

Housing needs and desires in the Massachusetts autism community



Catherine Boyle
Autism Housing Pathways
Building A Home Conference
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Autism Housing Pathways

- Family-driven non-profit, focused on:
 - Connecting families with existing housing resources
 - Developing new models to meet unmet needs
 - Raising awareness in the public and private sectors of housing needs and effective supports
 - Improving training of residential staff

The AHP housing survey

- Conducted from Aug. 2011-Jan. 2012
- Reached respondents through:
 - Email lists
 - Outreach to organizations that emailed their members
 - Community outreach through booths at autism-related runs, walks, resource fairs
- After eliminating duplicates, there were 276 useable responses

Survey rationale

- The 2009 “Opening Doors”¹ report called for market research into autism housing demand
- 12,000 Mass. students with autism were identified in the 2010 IDEA Oct. 1st headcount
 - full time employment rates for adults with autism hover around 10%.
 - The implication is a need for approximately 8-10,000 units of affordable housing for adults with autism over the next 20 years beyond those provided by DDS

¹ <http://www.autismcenter.org/openingdoors.aspx>

Survey limitations

- Since there are no good data on the total number of individuals with autism in Mass., it is impossible to tell what the sample size is or how representative it is²
- Obvious bias includes skewing toward families that are “joiners”, and have a presence in the venues where outreach took place
- These limitations underscore the need for the state to improve data collection

²With the data collected, it appears to be possible to derive a defined sample size of 18-21 year olds in the IDEA Oct. 1, 2011 headcount by reaching out to certain individuals who provided contact information and asking them if their family member is on an IEP with autism listed as the reason for services. This is a future project.

Survey design

- The survey was designed to determine
 - What existing services respondents might be eligible for
 - Respondents' awareness of services, and of their eligibility for services
 - Which respondents have needs that are not aligned with existing services
 - Preferred living situations and supports

Group definitions

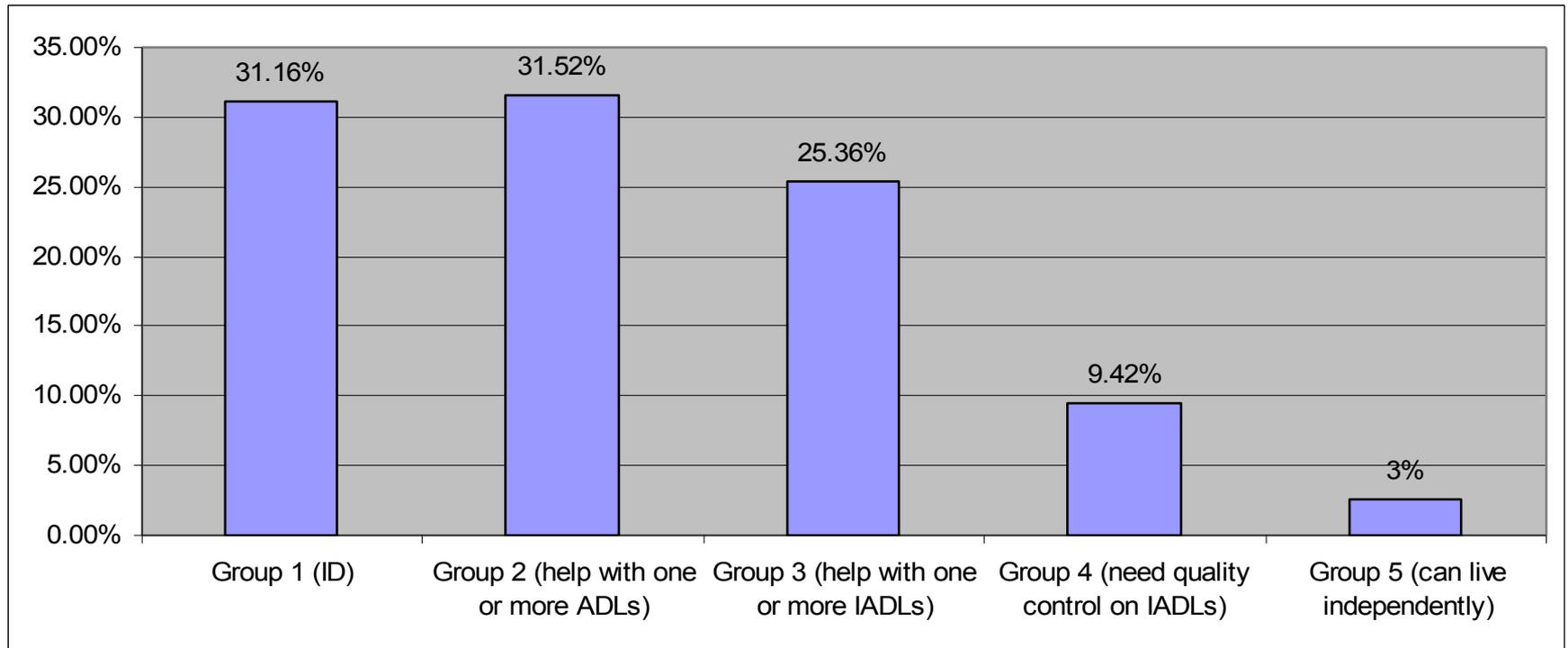
- Respondents were assigned to one of five categories:
 - Group 1: having an intellectual disability (ID)
 - Group 2: no ID, but needing prompting for one or more activities of daily living (ADLs)
 - Group 3: needing help with one or more instrumental activities of daily living (IADLs), but not meeting criteria for Group 1 or 2
 - Group 4: needing “quality control” with one or more IADLs, but not meeting criteria for any previous groups
 - Group 5: independent in both ADLs and IADLs

Groups as analogs

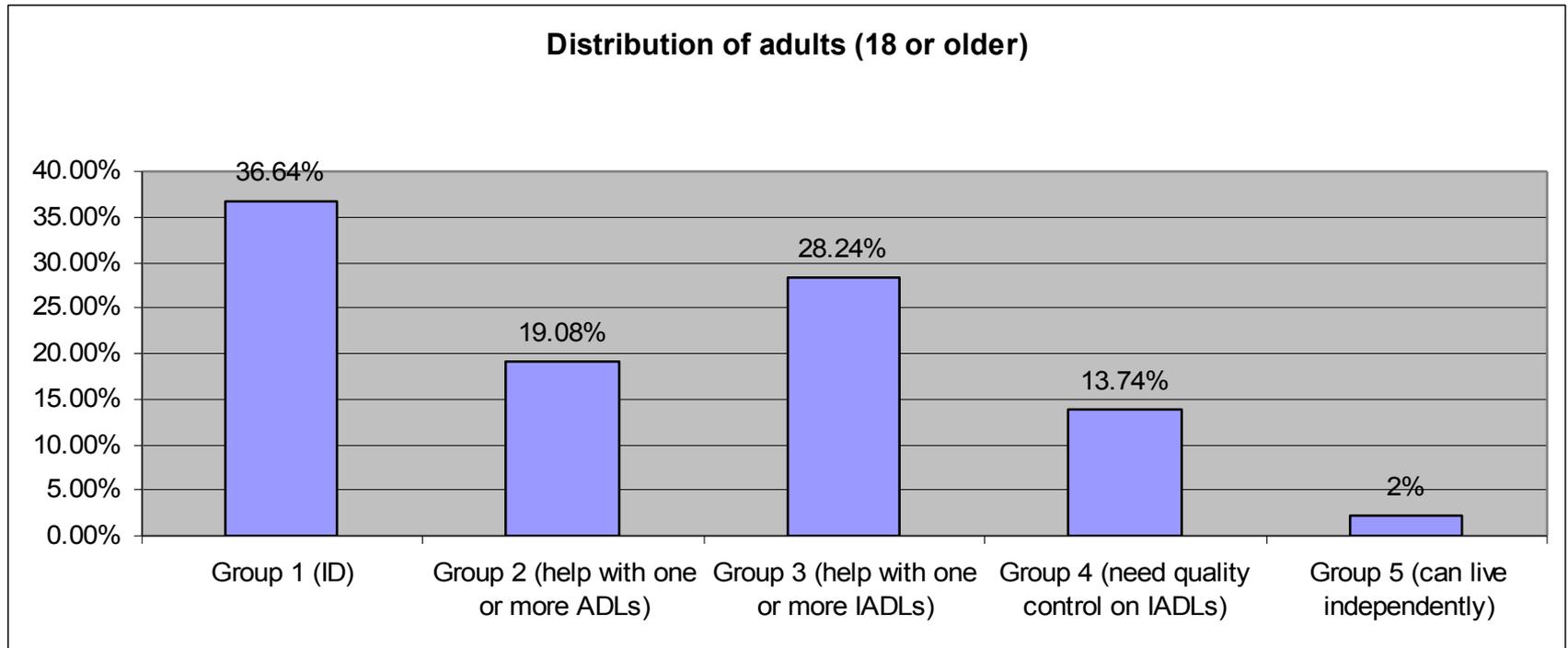
- Group 1 is considered an analog for eligibility for services through the Dept. of Developmental Services (DDS)³
- Group 2 is an analog for Adult Family Care, Adult Foster Care, or Group Adult Foster Care state plan services through MassHealth
- Groups 3 and 4 do not correspond to support services (with the possible exception of the Mass Rehab Homecare Assistance Program)
- Group 5 is an analog for independent living

³ This survey was conducted prior to the ruling in Tartarini vs. Department of Mental Retardation in July, 2012. It is not yet clear how the ruling, which struck down IQ as a “bright line” test for DDS eligibility, will affect eligibility as a practical matter.

