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Autism McLean: Housing for Adults with ASD

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Autism McLean: Housing for Adults with ASD



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under the supervision of Frank Beck, PhD, of the
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Background

- In January 2020, six graduate students from the Stevenson Center at Illinois State University were assigned to conduct social research for Autism McLean, a local, volunteer organization that aims to promote the general welfare of children and adults with autism and to provide support for their families.
- The objective was to conduct an applied research project that met Autism McLean's needs while providing an applied education to service-minded students.
- The focus of the research was specifically on the housing assets and programs available in McLean County and whether those assets match the needs of people with autism.

Research Methods and Data Collection

- Literature review of autism-friendly housing matters
- Interviews with McLean County housing authorities and providers
- Online survey of parents of children with ASD of any age
- Focus groups with two (2) groups of parents of adult children ages 22 or older with ASD
- Semi-structured interviews with six (6) adults with ASD



Literature Review



Literature Review

Findings:

- Case Studies
- Common Challenges and Statistics
- Trending Themes and Recommendations

Case Studies:

- People with ASD and their needs
- Successful housing models
- Provide voice to families and their members with ASD on their needs

Common Challenges and Statistics:

- Need for dynamic process in resource attainment
- Global need for autism-friendly housing
- Individuals with ASD are more likely to have and spend twice as much on healthcare

Trending Themes and Recommendations:

- Attribute differences of people with ASD and their housing needs
- Recommendations for assisted living, campus housing, and building accommodations

Literature Review: Case Studies

Literature

- Charis Workhome (Mostafa 2010)
 - Architectural consideration of spatial attributes for housing for adults with ASD
- Social Living Complex (Doenyas 2016)
 - Five-year lease in "naturalistic learning environment" apartment with "buddy system" of children with and without ASD
- Sweetwater Spectrum (Holakiewicz)
 - Separation of accommodations and support service from housing so that if one falls through, the other does not

Key Findings

- Need to consider spatial: quality, organization, orientation, integration, and safety
- Need for: controlled visuals, lighting, sound, and odor as well as easy-to-use and easy-to-access amenities
- Success in "family-focused" model where neighborhood of families with and without ASD live nearby
- Success in "landlord and tenant" model where tenants find their own meal and transportation needs

Literature Review: Case Studies, continued

Literature

- Scotland's collaborative knowledge exchange (Jenkins et al 2014)
 - Communicate between housing and services providers with academia
- The Housing Options Council (Morey and Woolrych 2002)
 - Review the wants and needs of existing and potential services as well as of service development and provision
- Australia's transforming homes (Owen and McCann 2018)
 - House needs related to protection, feelings, and the making and unmaking of home

Key Findings

- Connect housing and service providers with academia to learn more about assets and limits
- Give people with ASD a voice to represent and advocate for self
- Home needs look like: locks and bells at the door, emotional and psychological experience with sensory spatial factors, and the management of micro-decisions such as a chore list

Literature Review: Common Challenges

Literature

- King and Bearman (2011)
 - Resource and diagnosis rates in California from 1992 to 2000
- Nagib and Williams (2017)
 - Found five design strategies for autism-friendly housing
- Rogge and Janssen (2019)
 - Economic challenges that families, individuals with ASD, and healthcare providers face

Key Findings

- Need to make the resource acquisition process “dynamic” and accommodating to the growing and changing population
- Need for housing design aspects of social and communication, sensory, imagination and perception, safety, and behavior
- Individuals with ASD are more likely to have and spend twice as much on healthcare within their lifetime

Literature Review: Statistics

Literature

- Steele and Ahrentzen (2015)
 - Surveys from Canada, Japan, UK, and U.S. from 1960 to 1999
- Dudley et al (2019)
 - Survey from North Carolina found a correlation between an individual's living situation and the unmet needs of adults with ASD
- Friedman, Erickson, Warfield and Parish (2013)
 - Adult with ASD transition from systems catered to children to ones for adults under the Individual with Disabilities Education Improvement Act

Key Findings

- 1-48% of people with ASD live (semi-) independently, while 22-93% live with their parents, showing the global need for autism-friendly housing
- 67.4% of youth with ASD do not attend system transition meetings, in comparison to the 49% of youth with other impairments that do attend
- Adults with ASD not living with their family were two to five times more likely to receive assistance in unemployment training, allied health, mental health services, and independent living skills
- Healthcare costs for those with ASD are up to seven times as much of those that do not have ASD

Literature Review: Trending Themes

Literature

- Robertson (2009)
 - Attribute differences of people with ASD
- Kinnaer, Baumers, and Heylighe (2014; 2016)
 - Attribute differences of housing in terms of neighborhood, housing type, layout, and interior

Key Findings

- People:
 - language, communication, and social interaction,
 - sensory processing,
 - motor skills execution,
 - goal oriented and reflexive thinking and planning
- Housing:
 - quietness versus reachability to other places,
 - detached housing versus apartments for privacy,
 - benefits between separate rooms versus a loft,
 - and keeping everything stowed away or displayed in the house.

