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Choices and control in daily life and services among adults with autism using services
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Choices and control in daily life and services among adults with autism using services in the United States: the role of race and ethnicity

Abstract

This study explores how adults with autism exercise choice and control. Using the 2018-2019 National Core Indicator - In-Person Survey, it compares choices in life and everyday decisions between adults with autism and those with other developmental disabilities (DD) receiving services and examines differences across race/ethnicity within adults with autism. Results showed that adults with autism had fewer life choices than adults with other DD. Hispanic adults with autism had less choice in daily schedules, free time, and spending money than non-Hispanic Whites. Non-Hispanic Black adults with autism also showed less choice in daily schedules and free time, but reported having enough choices in these areas. The study highlights disparities among racial and ethnic minorities, underscoring the need for culturally sensitive and inclusive support strategies.

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Exercising choice and making decisions that align with individual desires and needs is an essential component of self-determination and closely linked to quality of life and personal wellbeing (Brown & Brown, 2009; Neely-Barnes et al., 2008; Wehmeyer, 2020). By equipping individuals with agency to guide their lives, they can actively participate and integrate into their community, thereby fostering a sense of belonging and purpose (Neely-Barnes et al., 2008; Shogren et al., 2015). People with disabilities who make their own decisions are more likely to have an internal locus of control, greater perceived self-efficacy, and greater knowledge and

awareness of oneself (Wehmeyer & Bolding, 2001). Driven by the disability movement (Barnes, 1992; Morris, 2006), there has been increasing attention on providing opportunities for people with intellectual and developmental disabilities (IDD), including people with autism,¹ to participate in decision-making about services and life choices in the United States (US).

Like all adults, adults with autism face major decisions regarding their living arrangements, employment, education, and social life. Many people with autism need specialized health care and supportive community services throughout adulthood (Shattuck et al., 2020). However, research has highlighted that adults with autism often experience less optimal outcomes in key life domains, including employment, residential independence, friendship and family relationships, and overall community participation, compared with people with other developmental disabilities (DD) or typically developing adults (Anderson et al., 2021; Howlin & Magiati, 2017; Mason et al., 2021; Roux et al., 2015; Song et al., 2021; Steinhausen et al., 2016). The growing number of individuals with autism aging into adulthood increases the urgency to describe and understand what factors reliably contribute to heterogeneity in outcomes and acquisition of independence in different life areas, thus extending the discussion about autonomy and self-determination to this population facing unique challenges.

Two studies have found that individuals' self-determination was positively associated with quality of life among adults with autism (Kim, 2019; White et al., 2018). A lack of choice in job selection and low self-determination were associated with difficulty obtaining and keeping employment among adults with autism (Haertl et al., 2013). Furthermore, a qualitative study revealed that adults with autism who chose to engage in preferred activities experienced greater enjoyment, social opportunities, and a sense of community involvement (Müller et al., 2008).

¹ We use person-first language in this article to adhere to the journal requirement.

These studies collectively underscore the importance of empowering adults with autism through exercising choices. Knowledge about experiences of adults with autism who may or may not have intellectual disability (ID) in making choices provides critical foundations for improving the practice of decision-making within this population, thus contributing to their independence and overall quality of life.

Much of our understanding of choice and its correlates comes from research on adults with IDD overall (Dinora et al., 2020; Houseworth et al., 2018; Tichá et al., 2012), with a few focusing on adults with autism. Utilizing National Core Indicator (NCI) data, two studies have shown that adults with autism receiving state-funded developmental disabilities services, including those with co-occurring ID, exercised lower levels of choice-making compared to individuals with other DD (Bush & Tassé, 2017; Mehling & Tassé, 2015). Bush and Tassé (2017), who studied adults with both autism and ID, found reduced autonomy in both short-term choices, such as free time, daily schedules, and purchases, and long-term choices, including living arrangements and case management. Similarly, Mehling and Tassé (2015), whose autism sample consisted of 80-90% individuals with ID, reported lower levels of self determination in areas such as free time, daily schedule, purchases, and dating, but no differences were found in exercising choices in staff and case manager. Bush and Tasse (2017) also noted a strong association between short-term choice-making and employment status, second only to the severity of ID. A key limitation of these studies is that they treated choice as a broad concept using aggregate scales, which failed to capture the nuances in different life areas and left a gap in comprehensively understanding the choice experiences of adults with autism. Analyzing each choice areas offers more precise insights into domain-specific patterns of autonomy and can guide interventions aimed at improving decision-making in specific areas, such as housing,

employment, or daily schedule. Moreover, these studies have not sufficiently examined how racial and ethnic backgrounds intersect with autism to influence choice-making, creating a critical gap in our understanding of how systematic, social, and cultural factors shape autonomy and decision-making.