Group breakdown



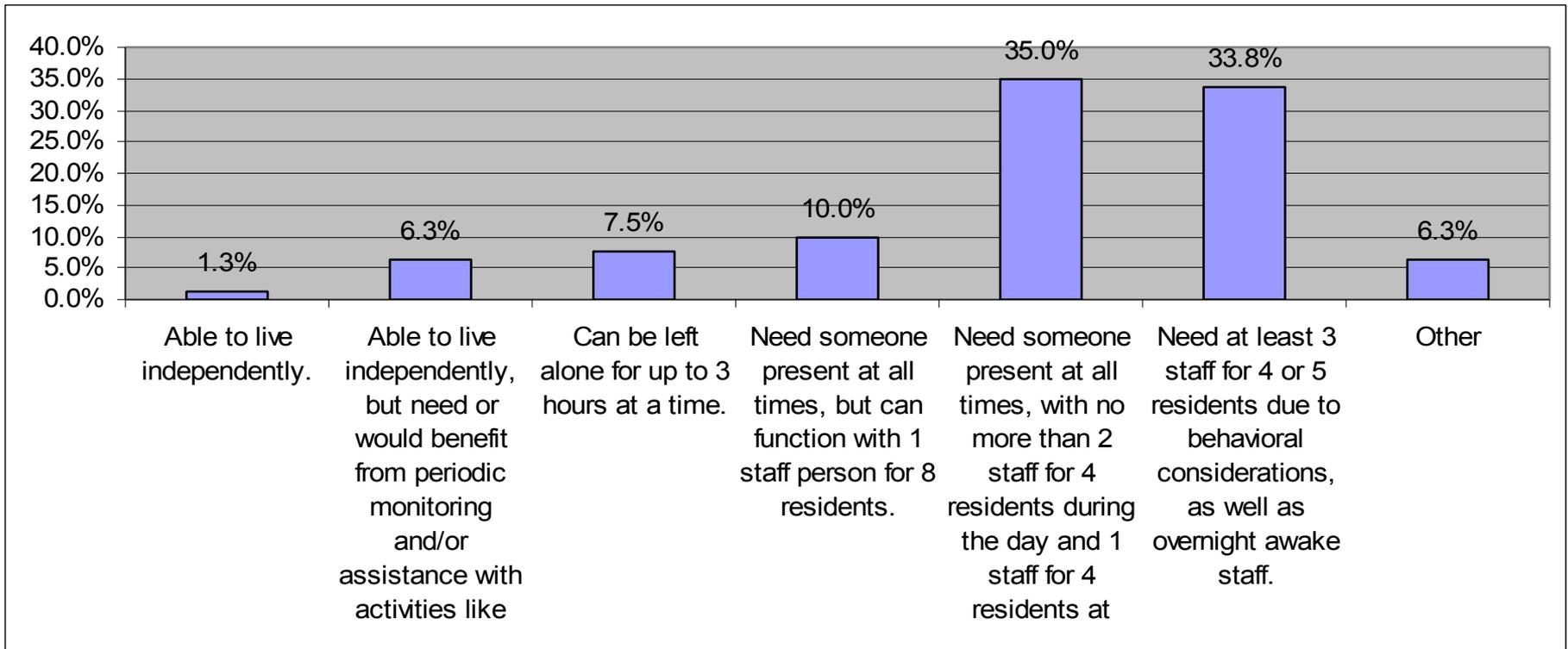
Age-adjusted group breakdown



Relationship of the safety net to need

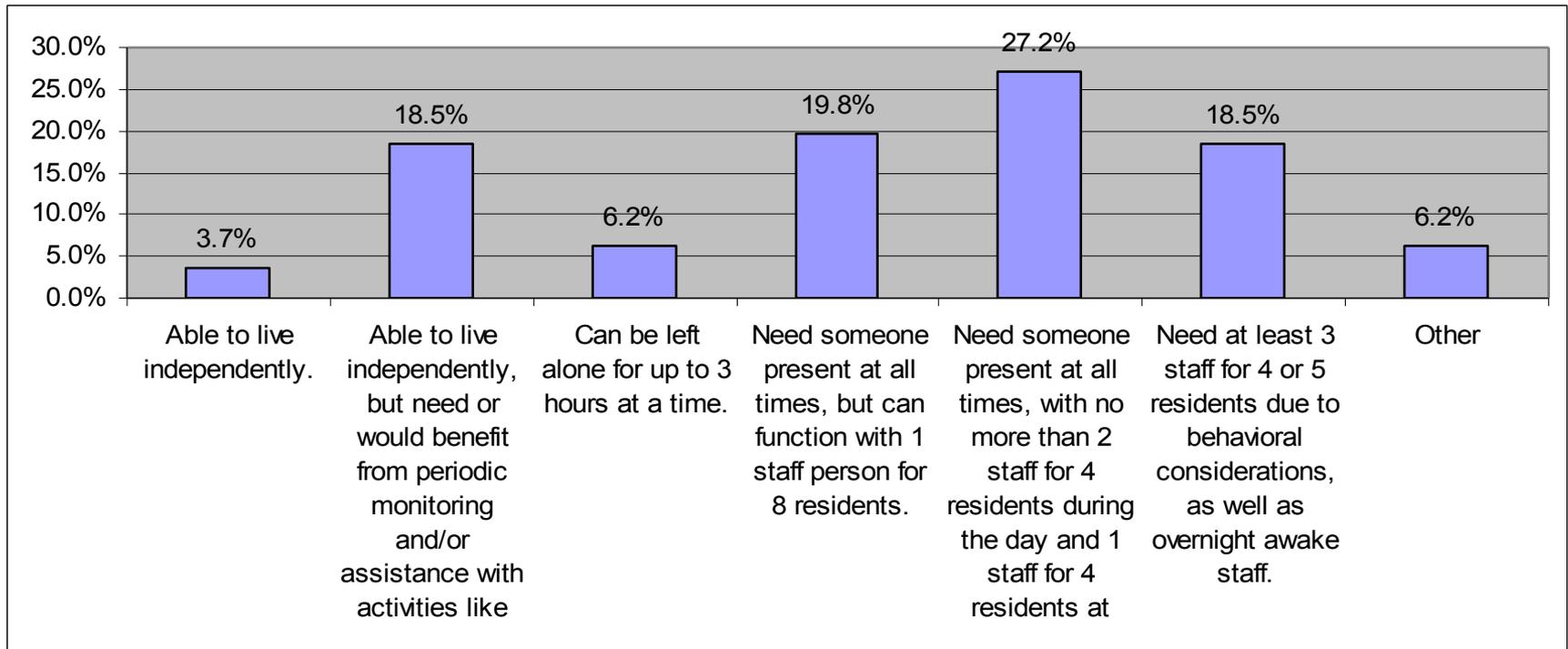
- 63% of the total sample of those 18 or older is not eligible for services from DDS, but is not able to live independently
- 42% of the total sample of those 18 or older is not eligible for DDS or MassHealth state plan services, but is not able to live independently

Group 1: Level of support needed



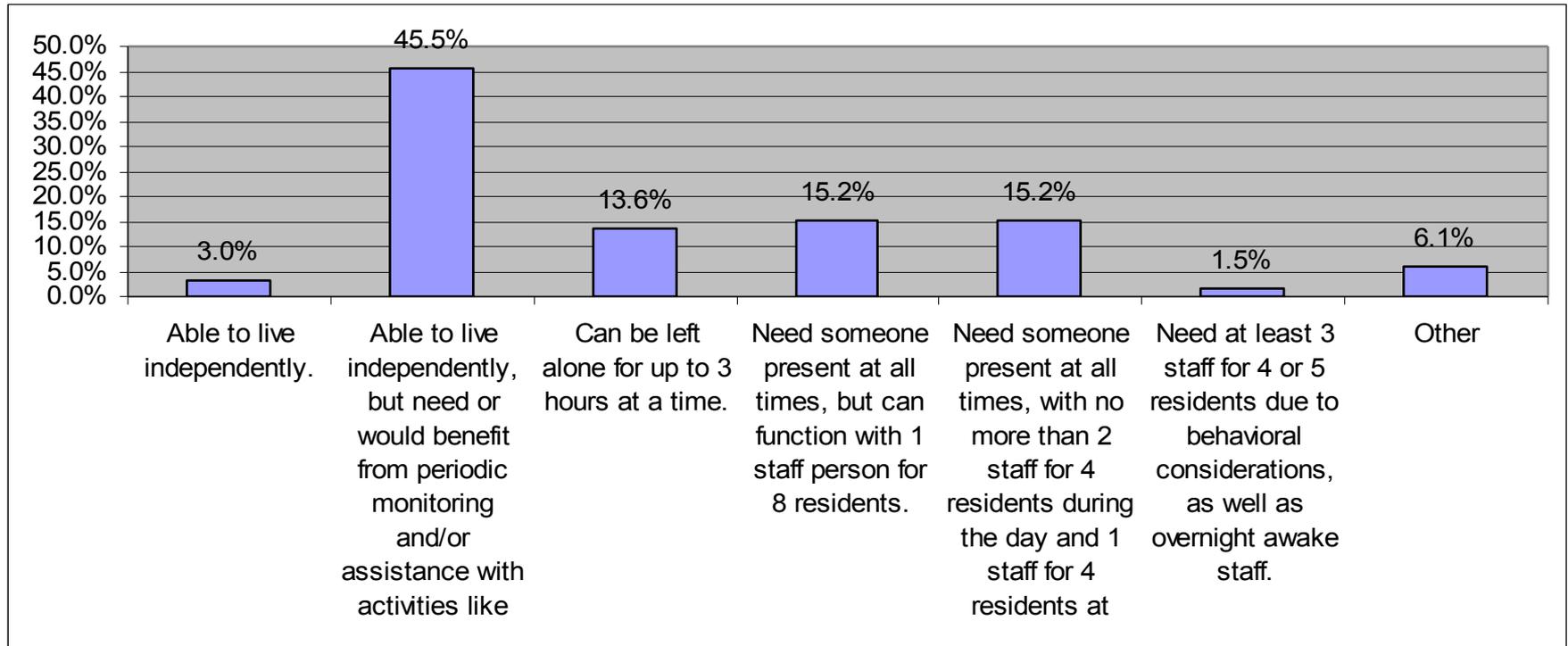
- Note that 33% indicate a need for more intensive staffing than 2:4 by day. These individuals are more likely to be Priority 1 for residential placement at age 22. In general, about 15% of the DDS caseload is likely to be Priority 1 at age 22; this implies individuals with autism may be more likely to be Priority 1 than other individuals with an ID
- If they are safe in the family home, individuals requiring 2:4 staffing may not qualify as Priority 1 at age 22. It is important for these families to be aware of other options, such as MassHealth state plan services

Group 2: Level of support needed



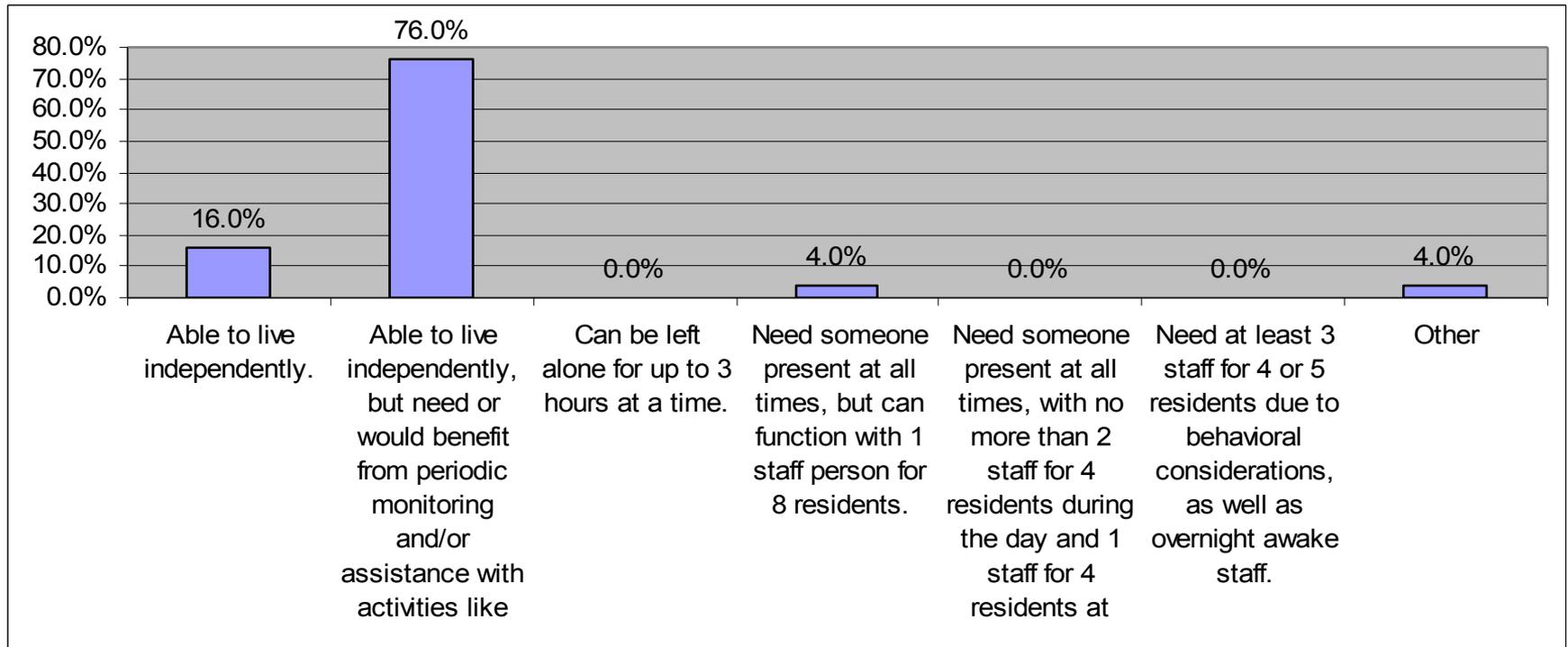
- While someone needing 2:4 staffing could have their needs met in the context of Adult Family Care or Adult Foster Care, the 18.5% who indicate a need for at least 3:5 staffing do not have any appropriate care options