Literature Review: Recommendations

Literature

- Felce et al (2011)
 - Interviewed care-givers working in assisted housing
- Atsmon, Yaakobi, and Lowinge (2019)
 - Architectural recommendations of building a house for people with ASD
- Ackles, Fields, and Skinner (2013)
 - Recommended accommodations for university students with ASD in campus housing

Key Findings

- Assisted Living looked at: rigidity of routine, block treatment, social distance between staff and residents, and depersonalization
- Recommend to build houses with
 - 1) acoustics reduce internal/external noise
 - 2) spatial sequencing for daily routine
 - 3) escape spaces for sensory neutrality and accessibility
 - 4) compartmentalization rooms for different purposes
 - 5) transitional spaces between activities
 - 6) sensory zoning
 - 7) safety
- Campus Housing looked at: scheduling early move-in days, providing support personnel, developing ways to assist students who are not conscious of their condition



Housing Provider Interview Findings



Housing Provider Interviews: Bloomington Housing Authority (BHA)

- Irvin Apartments (with MarcFirst)
 - Semi-independent (meals, personal assistance, transportation provided)
 - Individuals have jobs and are active in the community
- Barriers:
 - "There is very little supportive housing in general."
 - "I could envision many individuals with ASD thriving in non-supportive housing with a few simple accommodations and sporadic support."
 - "We have a few people on our staff with significant training, but not everyone is as prepared as they could be. I would like to see more staff, such as the maintenance department, receive basic training."

Housing Provider Interviews: MarcFirst

- Community Integrated Living Arrangements (CILA)
 - 24 hr/7 day support, overnight staff
 - 4-8 people per site, 10 sites
- Intermittent CILA
 - Less than 24 hr/7 day support
 - Medication, medical, activities, and daily living support
- Barriers:
 - Providers are underfunded. It is difficult to plan or provide services.
 - "Organizations are decreasing their capacity to serve. Even when individuals receive funding, there are no services available."

Additional Stakeholder Input: LIFE CIL

- Referrals to providers
- Advocacy for individuals with disabilities
- Offers medical equipment and customizable, amplified phones to encourage their clients' independence
- Barrier to clients:
 - "The PUNS list has about 8,000 people on it, so it could easily be a 5-year wait for funds."

Additional Stakeholder Input: Supportive Housing Provider Association (SHPA)

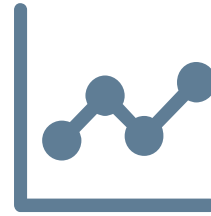
- 85 housing providers in IL
- Advocacy for support: finance, operation, and services
- Training for residential leadership alongside staff
- "The industry is more community-based now...but there is a need for all types of housing. This allows for choice. It offers an individual a setting for success."

Additional Stakeholder Input: Education

- Regional Office of Education (ROE)
 - Assists individuals with transitioning out of the high school system/services
 - "Families are often not ready to think about housing. They say they would never consider moving them, but that conversation can change in 5-10 years."
 - "I am concerned about the sustainability of independent living. It can be expensive, especially if the individual needs constant care."
- Illinois Report Card Data (2019)
 - 162 individuals with ASD in high schools in McLean County

Provider Interview Take-aways

- There is at least one option for housing at each level of care, but there are not enough units at any level.
 - Stakeholders are concerned about the feasibility and sustainability of increased independent housing options.
 - Frequent barriers to providers: funding, staff training, awareness
 - Frequent barriers to individuals: funding, transportation, minimal planning for future housing needs
- **Additional stakeholders, such as Homes of Hope, should be invited to the conversation once the pandemic is over**



Survey Results



Survey Results

Survey Respondents: 69

Son/daughter with ASD: 84

Individuals in family with ASD:

- One: 47
- Two or more: 15

Gender of those with ASD:

- Male: 62
- Female: 22

Age of those with ASD:

- 16 yrs & under: 45
- 17 - 21 yrs: 15
- 22 - 34 yrs: 21
- 35 - 54 yrs: 2
- 55 and older: 1

Where people with ASD live:

- With parents or family member: 77
- Independently or Semi-Independently: 6
- Other (Northern Illinois Academy): 1

Survey Results, continued

Race

- African American: 3
- Asian/South Asian: 5
- Caucasian/White: 51
- Hispanic/Latinx: 2

Income

- Under \$40,000: 10
- \$40,000-\$59,999: 8
- \$60,000-\$79,999: 8
- \$80,000-\$99,999: 13
- \$100,000-\$124,999: 8
- Above \$125,000: 7
- Prefer not to answer: 5

Zip Code

- 61701: 2
- 61702: 1
- 61704: 16
- 61705: 3
- 61723: 1
- 61725: 2
- 61728: 1
- 61747: 1
- 61752: 1
- 61753: 1
- 61761: 29

