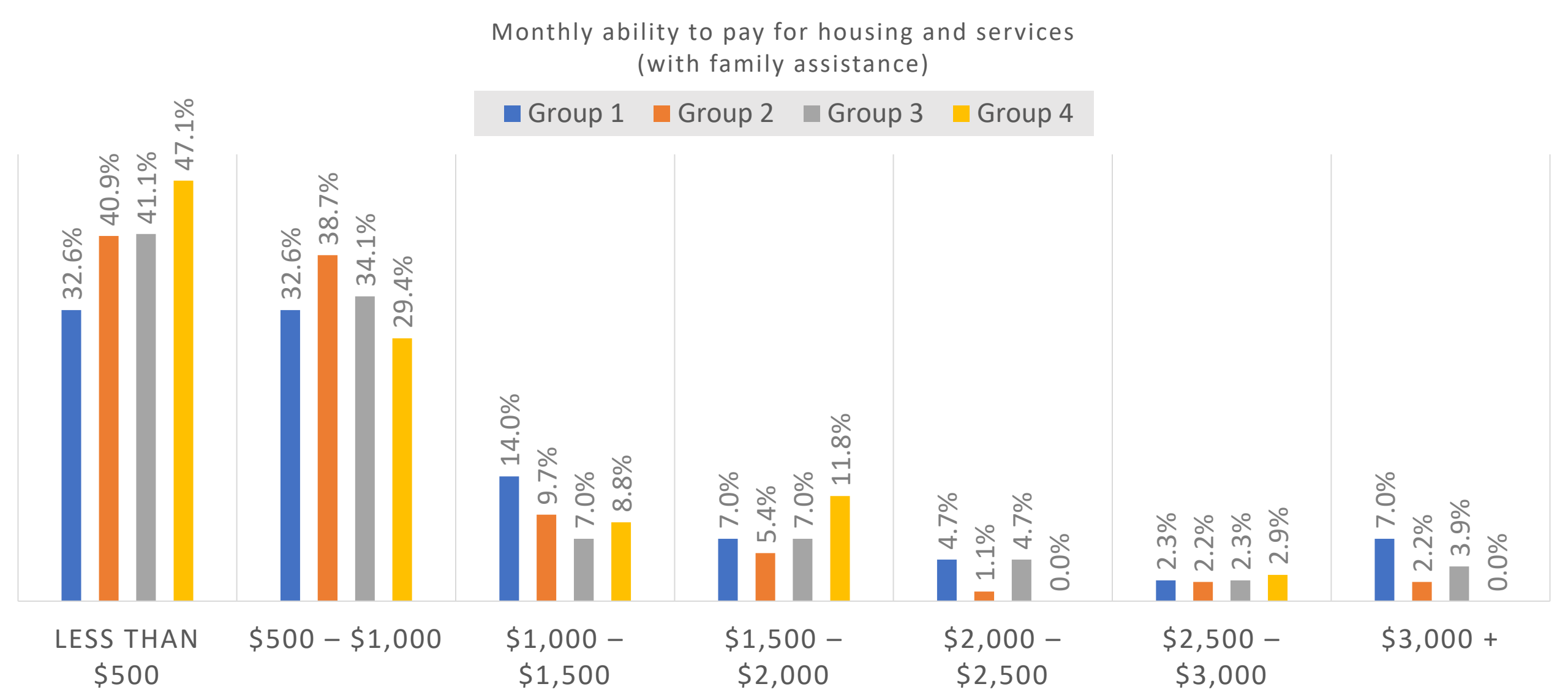


- Special needs trusts allow funds to be saved for the benefit of a person with a disability while preserving eligibility for certain government benefits.
- 52% of individuals are beneficiaries of special needs trusts, as opposed to 37.5% in our 2012 survey.

Are you the beneficiary of an ABLE account?