Group 3: Level of support needed



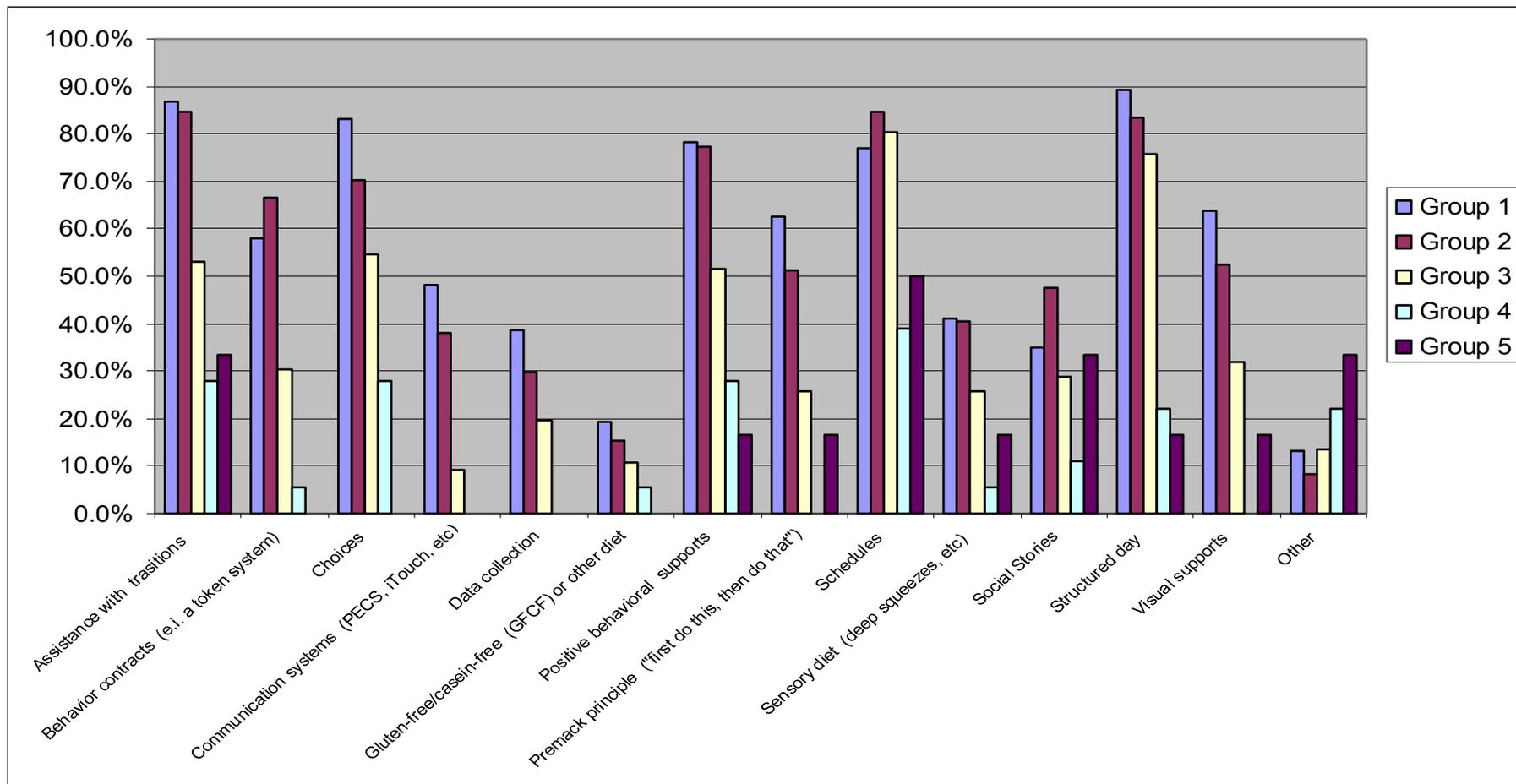
- Almost half of Group 3 would benefit from life coaching services, while most of the rest have more intensive needs, which do not conform to the eligibility requirements of MassHealth state plan services

Group 4: Level of support needed



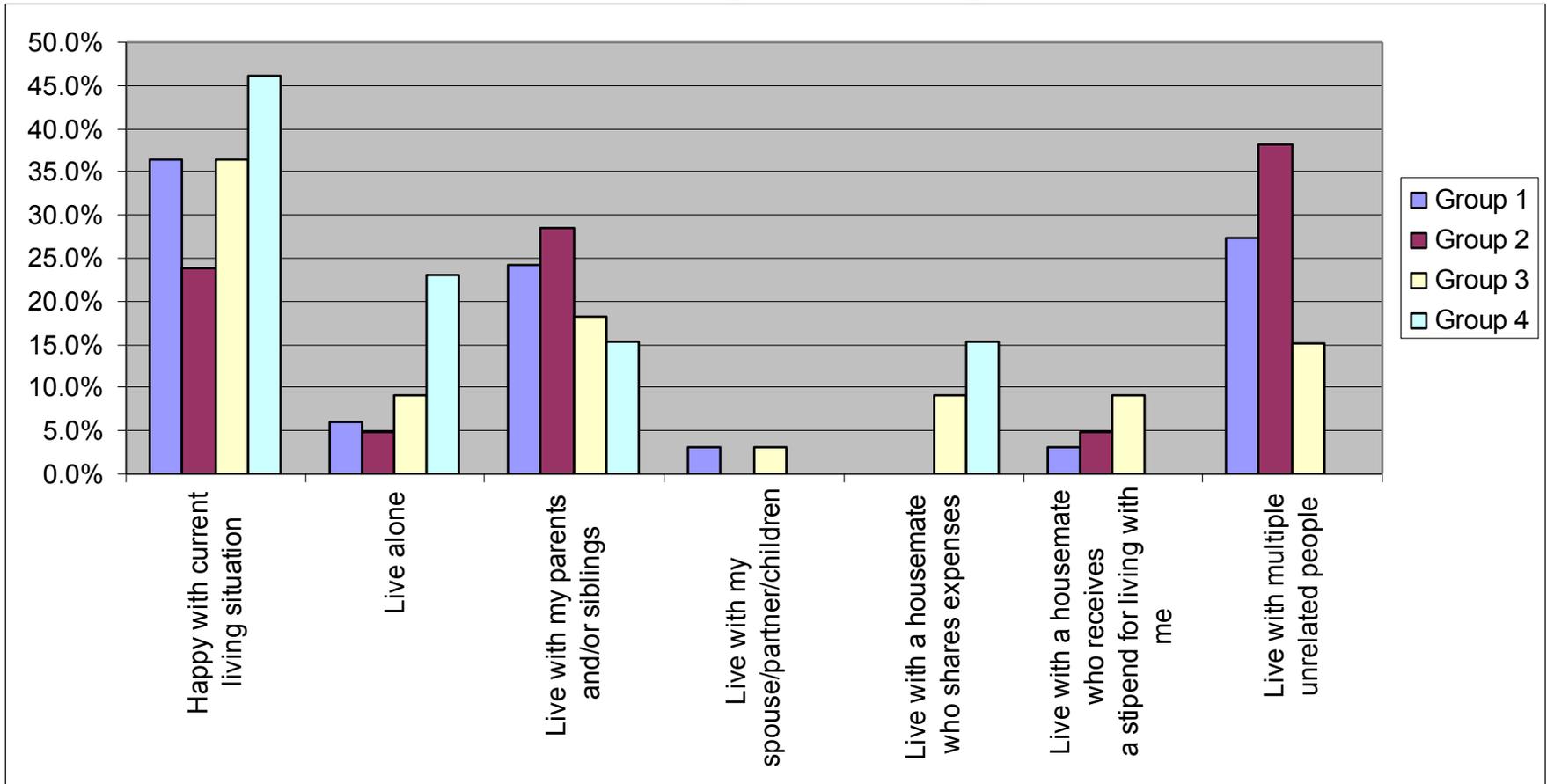
- Life coaching would appear to be the most crucial support needed by this group

Supports needed for success, by group



- Groups 1 and 2 have significant support needs, with over 50% of individuals in each group needing assistance with transitions, behavior contracts, choices, positive behavioral supports, schedules, a structured day, and visual supports. Significant minorities (25% or more) need additional supports
- 25% or more of Groups 3 and 4 also benefit from assistance with transitions, choices, positive behavioral supports and schedules