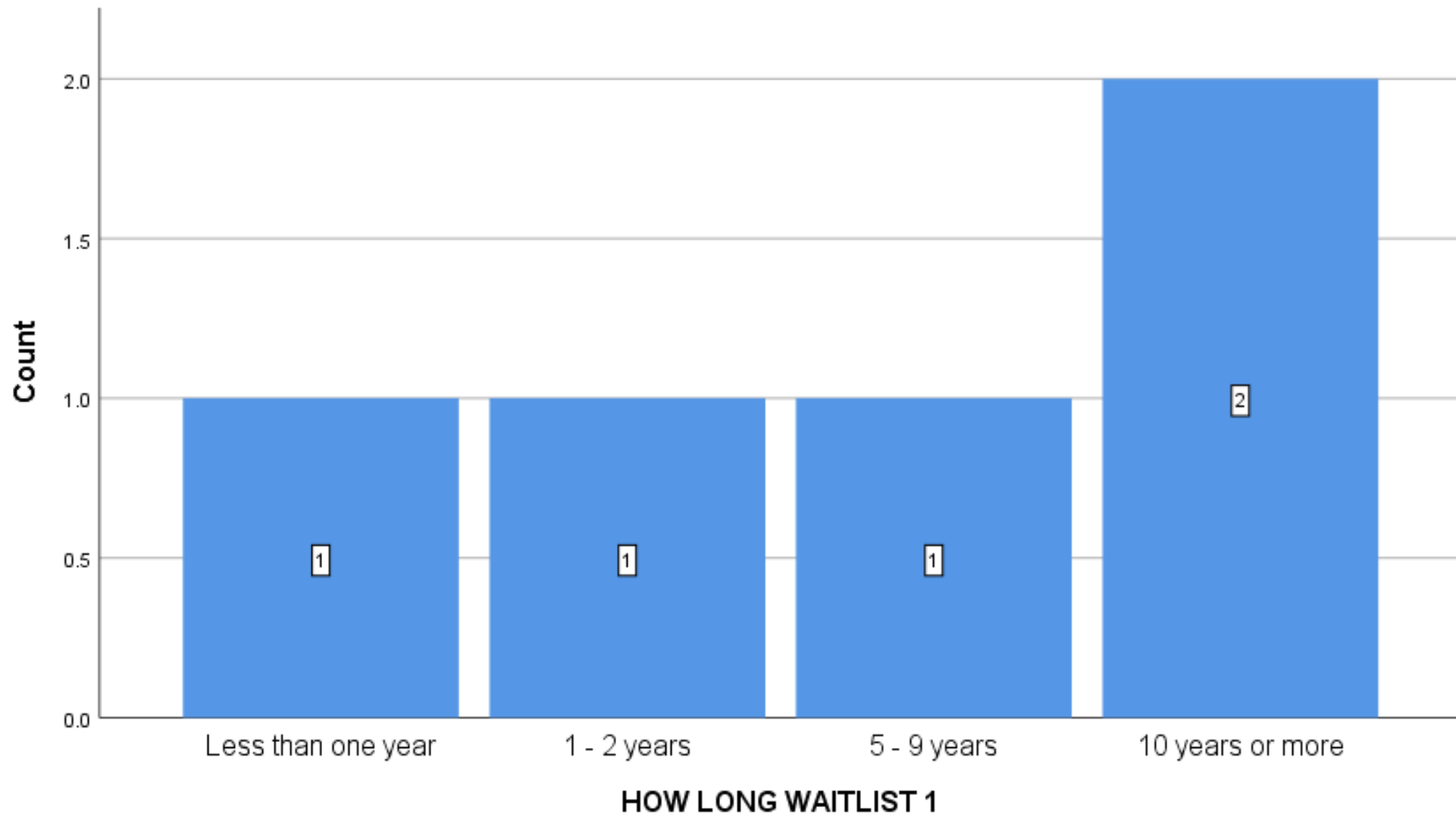
Are you presently seeking housing for your son or daughter with ASD?