Racial and ethnic background may further shape the choice-making experiences of adults with autism, as cultural identities can significantly influence how individuals perceive and experience exercising choices. For instance, family and community practices are pivotal in determining the autonomy of individuals with disabilities (Shogren, 2011; Wehmeyer et al., 2011). One study found that Hispanic youth with cognitive disabilities, including youth with autism, reported lower levels of autonomy (i.e., the feeling one has choices) than Black and White youth (Shogren et al., 2013). However, these patterns are not consistent as another study indicated that Black and Hispanic youth with autism had higher self-determination than their White peers (Shogren et al., 2021; Shogren et al., 2018). Furthermore, individuals from historically marginalized racial and ethnic groups often encounter barriers such as unequal access to healthcare, limited health knowledge, racial prejudices in providers, cultural stigma, and socioeconomic challenges (Bailey et al., 2017). These barriers contribute to the poorer quality of care received and further impact the service choice and decision-making processes of people with autism from historically marginalized groups. Given the sparse and inconsistent research available, our study seeks to deepen the understanding of how race and ethnicity affect autonomy and choice-making. Such research is essential to inform culturally responsive supports that accommodate the diverse needs of adults with autism across various racial and ethnic backgrounds.

This study uses a national sample of people with IDD receiving state-funded developmental disabilities services in the US from the 2018-2019 National Core Indicators In-Person Survey

(NCI-IPS) to address two aims. The first one is to explore the choice experience of adults with autism, with ID and without ID, and compare these experiences with their counterparts of other DD. The investigation potentially discerns any potential disparities and identifies areas for improvement to ensure that adults with autism can exercise choice as effectively as their peers with other DD. The second objective focuses on assessing racial and ethnic differences in the choice experiences among adults with autism. This examination will provide insights into any disparities related to race and ethnicity, offering an opportunity to implement culturally tailored interventions and strategies. Through this study, we strive to fill the existing research gap and contribute to a more nuanced understanding of choice experiences among individuals with autism.

Methods

Data and sample

This study examined the 2018-2019 NCI-IPS (Human Services Research Institute [HSRI] & National Association of State Directors of Developmental Disability Services [NASDDDS], 2020), a national survey of adults 18 years or older with intellectual and developmental disabilities using state-funded developmental disabilities services in the US. NCI is a collaboration between HSRI, the NASDDDS, and state-funded developmental disabilities (DD) agencies. It is created as a system-wide quality assurance and outcome analysis measure for state developmental disability systems on several indicators, including employment, choices, rights, service planning, community inclusion, and health and safety.

For 2018-2019 NCI-IPS, 37 states participated in the survey, and each state interviewed at least 400 randomly selected adults receiving at least one public service, in addition to case management, from their state development disability system. All data were gathered and

submitted by June 2019, before the COVID-19 pandemic. The sample size of 400 per state allows for statistically valid comparisons across states with a 95% confidence interval and a margin of error of $\pm 5\%$. It ensures that results are representative of the larger population. States select participants using simple random sampling, stratified sampling, or proportionate sampling, or a combination of these techniques. A stratified or proportionate sampling techniques are often based on service types, funding sources, race/ethnicity, or region. After stratifying, states use random sampling to choose participants.

The NCI-IPS consists of three sections that are completed. Background section includes demographic information, diagnosis and medication, and basic information about services used by the person with IDD. Data in this section were primarily gathered from the individuals' service records prior to the interview. Sections I and II were administered through face-to-face interviews by trained interviewers residing in the same region as respondents. Questions in Section I pertained to personal experiences (e.g., satisfaction and opinions) that required subjective responses and were only answered by the individual. Items in Section II that measured the community involvement, their choices, and access to services could be answered by the individual or by a proxy who knew the individual well (e.g., parent, caregiver, partner, family member, or staff). A proxy was only used when the individual was unable to respond to the question and the proxy was knowledgeable about the topic. Data for this study came from the background section and Section II of the NCI-IPS.

Our sample consisted of 4,253 adults with autism and 16,625 adults with other DDs. Individuals with autism were identified if a diagnosis of autism was listed in their service record, as identified in the background information section of the survey. Those without an autism diagnosis were categorized into the DD group. Both groups included individuals with and

without a diagnosis of intellectual disability. The demographics of the two groups are presented in Table 1.