Preferred living arrangements

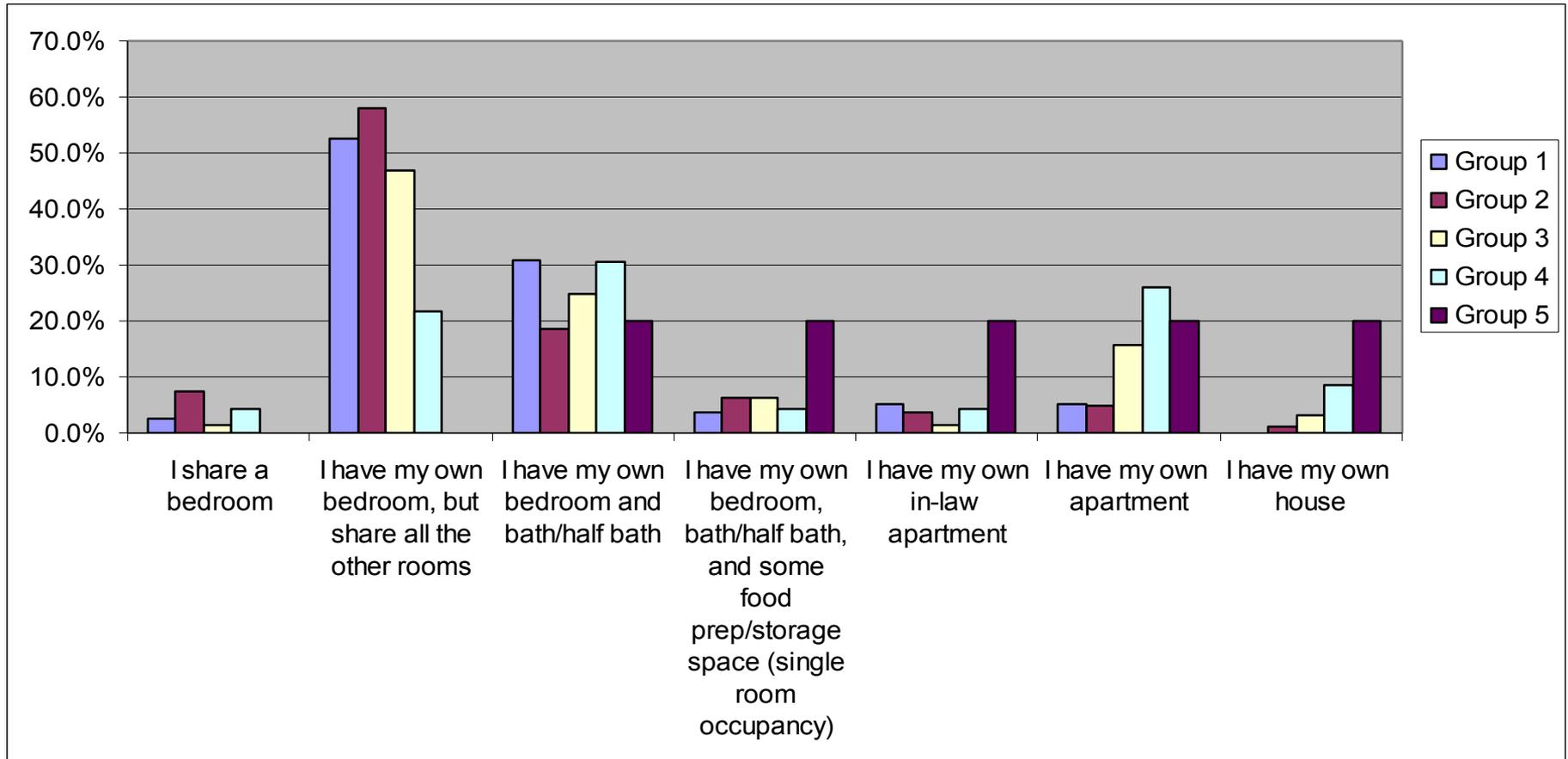


- The most popular living arrangements are living with parents and group living. Living alone or with a housemate is, not surprisingly, more popular with those in Group 4 than with those in other groups
- Among those stating they were happy in their current situation, adults in Group 1 were divided between those living with parents and those in group situations, in Group 2 leaned toward group living, and in Group 3 split between parents and living alone, with Group 4 leaning toward living alone

Housemates

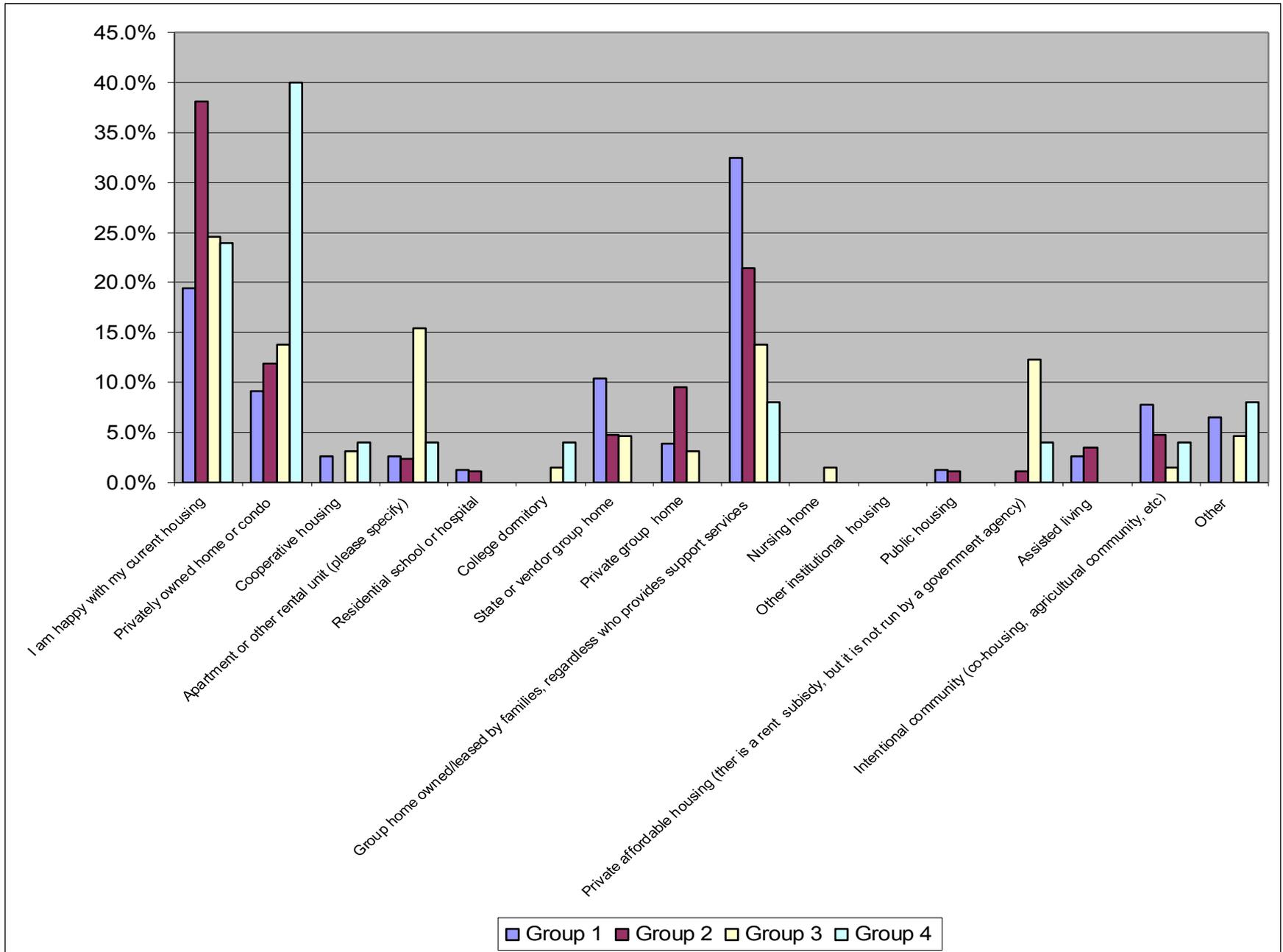
- In Groups 1-4, there was a strong preference (40% or more) for a mixture of housemates with and without developmental disabilities
- In Groups 1 and 2, the second strongest preference (35% and 30%, respectively) was for housemates with autism, rather than those with other developmental disabilities or those without developmental disabilities)
- In Group 3, 1/3 preferred a housemate without a developmental disability
- In group living situations, there was a slight preference for a house with no more than four residents over a house with 4-8 residents

Housing layout, by group



- A family-style living situation is most popular in Groups 1-3, with a significant minority wanting a bathroom en suite. Group 4 favors more privacy, preferring at least a private bath, and is more likely to prefer living alone than the other groups