#	Answer	%	Count
1	Yes	10.14%	7
2	No	89.86%	62
	Total	100%	69

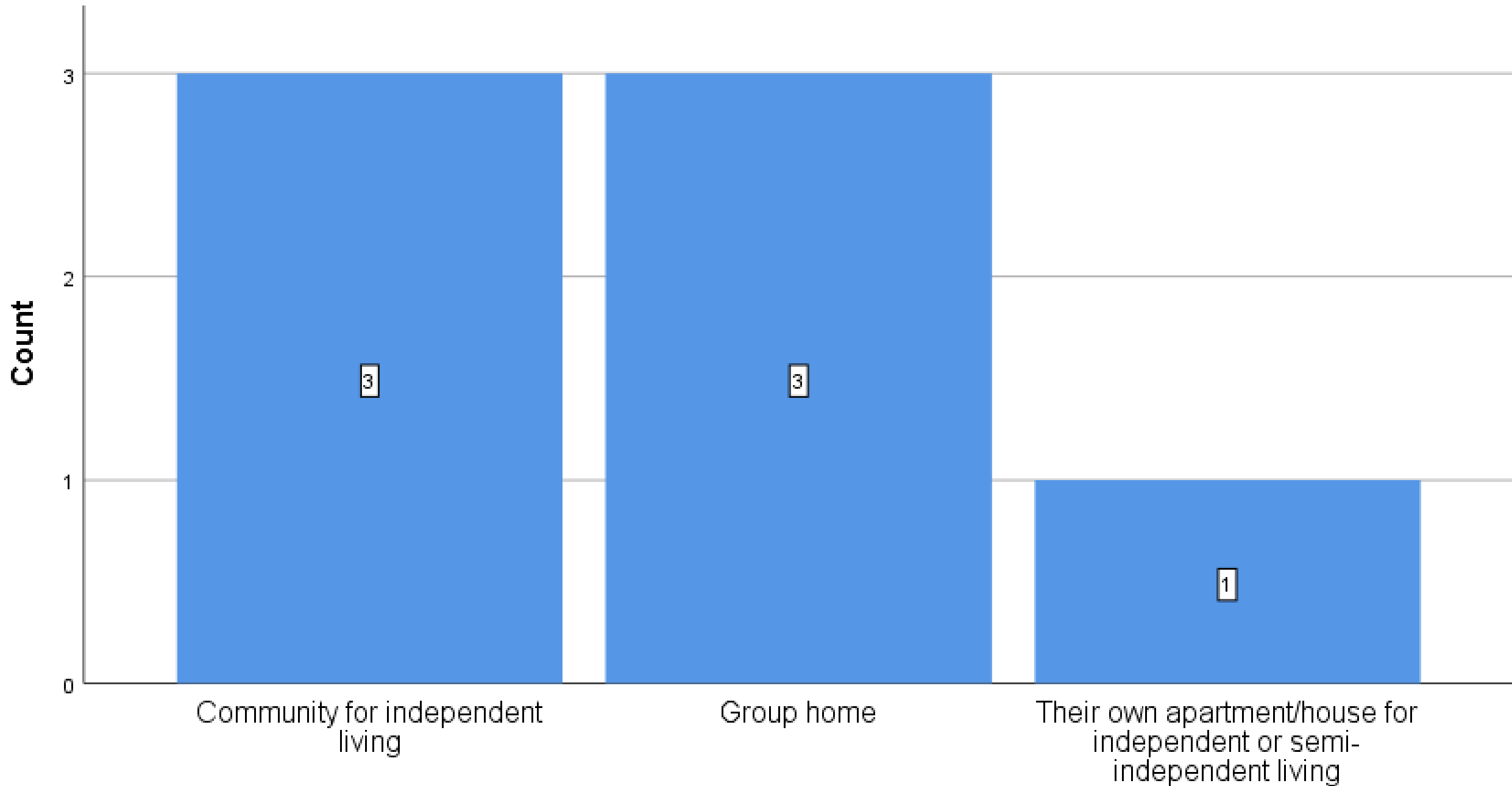
Families on Waitlist for Housing Assistance