Measures

Choice variables

Items were selected from the "Choice and Decision-Making" questions in Section II and included questions on Life Decisions and Everyday Choices. *Life Decisions* items included staff, choices of residence (if not living in family home), work (if had a paid community job), day program (if went to a day program or workshop), and roommate (if not living in family home or living alone). An additional choice item asked if the person could change their case manager/service coordinator if they wanted to (Yes, No). The *Everyday Choice* items included input in the daily schedule, personal spending money, and spending free time. All items (except for changing case manager/service coordinator) had three response options (person makes the choice or decides, the person has some input or has help deciding, someone else chooses or decides). Two additional questions asked participants if they had enough choice about what to do in their free time and in daily schedule (1=Yes, 0= No). Proxy responses were allowed for these questions.

Items related to choice of residence, work, day program, and roommate were only administered to individuals who were applicable (e.g., "choice of residence" was coded as Not Applicable [NA] for those living in the family home). Thus, we restricted analyses to participants eligible for that specific item. Consequently, the analytic sample size varied across items. This ensured that our item-level analyses accurately capture meaningful responses related to choice-making.

Race and ethnicity

Race and ethnicity were collected from existing administrative data records and were collapsed into the following four groups: non-Hispanic White (henceforth White), non-Hispanic Black (henceforth Black), Hispanic/Latino (henceforth Hispanic), and non-Hispanic multi/other (henceforth multi/other). Asian, American Indian or Alaska Native, and Pacific Islander were unable to be analyzed separately due to limited sample size.

Proxy status

Section II allowed for proxy response on a per-question basis, allowing for variability in the individual- versus proxy-response pattern. For each participant, we generated a specific variable to represent their proxy status. If 50% or more of the questions were answered by a proxy, the participant was classified under the "High Proxy Involvement" category. If less than 50% of the survey questions were answered by a proxy, the participant was classified under "Low Proxy Involvement". Proxy status was used as a stratification or control variable in the analysis, as there are potential differences in perspectives between individual responses and proxy responses.

Analytic Approaches

We examined the background variables for adults with autism and adults with other DD, using bivariable logistic regression to statistically compare the two groups accounting for the survey weighting. To examine the associations of individual versus proxy response, we investigated the same background variables by proxy status. To explore the choice experience of adults with autism compared to adults with other DD, we used multinomial logistic regression where each choice variable was the dependent variable and the disability group (autism or other DD) was the independent variable of interest while controlling for race and ethnicity, age (continuous), sex (male or female), intellectual disability (yes or no), and proxy status. Multinomial logistic regression was used in order to account for multiple response options, estimating relative risk

ratios (RRRs) with 99% confidence intervals (CI). RRRs are the ratios of the probability of choosing/deciding or having help choosing/deciding to the probability of having someone else decide/choose (i.e., reference category). An RRR greater than 1 means that the predictor is associated with a higher relative likelihood of being in the specified outcome category, where an RRR below one indicates a lower relative likelihood. Then, to explore racial and ethnic differences in choices among adults with autism, we repeated multinomial logistic regression within the autism group and highlighted associations with race and ethnicity while controlling for age (continuous), sex (male or female), intellectual disability (yes or no), and proxy status. RRRs were reported with 99% CI for racial and ethnic groups with the White group as the reference group. We applied a Bonferroni adjustment (adjusted $\alpha = 0.05/35 = 0.001$) to maintain appropriate control over Type I error rates.

Survey weights were used in all analyses to reflect the population of each state, approximating a nationally representative sample (HSRI & NASDDDS, 2020). All analyses were conducted in Stata 18.0.

Results

Sample characteristics

The weighted sample characteristics by disability group are presented in Table 1. Adults with autism were more represented in the younger age group (18-30) than adults with other DD (52.8% vs. 21.9%). Adults with autism were more likely to be male (75.3% vs. 53.5%), live with parents or relatives (47.5% vs. 35.3%), and have mental health conditions (75.7% vs. 58.5%; e.g., anxiety disorder, behavioral challenges). Adults with autism were less likely to have physical health conditions (8.3% vs. 14.9%), use mobility aids (8.3% vs. 27.5%), and use spoken language (69.5% vs. 81.9%). The percentage of adults without an ID diagnosis was higher in

adults with autism than in adults with DD (20.6% vs. 7.4%). Race and ethnicity were largely the same across groups.