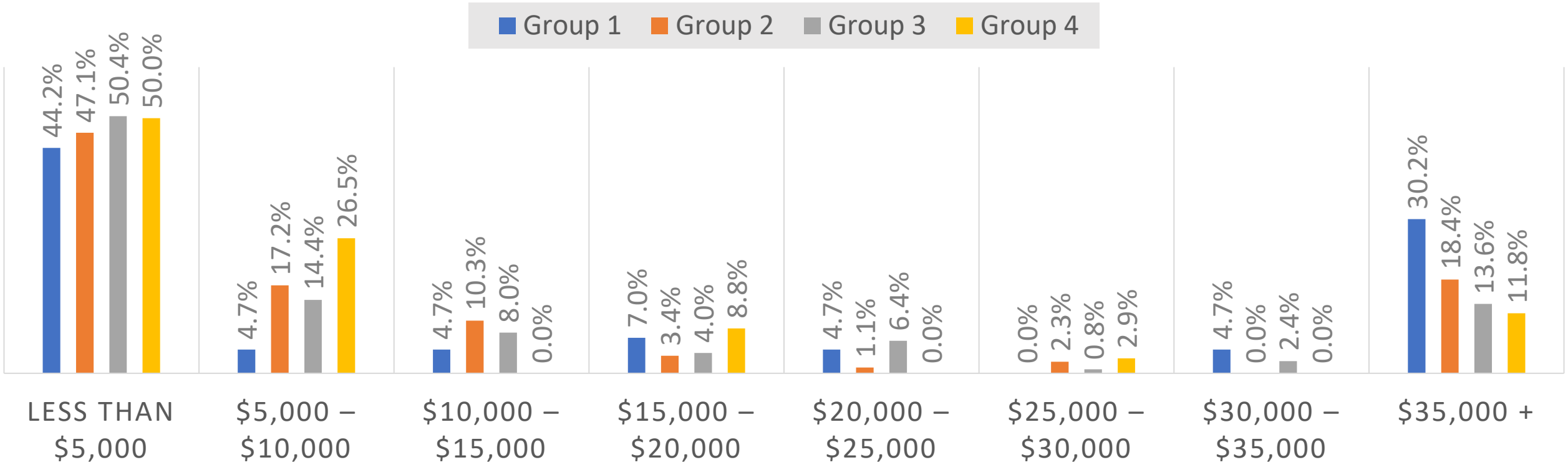


- ABLE accounts are another (and relatively new) way to save for the benefit of a person with a disability while preserving eligibility for certain government benefits. They resemble 529 college savings accounts.
- The relatively poor uptake (28%) implies ABLE accounts are gaining ground slowly, despite not having as many barriers to admission as a special needs trust and having a degree of flexibility special needs trusts do not.
- Group 3 has the strongest participation rate (36.4%), followed by Group 1 (34%), while Groups 2 and 4 are each at <20%. It is possible to roll funds over from a 529 account into an ABLE account. Group 3 is a group that may have had 529 accounts and not been able to use them.