#	Answer	%	Count
1	Yes	7.81%	5
2	No	92.19%	59
	Total	100%	64

HOW LONG ON WAITLIST

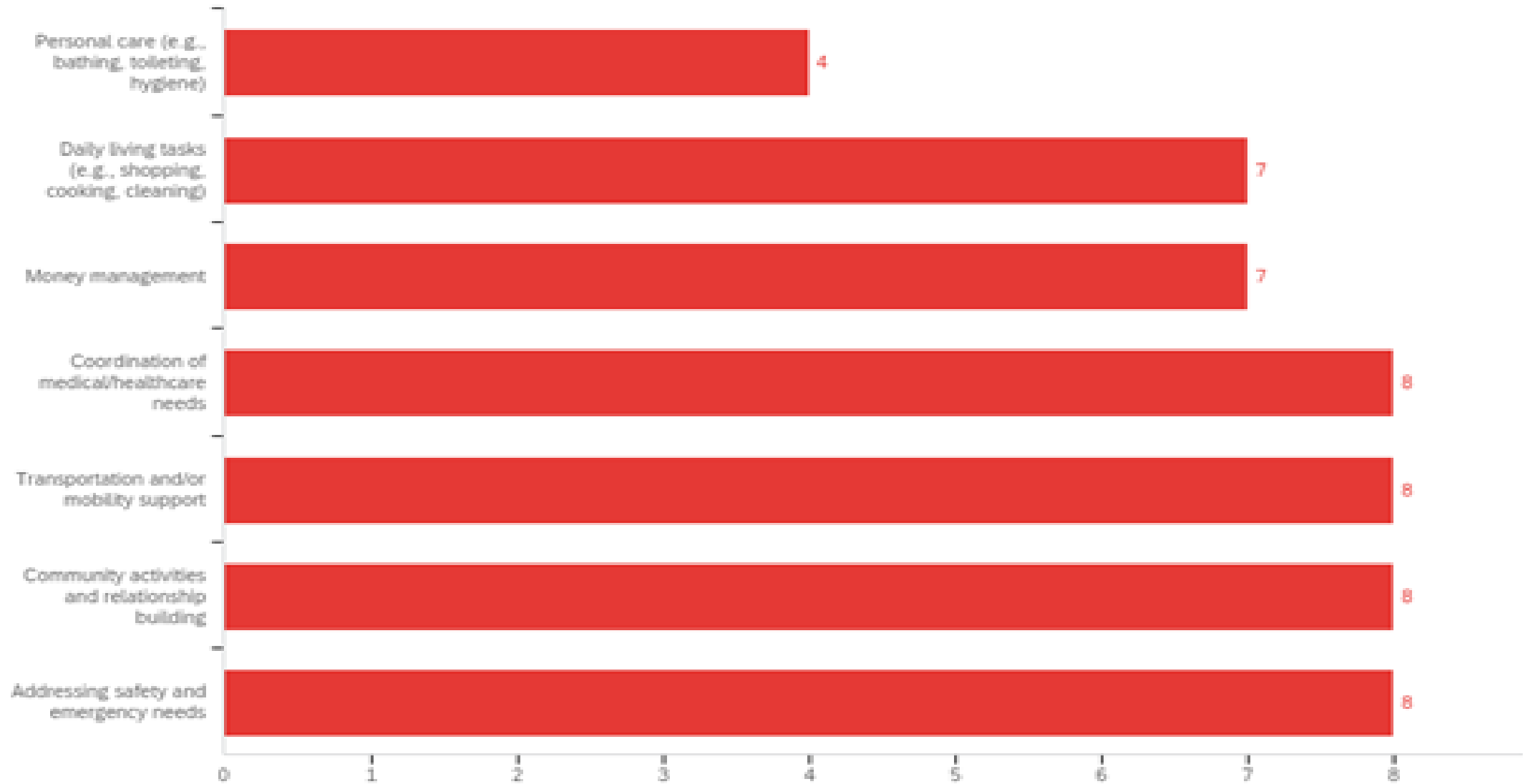


TYPE OF HOUSING BEING SOUGHT



TYPE OF HOUSING 1

Type Of Support Services



Does your son or daughter with ASD receive financial assistance from you or another organization for housing or residential services?