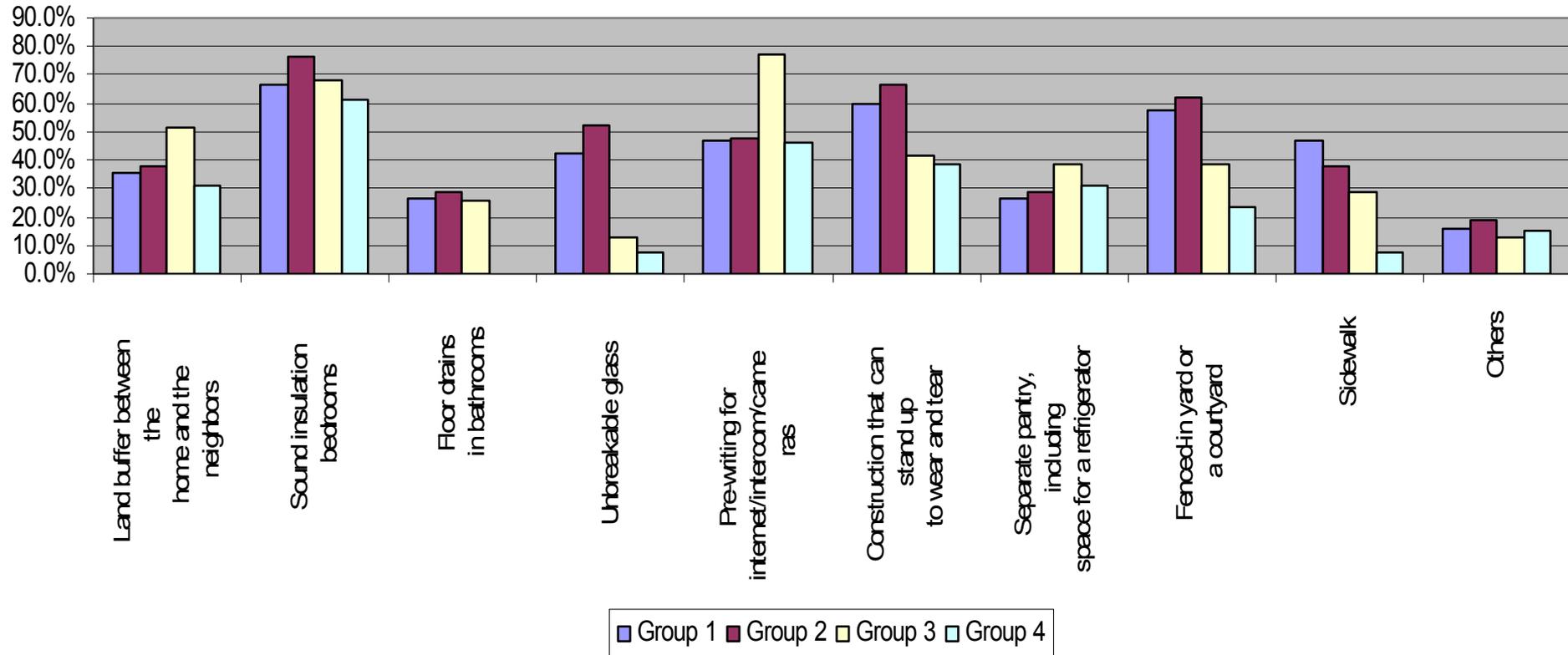
Housing type, by group



Housing type

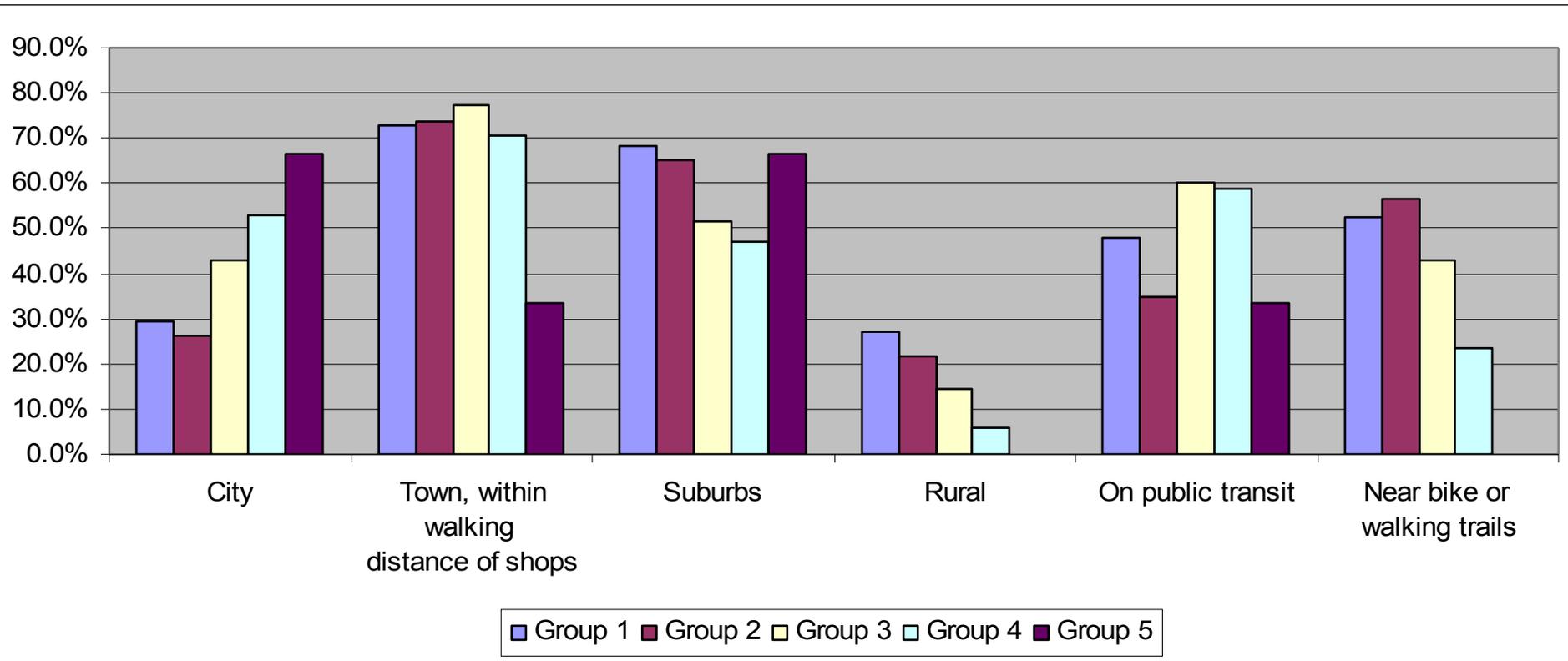
- The most dramatic finding here is a significant plurality in Groups 1 and 2 (33% and 21%, respectively) favoring a group home situation where the property is controlled by the families of the residents over a group home owned or leased by the state or a vendor
- Group 4 strongly favors a private home or condo
- Among adults happy with their living situation, the majority are in a private home or condo

Environmental modifications, ages 18+, by group



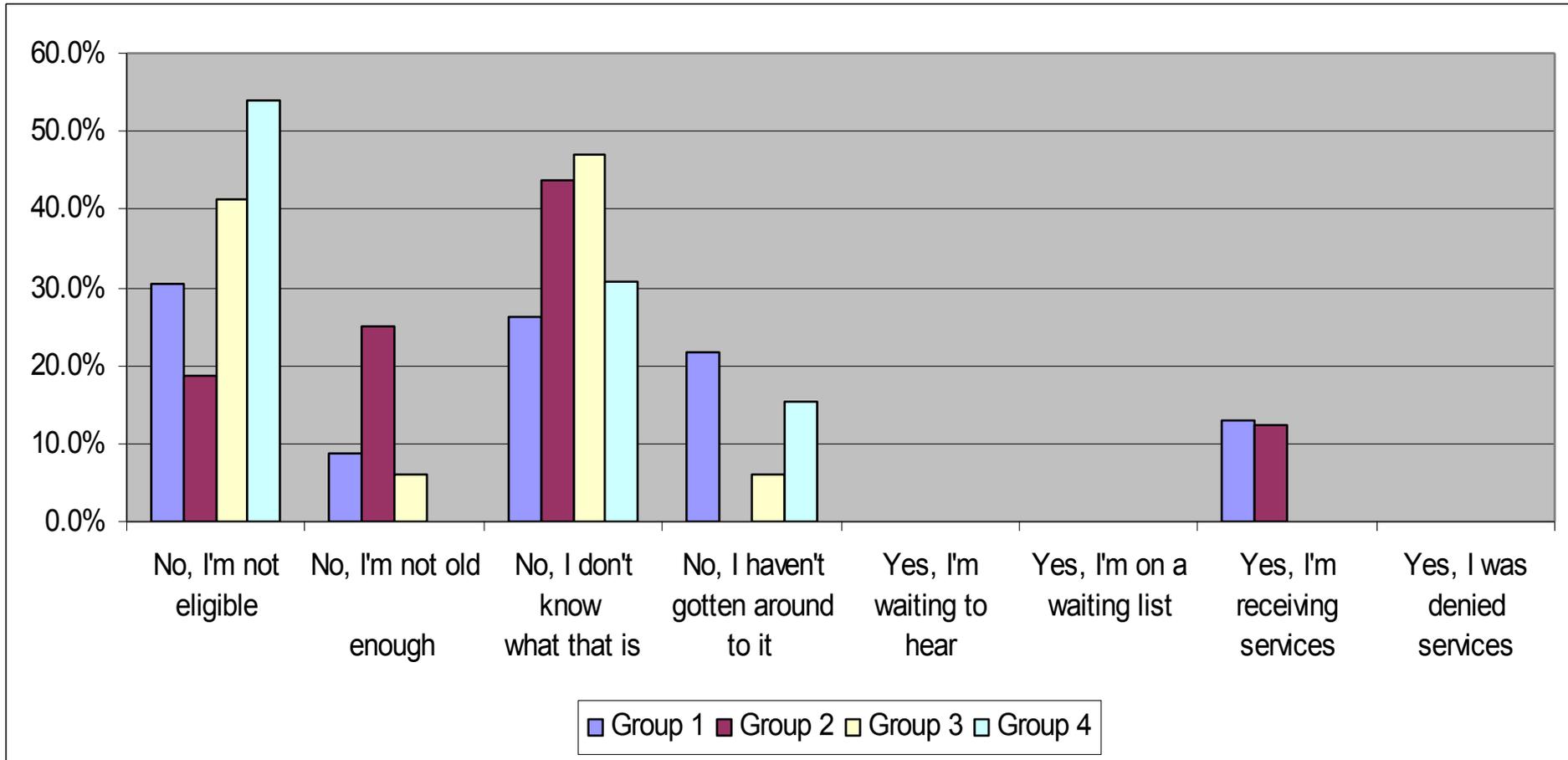
- The most striking finding here was a strong majority that would benefit from sound proof bedrooms. Other important adaptations include construction that will stand up to wear and tear, pre-wiring for internet/intercom/cameras, a fenced in yard, and a sidewalk
- Significant minorities needed a land buffer with the neighbors, a separate pantry, and floor drains in the bathroom
- Over 40% of Groups 1 and 2 needed unbreakable glass

Preferred locations, ages 18+, by group



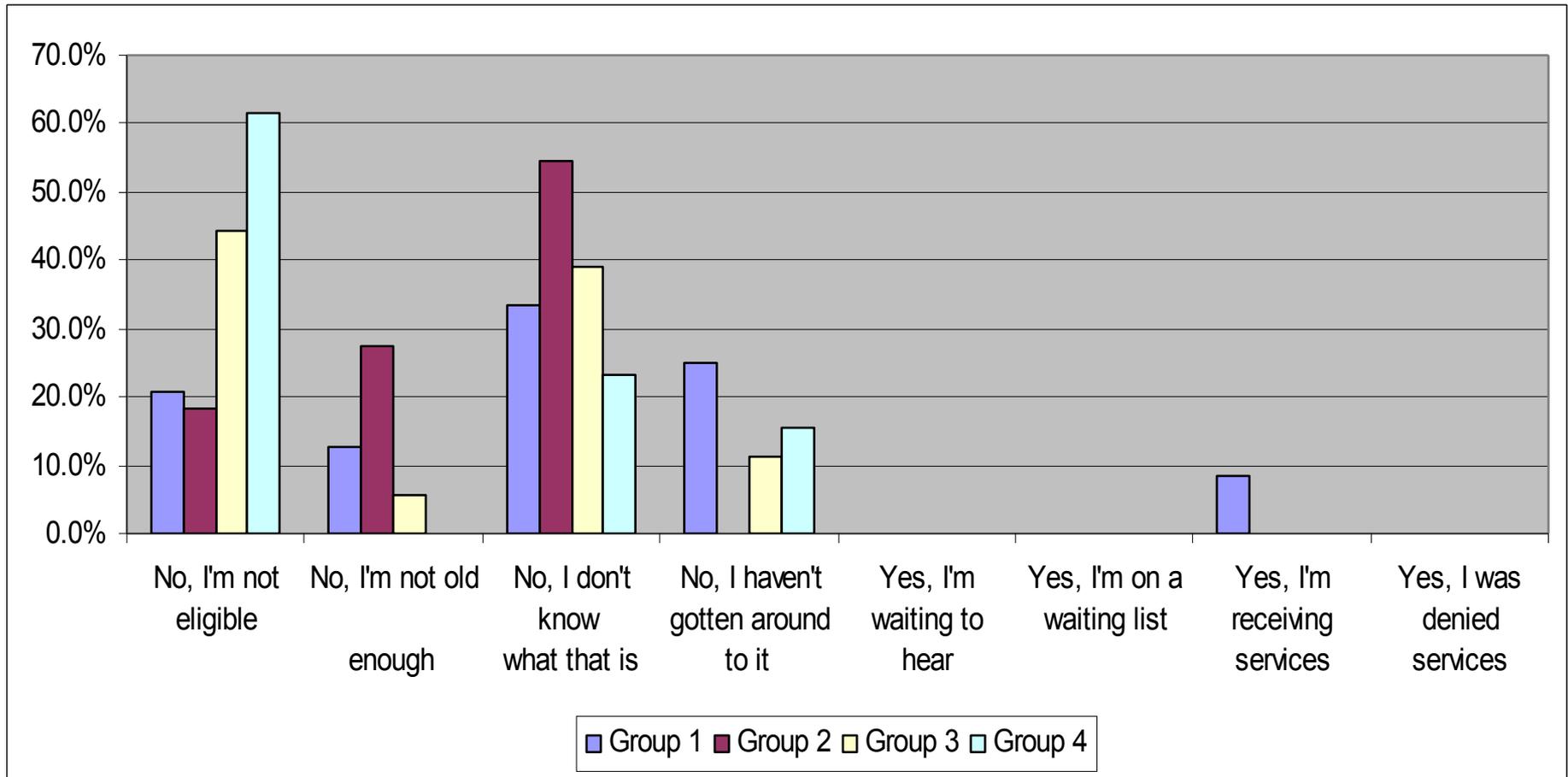
- In general, a “walkable” location is most popular, with suburbs running in second place
- The city becomes progressively more popular, and the country less so, in moving from Group 1 to Group 4. Not surprisingly, public transit is more important for Groups 3 and 4