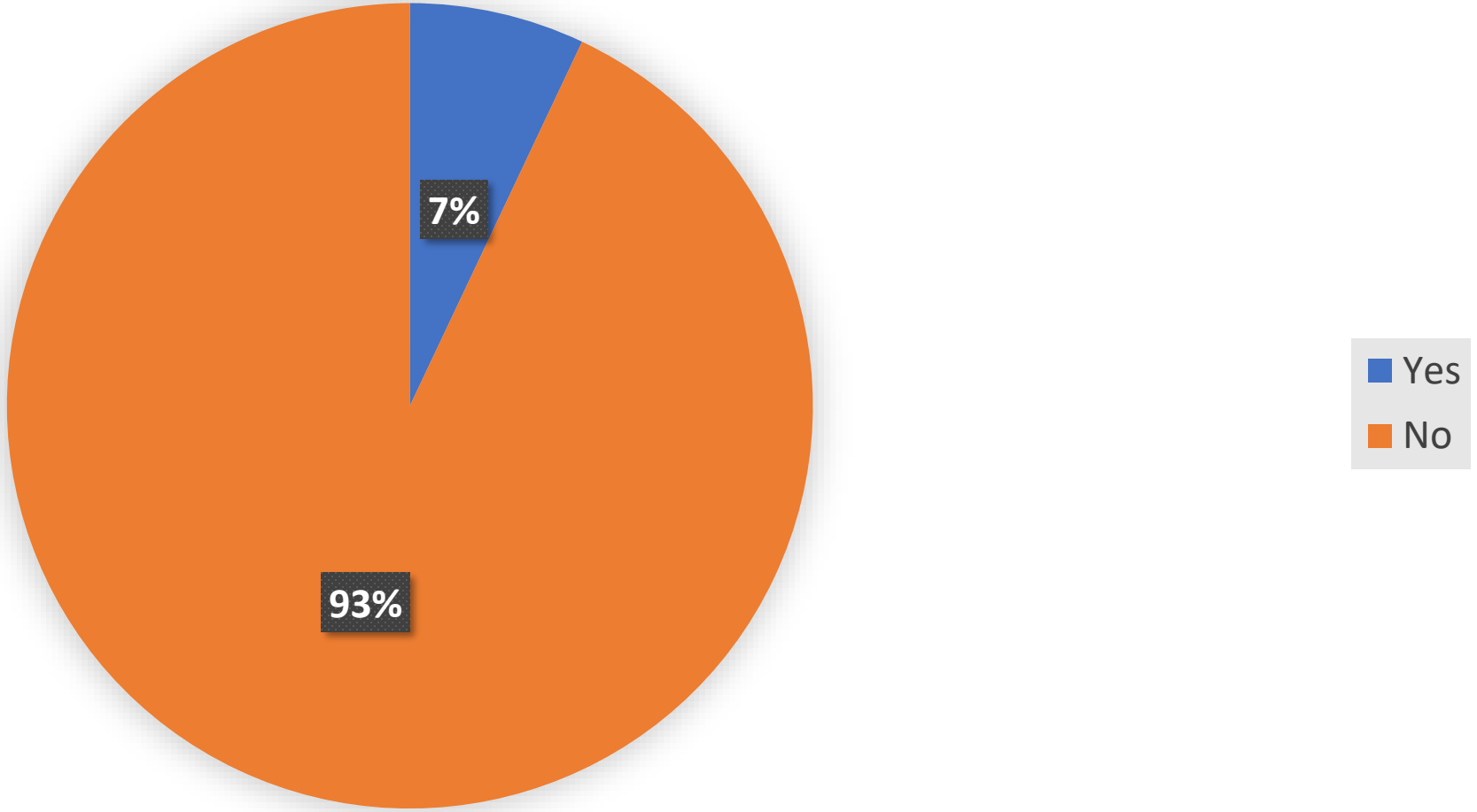
- Between 30% and 50% of individuals in each group cannot afford even $500 a month for housing and services. Overall, 75.3% cannot pay over $1,000/month for rent and services on a sustainable basis.
- Private pay housing models do exist in Massachusetts. In general, they focus on those who can be left alone up to 6 hours at a time, and the rate can run from about $1,200/month to over $6,000/month.

Down payment possible (with family assistance)



- While about half of people can afford less than $5,000 for a down payment, there is a reasonable amount of scatter in the data. That, taken together with a significant number of people who can afford a down payment of over $35,000, indicates 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.
- The large percentage who can afford less than $5,000 may also struggle with a security deposit even if they have a housing voucher. In greater Boston, last month and security deposit for a one bedroom rented from a private landlord may be as much as $4,000, even if one has a voucher. Further, without an ABLE account, saving this amount could imperil benefits.

Do you know your 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: gaps in the service menu

- The data shine a light on gaps in the current menu of services, including:
  - Half the cohort has too many skills to qualify for DDS residential 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
  - Staff need training to work with individuals with intensive support needs
  - Drop-in services for cueing 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

Discussion: 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

Discussion: possible roads ahead -- workforce

- 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 providers only commit to a year
- Modify the MassHealth Personal Care Attendant program to cover drop-in services for cueing

Discussion: possible roads ahead -- housing

- 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; these funds could be used to pilot some of the housing models identified by the 2016 MA Housing Think Tank.
- 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

Discussion: possible roads ahead – improving family awareness through teacher training

- 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
- Ideally, people with autism should exit secondary school having completed applications for a range of affordable and subsidized housing programs[1]
  - Toward this end, education about the full range of affordable and subsidized housing programs should be included as part of the curriculum for the Department of Elementary and Secondary Education (DESE) Transition Specialist Endorsement
- 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

[1] Even those eligible for DDS group homes should complete applications for the Section 8 Centralized Waiting List and the DHCD Section 8 Housing Choice Voucher Program

Discussion: possible roads ahead – autism training for gatekeepers

- Difficulties handling paperwork put people with ASD at high risk of losing benefits such as housing, Social Security, etc., even if they are able to access them initially
- While organizations already exist to help people through accessing benefits, specialty training in autism could make them more affective; those who could benefit from such training include:
  - Options and Shine counselors as Aging Service Access Points and Councils on Aging
  - Staff at Housing Consumer Education Centers