#	Answer	%	Count
1	Yes	49.28%	34
2	No	50.72%	35
	Total	100%	69

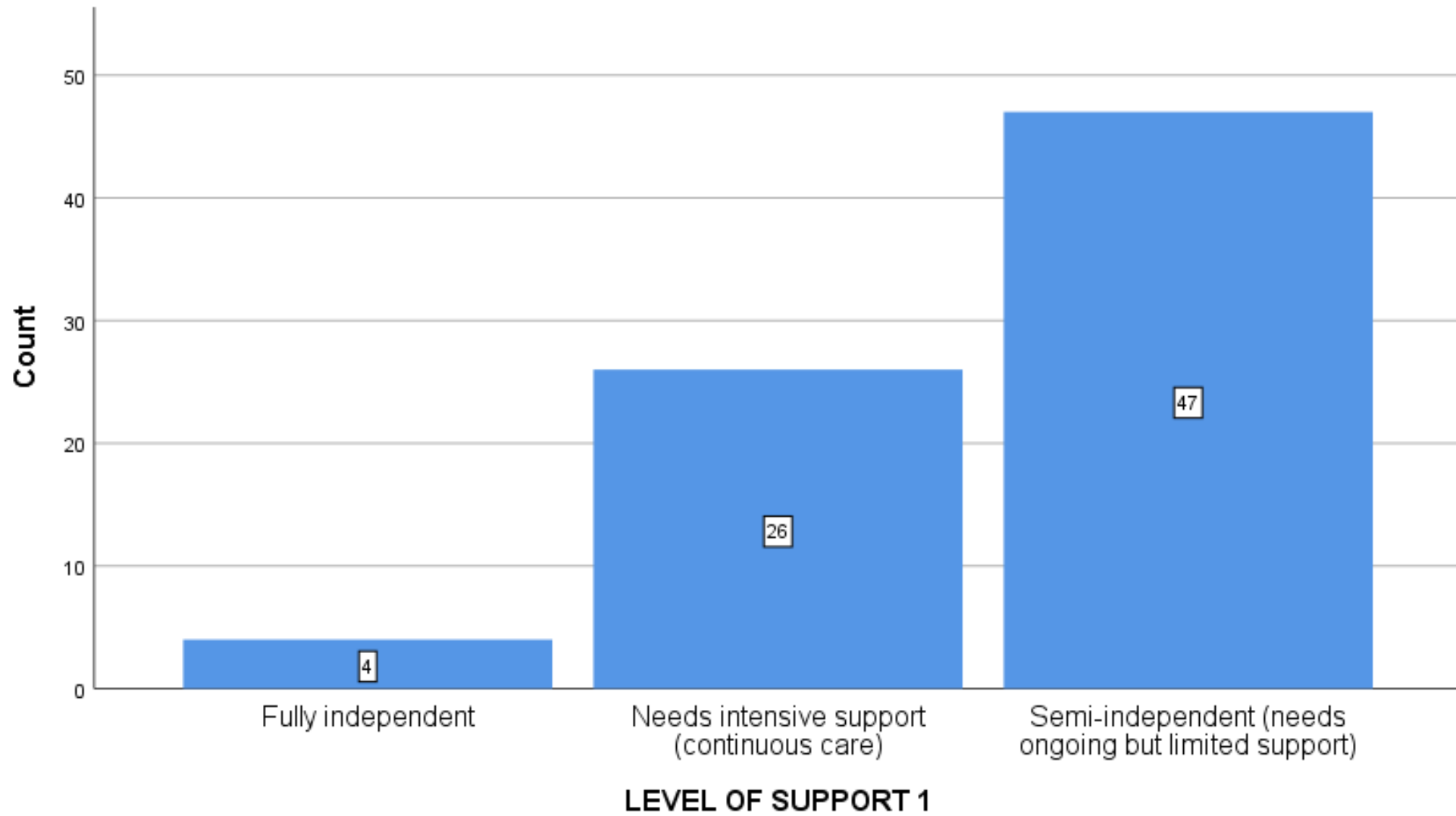
TYPE OF FINANCIAL ASSISTANCE

Count	Assistance from me or another family member Count	Assistance from me or another family member, Medicaid Count	Assistance from me or another family member, Medicaid , Other (please specify below) Count	Assistance from me or another family member, Medicaid , Social Security Insurance/Social Security Disability Insurance Count	Assistance from me or another family member, Medicaid , Social Security Insurance/Social Security Disability Insurance, Other (please specify below) Count	Assistance from me or another family member, Other (please specify below) Count	Assistance from me or another family member, Social Security Insurance/Social Security Disability Insurance Count	Medicaid Count	Medicaid , Social Security Insurance/Social Security Disability Insurance Count	Other (please specify below) Count	Social Security Insurance/Social Security Disability Insurance Count
46	8	2	2	3	1	1	9	1	4	1	10