In the examination of characteristics that differ by proxy status (Supplementary Material Table S1), we found several differences highlighting the importance of controlling for proxy status. White adults with autism were more likely to be in the low proxy involvement group. The high proxy involvement group was less likely to live in their own home or apartment (9.5% vs. 19.9%), have a paid job (18.6% vs. 36.5%), and use spoken language (52.7% vs. 94.0%). They were also more likely to receive 24-hour onsite paid support (55.9% vs. 38.0%). In terms of ID, the high proxy involvement group was more likely to have a moderate, severe, or profound ID than the low proxy involvement group. The high proxy involvement group was more likely to have behavioral challenges (57.2% vs. 20.3%), while the lower proxy involvement group was less likely to have other mental health conditions. No group differences were found in age, gender, general health status, and physical health conditions.

Choice of adults with autism compared with adults with other DD

Figure 1 illustrates the weighted descriptive findings for choice-making among adults with autism. Among life decisions, almost half or more than half of the adults with autism had someone else choose or decide for them in housemate (64.4%), where to live (54.0%), and day programs (49.3%). A relatively small percentage of adults with autism had someone else choose or decide for them in service staff (38.3%) and where to work (17.8%). About 86.6% of adults with autism could change their case managers or support coordinators if they wanted. Low percentages of having someone else choose or decide were observed in all everyday choices, including what to do with free time (8.0%), how to spend money (12.9%), and daily schedule (18.1%).

Figure 2 presents the adjusted relative risk ratios from weighted logistic regression in perceived choice and control between adults with autism and adults with other DD. We found that adults with autism were less likely to make choices in all life decision areas than adults with other DD. Specifically, they were less likely to choose staff by themselves (RRR=0.76, 99%CI[0.66, 0.92]), choose day program (RRR=0.69, 95%CI[0.54, 0.88], choose where they lived (RRR=0.65, 99%CI=[0.50, 0.84]), choose their housemates (RRR=0.67, 99%CI=[0.52, 0.86]), and choose where to work (RRR=0.68, 99%CI[0.47, 1.00]) than adults with other DD. They were also less likely to be able to change their case manager (RRR=0.79, 99%CI [0.65, 0.96]). Among everyday choices, adults with autism were significantly less likely than those with other DD to decide or choose daily schedule (RRR=0.80, 99%CI=[0.67, 0.97]). They were also less likely to choose how to spend money, although this result was only marginally significant (RRR=0.82, 99%CI=[0.69, 1.03]). However, no group differences were observed in choosing what to do with free time, if having enough choice in daily schedule, and if having enough choice in free time. It is also worth noting that the high proxy involvement group ($\geq 50\%$ of items answered by someone else) was consistently associated with the lower likelihood of making choices by themselves or with help compared to the low proxy involvement group across all outcomes except for if having enough choice in free time (Supplementary Materials Tables S2-S3).

Racial and ethnic differences in choice among adults with autism

Table 2 presents the findings of weighted logistic regression of choice-making by race and ethnicity among adults with autism. In life decisions, compared to White adults with autism, Black adults with autism were less likely to have help choosing their day program (RRR=0.60, 99%CI[0.39, 0.92]). Hispanic adults with autism were less likely to change staff if requested

(RRR=0.60, 99%CI[0.36, 1.00]) and be able to change case managers (RRR=0.41, 99%CI[0.24, 0.71]). Adults with autism from other races were also less likely to be able to change case manager (RRR=0.51, 99%CI[0.28, 0.92])..

Among everyday choices, Hispanic adults with autism were less likely to decide or have help deciding their daily schedule and what to do with free time, and choose or have help choosing how to spend money than their White counterparts (see Table 2). They were also less likely to have enough choice in their daily schedule (RRR=0.49, 99%CI[0.25, 0.96]) and marginally less likely to have enough choice in free time (RRR=0.50, 99%CI[0.24, 1.04]). Lastly, Hispanic adults with autism were less likely to choose how to spend money (RRR=0.44, 99%CI[0.24, 0.80]). Black adults with autism were also less likely to decide or have help deciding their daily schedule and what to do with free time than White adults with autism. However, they indicated enough choices in these areas comparable to that of White adults with autism. Similarly, adults with autism from other races were also less likely than White adults with autism to decide or have help deciding daily schedule and what to do with free time. Like Black adults with autism, they indicated enough choices in these areas comparable to that of White adults with autism. It is worth noting that among significant findings, comparison of adults with autism and those with DD showed RRRs ranging from 0.65 to 0.82, while racial and ethnic comparisons within adults with autism show some larger disparities, with RRRs ranging from 0.17 to 0.63.