Awareness of benefits, ages 18+, Adult Family Care



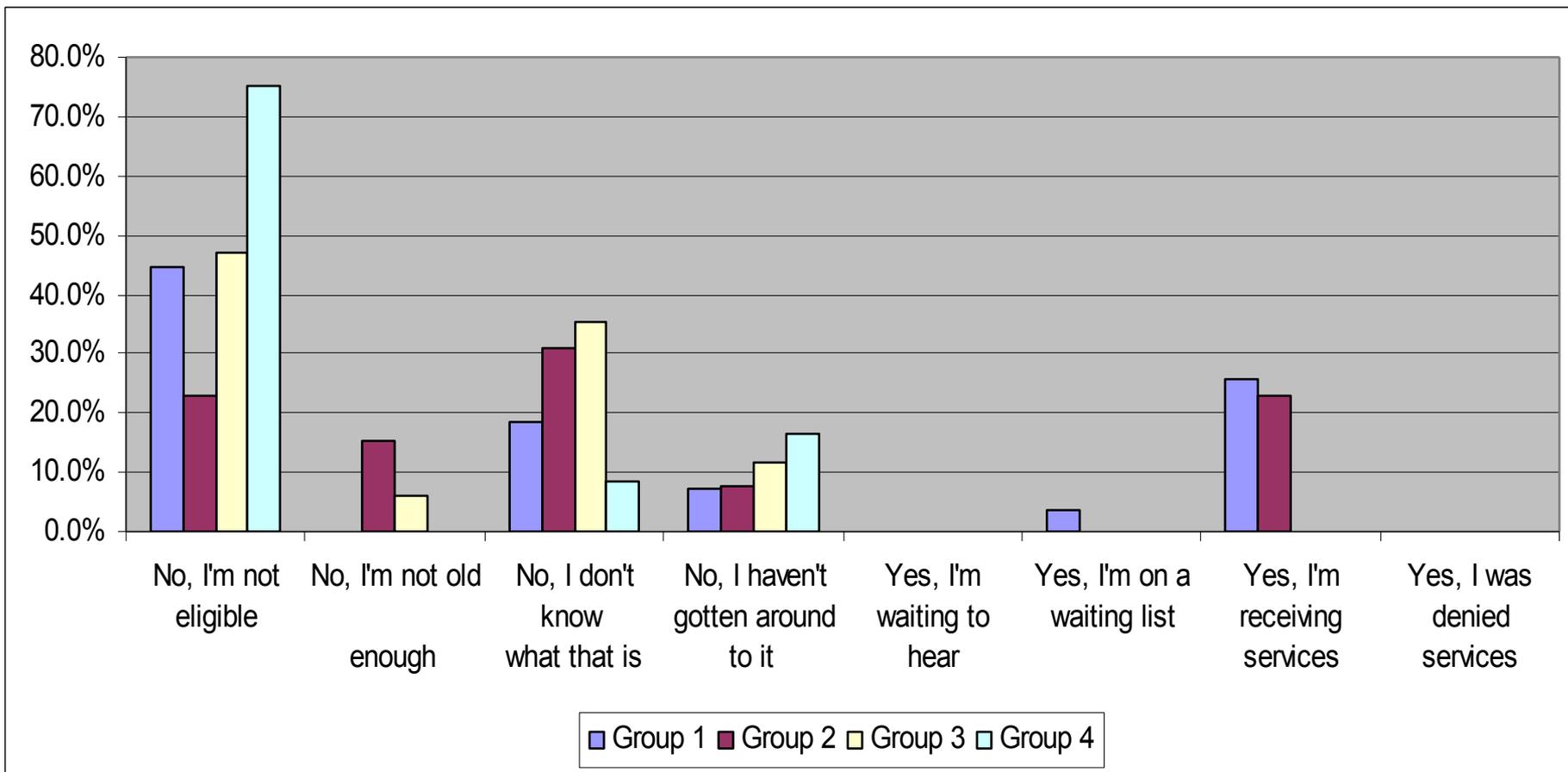
- The large percentage of those in Groups 1 and 2 (over 25% and 40%, respectively) who are unaware of Adult Family Care is of significant concern, as this is a primary source of support for those who don't qualify for DDS or are not Priority 1 for residential
- Similarly, internal evidence in the questionnaire indicates that some of those in Groups 1 and 2 stating they aren't eligible are indeed eligible

Awareness of benefits, 18+: AFC/GAFC



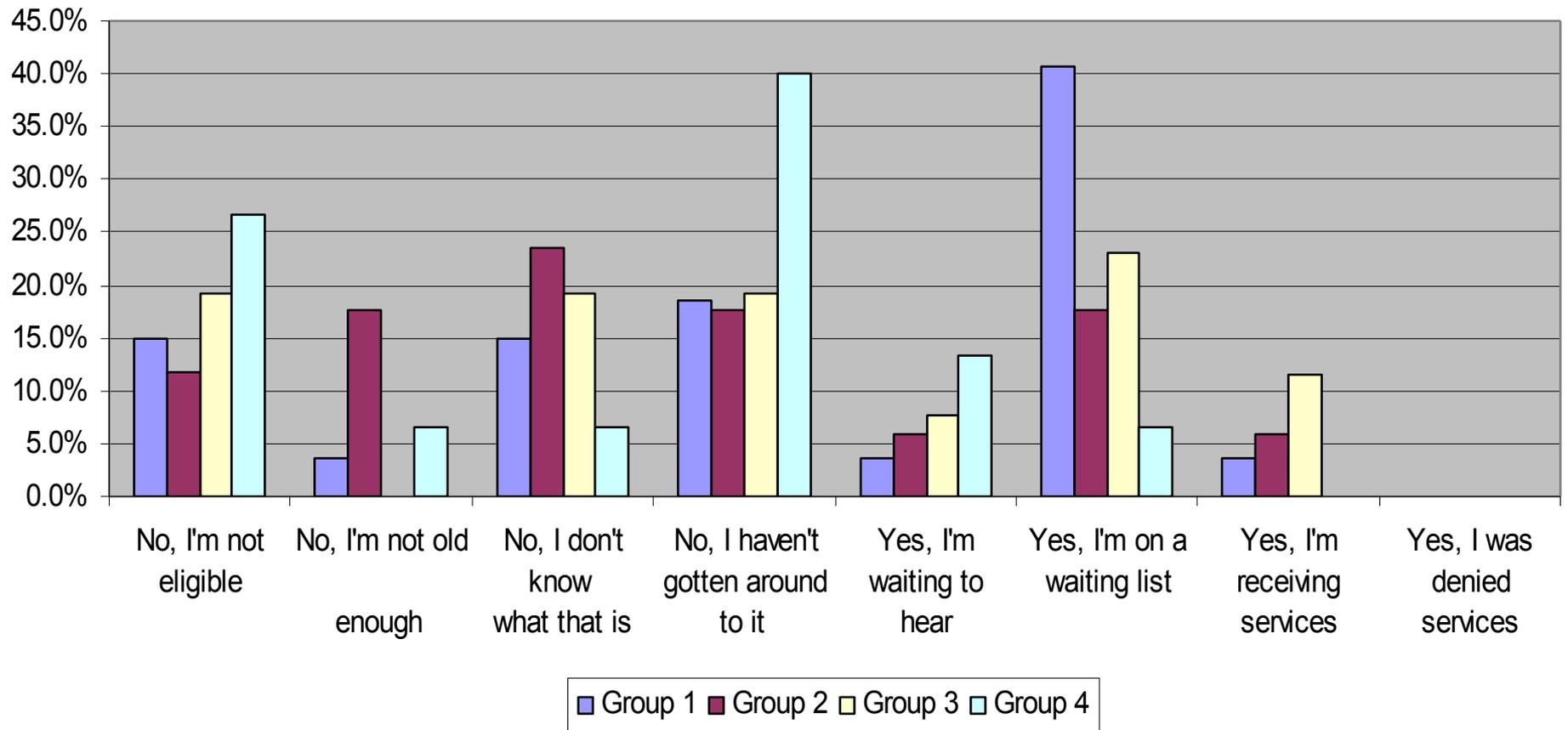
- A disturbing percentage of those in Groups 1 and 2 (over 30% and 50% respectively) are unaware of this benefit, and internal evidence shows that some of those saying they aren't eligible appear to be, in fact eligible

Awareness of benefits, 18+: PCA



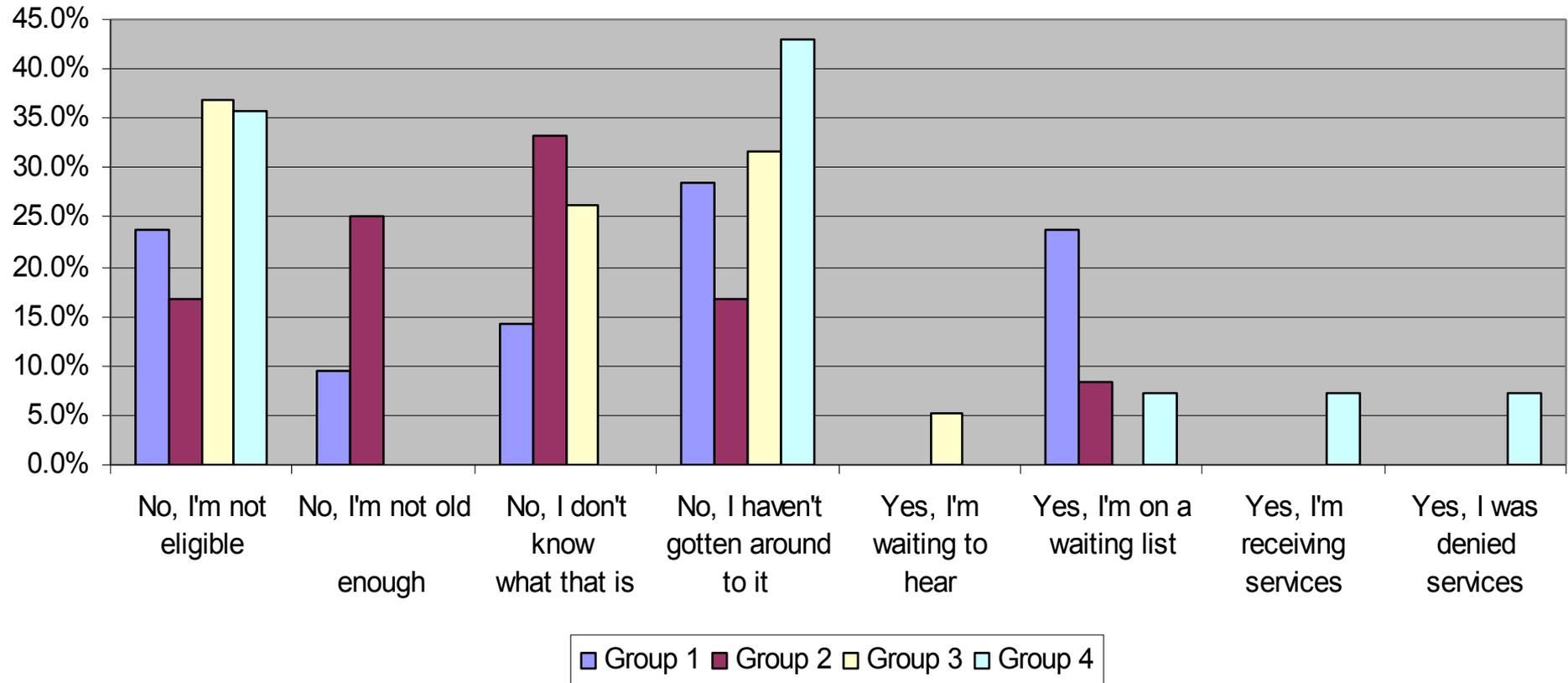
- Almost 20% of Group 1 and over 30% of Group 2 is unaware of the PCA program, and some of those stating they are not eligible appear to be, based on internal evidence in the questionnaire