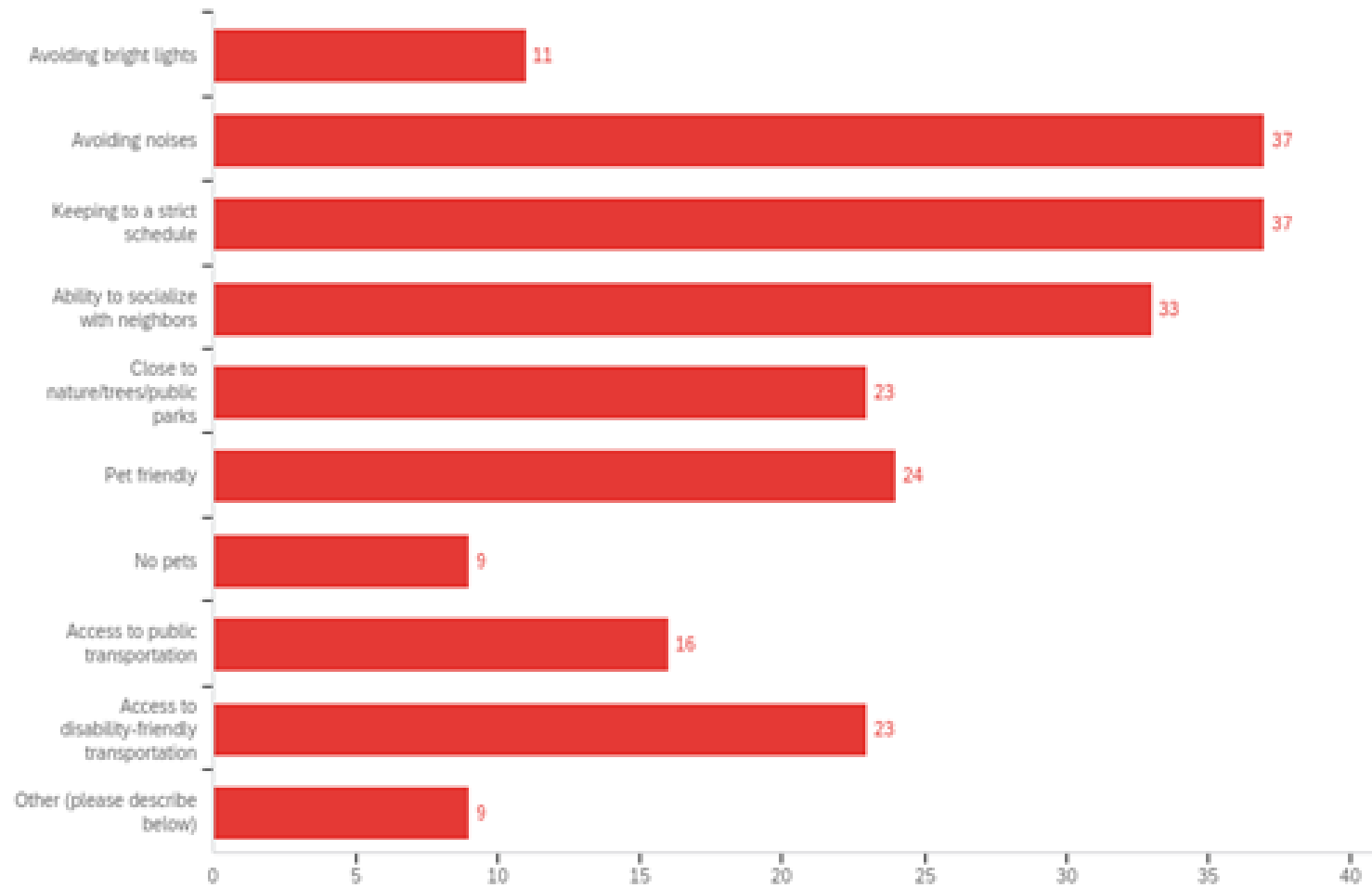
WHY NO FINANCIAL ASSISTANCE

Count	Other (please specify below) Count	They are able to work to support themselves Count	They are able to work to support themselves, They are funded by me or another family member Count	They are able to work to support themselves, They are funded by me or another family member,They have applied for assistance but are still waiting Count	They are funded by me or another family member Count	They are funded by me or another family member,They have been denied Medicaid or Social Security disability, Other (please specify below) Count	They are funded by me or another family member,They have been denied Medicaid or Social Security disability,They have applied for assistance but are still waiting Count	They have applied for assistance but are still waiting Count	They have been denied Medicaid or Social Security disability Count
53	6	2	1	1	19	1	1	2	2

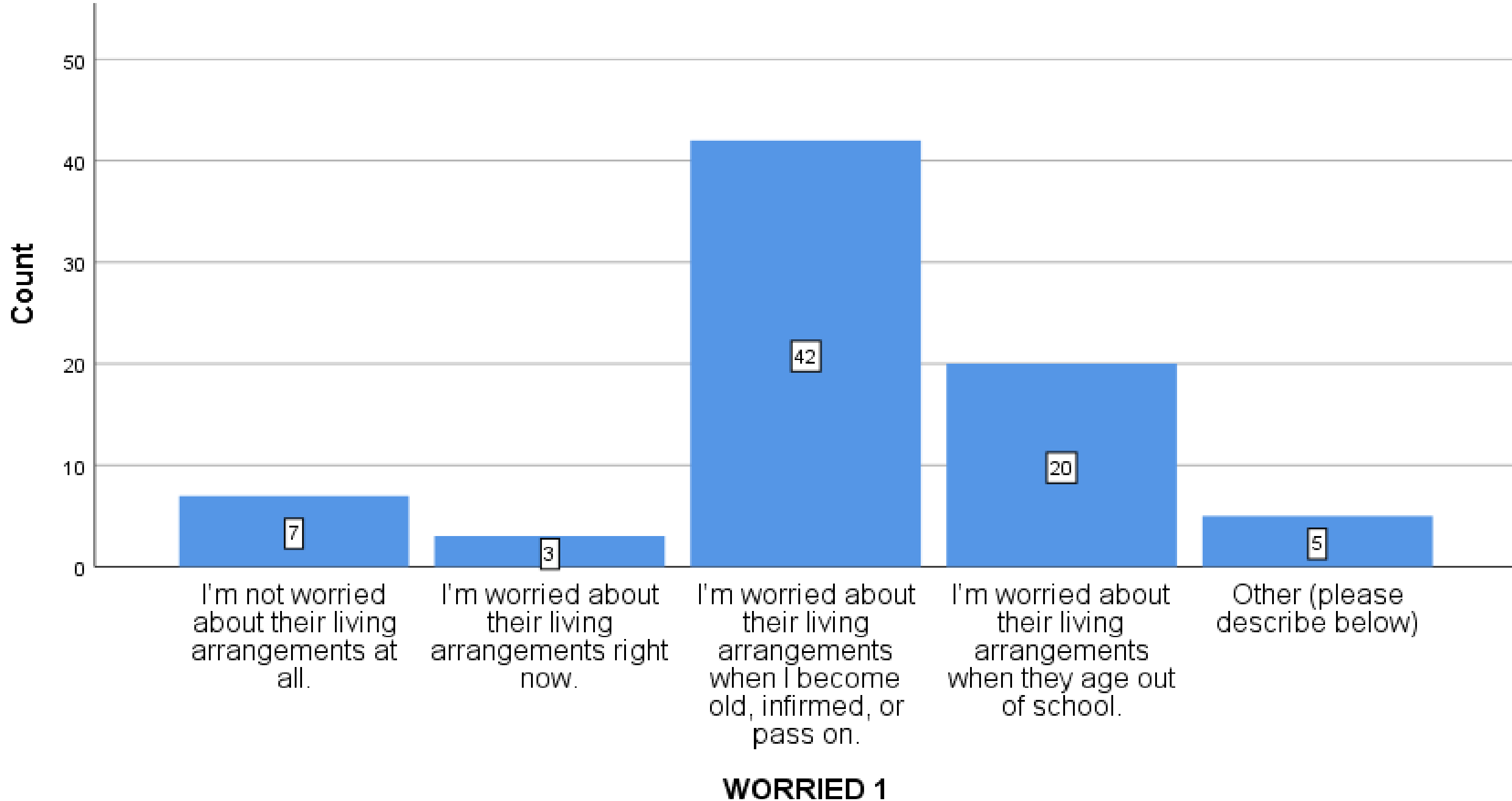
LEVEL OF SUPPORT NEEDED



HOUSING NEEDS



Worries about Son/Daughter Future Living Arrangement



On a scale of 1 – 10, how worried are you?