Discussion

Freedom to make choices is fundamental for individuals with autism and should not be taken for granted. The central aim of our study was to assess the extent of choice and control adults with autism who receive state-funded DD services, the majority of whom have a co-occurring diagnosis of ID, have in life decisions (i.e., who to live with, where to live, where to work, staff

members, case manager, work, and day program) and everyday choices (i.e., one's daily schedule, free time, and personal money), which is imperative to guide the development of policies that support personal choice and independent living within the community. First of all, choices were markedly lower for life choices than for everyday decisions among all adults with autism, reflecting the greater systematic control typically exerted over housing, employment, and service arrangements. Limited say in these high-stake areas may constrain long-term opportunities for community inclusion, financial advancement, and self-determination. Second, our study found that compared to adults with other developmental disabilities receiving the state-funded DD services, adults with autism reported having fewer choices in key life decisions but showed no differences in everyday choices. Notably, the differences typically fell in a small to moderate range (RRRs ranging from 0.65 to 0.82), where our subsequent race and ethnicity analyses showed relatively larger gaps (RRRs ranging from 0.17 to 0.63; Chen et al., 2010), underscoring even greater disparities within the autism population. Lastly, when considering race and ethnicity, our study revealed that racial minorities, especially Hispanic adults with autism, were less likely to have control over the service aspects of their life decisions and have limited everyday choices compared to their White counterparts. Our examination of differences in choice and control across life decisions and everyday decisions revealed distinct patterns for adults with autism compared to those with other DD. Adults with autism were generally less likely to exercise choice in all major life decisions and some everyday choices (i.e., daily schedule and how to spend money). The lower level of choice in life decisions is likely due to constraints from environmental and systemic constraints, such as housing policies, financial limitations, service accessibility, and support network (Houseworth et al., 2018). For adults with autism who are not living in the family home, decisions regarding residence and roommates are often shaped less by

personal preferences than by the availability of affordable, neurodiverse-friendly housing options, eligibility for autism-specific services, and financial constraints that may respect their options more sharply than those faced by adults with other DD. Additionally, previous studies using NCI data consistently found that residence types (e.g., living in one's own home, with family, or living in agency-operated settings) were associated with choices in life decisions among adults with IDD (Lakin et al., 2008; Tichá et al., 2012). Almost half of the adults with autism in our sample lived with family members (47.5%), significantly more than adults with other DD, which may lead to prioritizing collective decisions and being less oriented to individuals in terms of life decision and everyday choices of the family member with autism, especially when family members have low expectations of individual autonomy and independence. Future research could explore how distinct, family-centered living arrangements interact with family dynamics and autonomy expectations of adults with autism differently than other DD groups, offering insights into targeted intervention and services that promote greater self-determination.

Furthermore, communication differences may further explain the different levels of choices between adults with autism and other DD. Although our study did not directly investigate this relationship, previous research suggests a positive correlation between the use of verbal communication as the primary means of communication and a broader range of life choices among people with IDD (Houseworth et al., 2018; Tichá et al., 2012). In our sample, a smaller percentage of adults with autism used verbal communication (69.5%) compared to those with other DD (81.9%). Because people with limited speaking communication abilities are often disadvantaged in effectively expressing their needs, preferences, and choices, this may lead to the needs of individuals with limited verbal communication being misunderstood or overlooked,

resulting in choices that may not fully align with their true desires and interests. Developing or enhancing staff training, implementing flexible service models, and proactively involving people who use augmentative and alternative communication in care planning could be critical steps toward reducing communication-related disparities. Future research could explore whether and how augmentative and alternative communication methods might address the disparities in choice-making by enabling individuals with limited verbal communication to more effectively express their preferences and needs.

The second purpose of the study was to examine the role of race and ethnicity in choice and control among adults with autism. Our findings indicated significant variations in both life decisions and everyday choices between White adults with autism and those from other racial groups, particularly the Hispanic community. Hispanic adults with autism were less likely to make everyday choices, on their own or with help, including deciding daily schedules, what to do with free time, and how to spend money, than their White counterparts. Prior studies have revealed that Hispanic youth with disabilities tended to score the lowest in levels of self-determination (Shogren et al., 2013; Shogren et al., 2018), although racial/ethnic differences remain inconsistent within adults with autism (Cheak-Zamora et al., 2019). One possible explanation lies in the family context within many Hispanic communities, where a collective, family-oriented approach to decision-making is common. In such settings, decisions impacting an individual are often forged through familial consensus rather than reflecting personal preferences; while this approach can offer strong support, it potentially limits the expression of individual autonomy and self-determined behaviors (Wehmeyer et al., 2011).