Awareness of benefits, 18+: Sec. 8



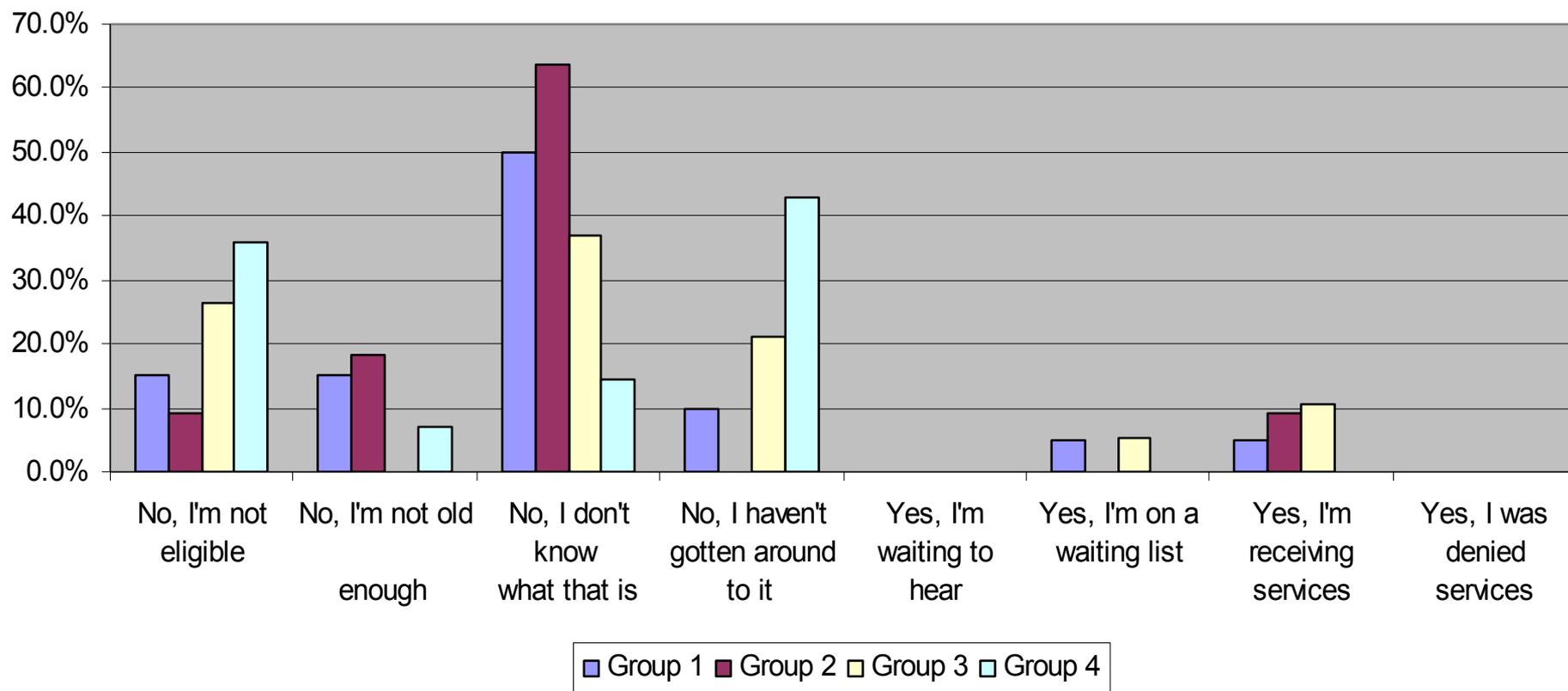
- Almost 25% of Group 2 and 20% of Group 3 are unaware of Sec. 8.
- While there is no internal evidence in the survey related to eligibility, past conversations indicate that many families don't understand that it is the income of the adult with autism that determines eligibility, not family income

Awareness of benefits, 18+: Public housing



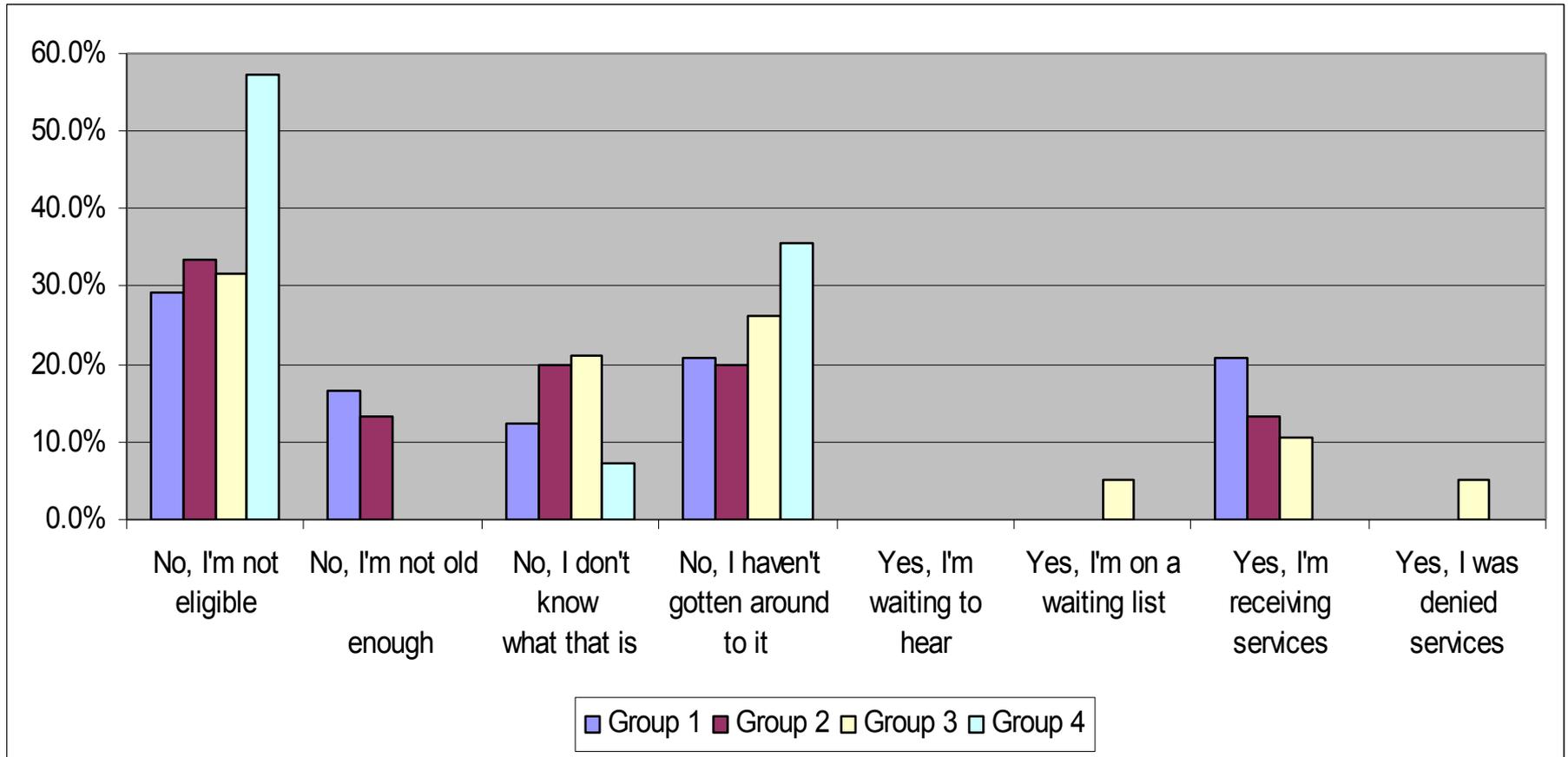
- Almost 35% of Group 2 and over 25% of Group 3 are unaware of public housing

Awareness of benefits, 18+: Private subsidized housing



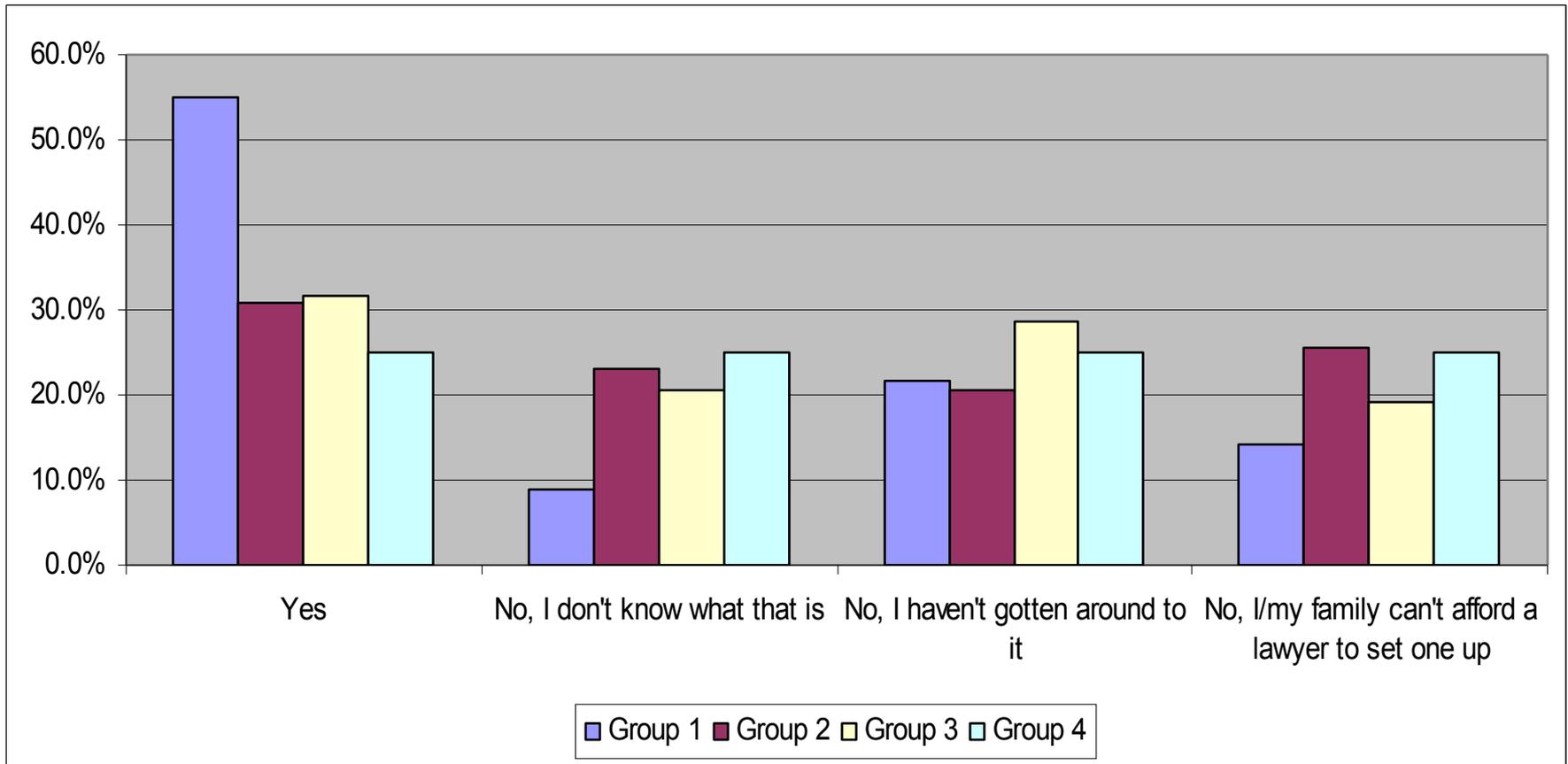
- Private subsidized housing is relatively unknown.
- While not “affordable” in the way that Sec. 8 or public housing is, it may be an important resource for those in Groups 3 and 4. One difficulty is that a family member can’t subsidize rent payments; the individual must have sufficient income to pay the rent