Parents who were worried:

- now reported being an 8 on the worry scale.
- when child ages out of school reported being an 7.75
- when they themselves are old, infirm or pass on reported being an 8.33

Only 7 parents were not worried at all.

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
WORRIED NOW 1_1	3	6	10	8.00	2.000
WORRIED AGE OUT 1_1	20	1	10	7.75	2.613
WORRIED OLD 1_1	42	3	10	8.33	2.008

Survey Takeaways

- 90% of families are currently not seeking housing
- Only 5 families are on housing assistance waitlist with time on waitlist ranging from less than 1 year to 10 or more years
- Half of families receive some form of financial assistance
- Most needed types of services concern healthcare, transportation, community, and safety
- Largest housing needs are avoiding noises, keeping a strict schedule, and socializing with neighbors
- Largest worry of parents is when they become old, infirmed or pass on



Focus Groups Findings



Focus Group Discussions

Focus groups consisted of two groups of parents (nine total) whose children are adults with ASD aged 22 and older. The following are housing-based priorities that participants provided:

- Access to **safe, reliable transportation** near housing
- Ensuring that **medical, safety, and other concerns are ameliorated**
- **Individualized living settings** which accommodate for everyone's cognitive, sensory, and social needs
- A desire for **housing intended solely for individuals with ASD**
- **Programs that facilitate and cultivate problem solving skills** for adults with ASD

Focus Group Discussions, continued

- Lack of opportunities for adults with ASD to interact in a safe social environment
- The burden of discovering, accessing and securing autism-friendly housing tends to fall upon individuals with ASD and their families in McLean County
- Funding sources fluctuate depending on a myriad of local, state and federal laws, waivers, and wait-lists
- Individuals with ASD face challenges that are unique to their own lived experience; accommodations must be in accordance with that individual's *specific* housing needs
- Lack of comprehensive, strategic planning amongst state government, service providers, and families of persons with ASD leads to confusion



Semi-Structured Interviews Findings



Semi-structured Interviews



Interview 1

- Lives with parents
- Works and drives
- Would like to find an apartment
- Loves to cook and wants a great kitchen



Interview 2

- Lives with parents
- Looking for a job before looking for housing
- “I liked living with a roommate during college. I want that connection again.”



Interview 3

- Soon to move into apartment with a friend
- Works on campus
- Public transit is a must
- Would like a “vent” room

Semi-structured Interviews



Interview 4

- Lives independently but near family
- Pet friendly accommodations are a high priority
- Does not like loud noises – loud voices in particular



Interview 5

- Enjoys living with parents
- Currently works
- Cooking limited to microwave
- Independent but would need parents help to look for housing



Interview 6

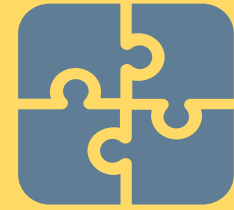
- Has been living independently for nearly a decade
- Found housing through a friend
- Qualifying for subsidized rent is a high priority

Interview Takeaways

- Interviews performed with high-functioning individuals
- Finding employment is an important precursor to finding housing
- Access to public transit is a high priority
- For some socializing and having roommates is important, for others isolation is preferred
- Like most people looking for housing for the first time, individuals with ASD rely on family, friends, and other social networks to locate housing rather than existing assistance programs



Recommendations for Autism McLean Leadership



- Encourage early testing for autism, the sooner a child is diagnosed the sooner parents can apply for assistance.
- Increase awareness around the existence of housing assistance and waiver programs. Encourage parents to apply for assistance as soon as possible.
- Develop trainings on common housing concerns for the autism community.
- Collaborate with schools and parents on distributing information – extend outreach to local government and service providers if possible.
- Collaborate with the SHPA on residential leadership programs.

For more information on housing...

- The Housing section of Bloomington's Comprehensive Plan
 - <https://mcplan.org/file/533/Chapter%203%20Housing.pdf>
- The Housing section of Normal's Comprehensive Plan
 - https://mcplan.org/file/226/Elements_Housing.pdf
- Executive Summary and Affordable Housing Study (p.37)
 - https://mcplan.org/file/493/2017_BN%20Home_Regional%20Housing%20Study_FIN_AL.pdf

**Stay tuned for SHPA's map of supporting housing in IL