Awareness of benefits, 18+: Food stamps



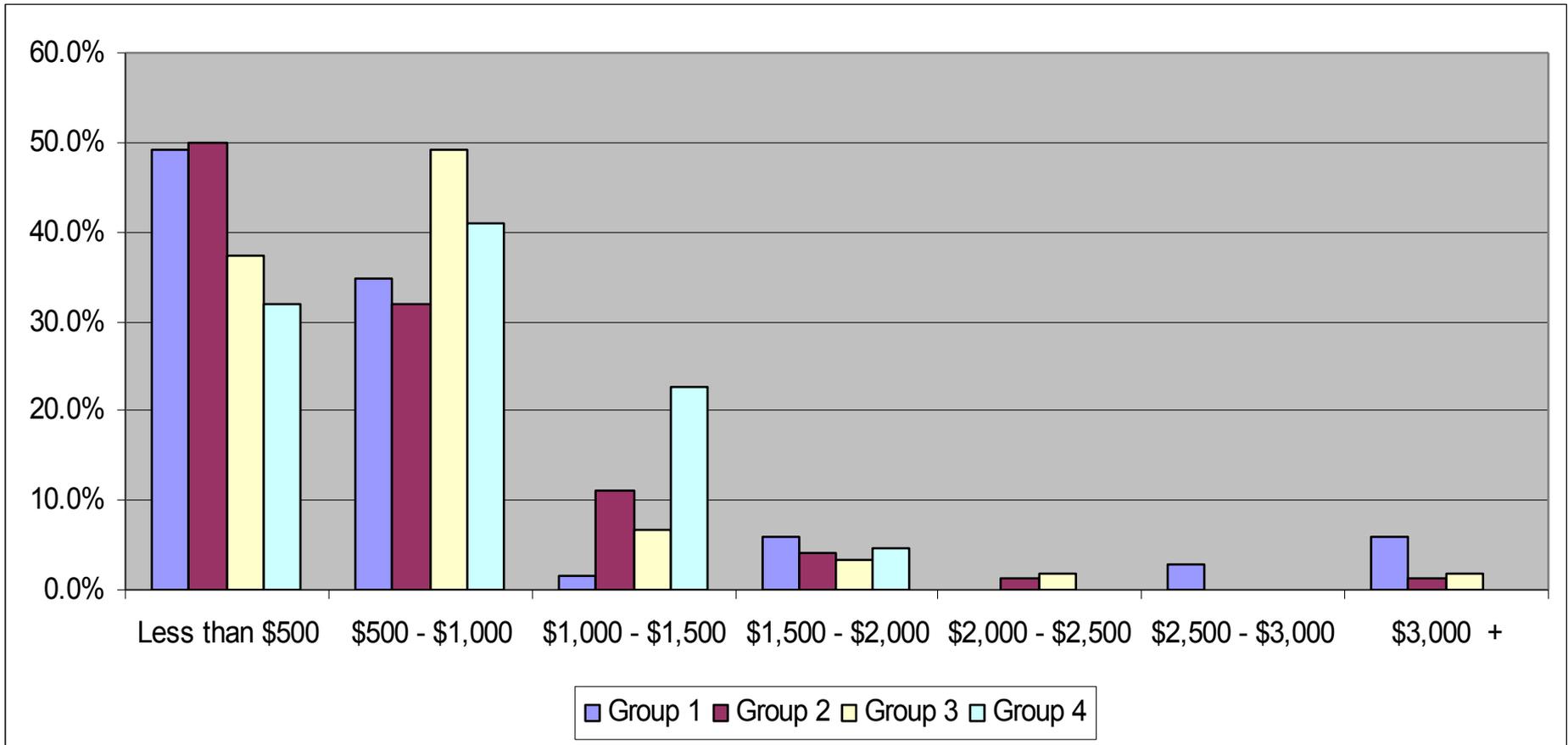
- About 20% of those in Groups 2 and 3 are unfamiliar with Food Stamps.

Special needs trusts



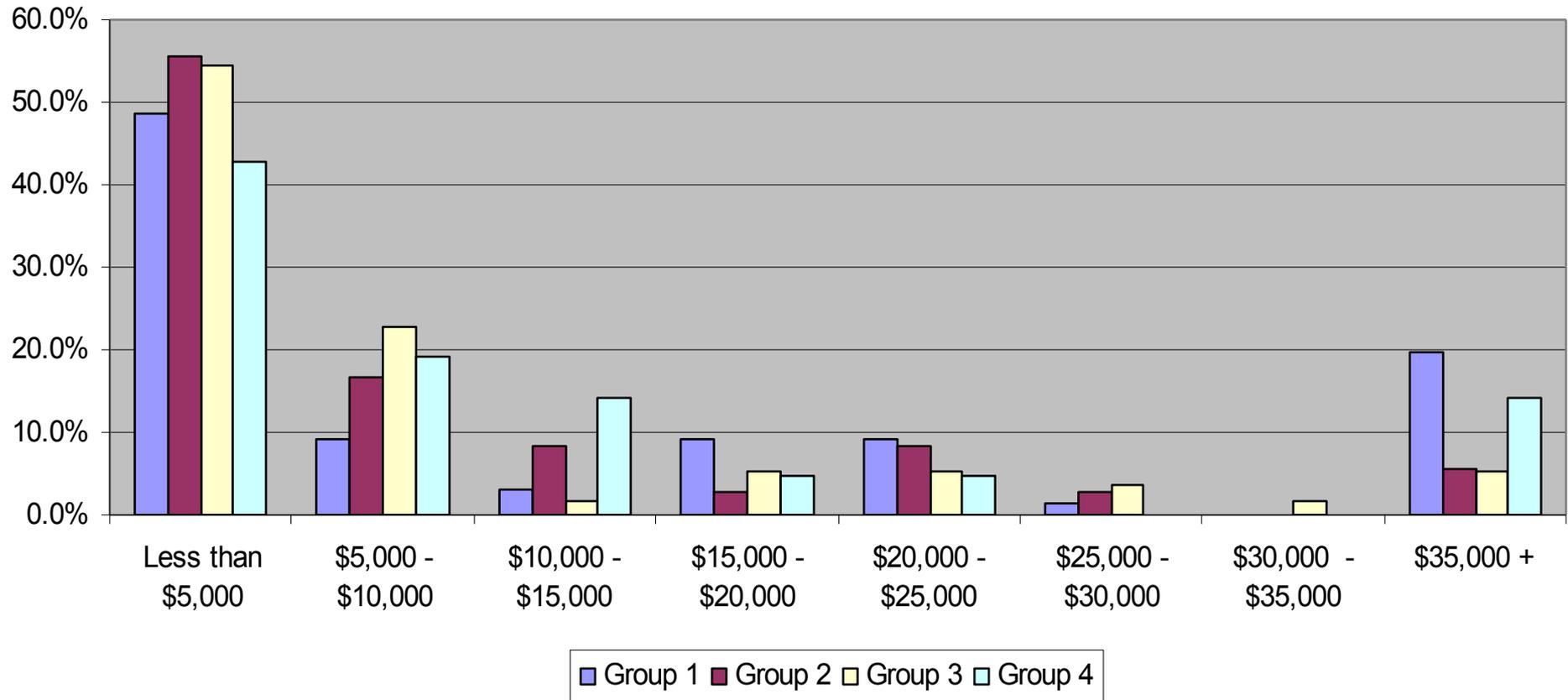
- Group 1 is reasonably aware of special needs trusts, but other groups are not so educated
- Given the percentage of those who can't afford to set up a trust, there may be a need for pro bono work on pooled trusts

Ability to pay for housing: monthly rent



- Between 30% and 50% of individuals in each group cannot afford even \$500 a month for housing
- Nonetheless, it is possible that options could be developed for the 30%-50% who can pay \$500-\$1,000/month. One model that could be adopted is that of Caritas Communities, which provides supervised single room occupancy housing

Ability to pay for housing: down payment



- 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.

Conclusions and implications

- There is a disconnect between existing need and available services, particularly for:
 - Those with intense behaviors but no intellectual disability
 - Those who need constant supervision, but can perform activities of daily living
 - Those who might be able to function well enough to afford market rate housing with the provision of life coaching

Conclusions and implications, cont'd.

- If it is true that the younger population is less likely to have an ID, it is even more urgent to develop additional residential supports beyond those provided by DDS; better data are necessary to establish whether this is the case
- There is a need to better educate individuals and families about supports that exist, particularly MassHealth state plan services

Conclusions and implications, cont'd.

- There is interest in, and potential for, “out of the box” solutions, such as family-driven group homes and mixed income housing; such solutions will require greater flexibility and a commitment to public-private partnerships
- Legislative and administrative initiatives can help:
 - The ABLE Act
 - The Real Lives Bill
 - Amending 40B to create an incentive for creation of group homes funded with MassHealth supports
 - Mass. participation in project rental assistance to state housing authorities through the reformed Sec. 811
 - Revamping MassHousing’s DDS/DMH set-aside program
- While “letting a million flowers bloom” will certainly improve individual outcomes, in the absence of new funding it is probably not scalable to fully mitigate the larger potential housing crisis over the next 20 years without development of “off-the-shelf” models; this was a key finding of the “Opening Doors” report

Conclusions and implications, cont'd.

- Training residential staff in autism-specific supports is essential to successful outcomes
- Modifying the built environment can improve outcomes



www.autismhousingpathways.net