It raises concerns when Hispanic adults with autism reported that they did not have enough choices in their daily schedule or free time. There is no inherent contradiction between valuing

collective decision-making within the broader familial framework and fostering individual autonomy. In many Hispanic families, autonomy is exercised within a close, interdependent family network where individuals' preferences are actively weighed and considered alongside the family's overall needs and values (Roche et al., 2014). However, in our data, Hispanic adults with autism often felt their preferences regarding daily schedules and free time were not adequately taken into account. This may reflect a paradox between cultural ideas and lived experiences, underscoring the need to prioritize the voice and choices of Hispanic adults with autism and ensure that their preferences are heard, understood, and meaningfully incorporated into everyday decisions. Consistently feeling that one's choices or desires are overlooked or not respected can lead to feelings of frustration, depression, and anxiety, particularly for adults with autism who might already face challenges in articulating their personal choices (Cribb et al., 2019). Thus, when Hispanic adults with autism explicitly report insufficient choices, service providers should balance collective cultural values with strategies that enable Hispanic adults with autism to participate actively in decisions about their daily lives. For example, developing family-centered service plans that respect cultural values while actively encouraging self-advocacy can help Hispanic adults with autism feel heard and respected in everyday routines. Providers could also engage in ongoing cultural competence training to recognize and address implicit biases that limit opportunities for meaningful choice-making.

In our study, Black adults and adults with autism from other races were less likely to choose daily schedules and what to do with free time, similar to the trends observed in Hispanic adults with autism. A notable difference, however, was that Black autistic adults reported a level of enough choice in these areas comparable to that of Whites, whereas adults with autism from other races indicated a lower level of sufficiency in decision-making regarding free time. This

suggests that perceptions of choice-making and autonomy may vary across different racial and ethnic groups. While underlying factors that influence these different perceptions are unclear, a qualitative study revealed that Black youth with IDD tended to have low expectations of their ability of decision-making (Taylor et al., 2023). This internalized perception might lead to a reluctance to make decisions and reduce opportunities to practice self-determination. These findings highlight the need for more research to better understand how cultural and social factors influence the perception and practice of autonomy among autistic adults with diverse backgrounds.

Another key finding of the study is a significant disparity in choices of services (e.g., case manager, staff, and day program) among racial and ethnic groups. Specifically, Hispanic were also less likely to change staff if requested, change case managers, or choose day programs with help; adults with autism from other races were less likely to choose day program; Black adults with autism were less likely to choose day program with help than White adults with autism. While all NCI-IPS participants were already receiving developmental disabilities services, Hispanic individuals may face systematic barriers that affect the quality and breadth of services they can access (Smith et al., 2020), such as language differences (St. Amant et al., 2018), limited knowledge of available service (Ferguson & Vigil, 2019), and residential areas with fewer resources (Liu et al., 2023). Broader issues of discrimination and systematic bias within healthcare and social services further compound these limitations, restricting autonomy and control over services for all racial and ethnic groups. Addressing these structural barriers requires targeted policy initiatives, such as expanding culturally informed decision support, allocating resources to underserved areas, and increasing access to evidence-based and culturally competent practices in the native language, to bolster opportunities for service choices. Collaboration

among service staff, family members, and self-advocates from diverse backgrounds can promote more equitable access and outcomes, ensuring all individuals can exert meaningful control over their support.

Limitations

NCI-IPS presents a valuable opportunity to examine the needs of adults with intellectual and developmental disabilities across the US. It is one of the rare data collection efforts in the US that focuses on this population. However, the NCI-IPS is not a representative sample of all adults with autism; it consists of individuals receiving support through the state developmental disabilities services systems. These systems typically serve individuals with more significant support needs, and eligibility criteria in many states require a co-occurring diagnosis of ID (Carey et al., 2023). In our sample, 79.4% of adults with autism had a documented ID diagnosis. This proportion is substantially higher than the estimate from population-based autism research, which suggests that approximately 39.6% of the population have co-occurring ID (Shaw et al., 2025). Thus, findings of this study should be interpreted as applying to adults with autism receiving state-funded DD services, particularly those with higher support needs, and may not generalize to the broader population with autism, including those who are not eligible for or do not utilize state-funded services. Moreover, race and ethnicity are collected from service records and may have been recorded by many means, including staff perception. The small sample size of certain groups also precluded analysis of some racial and ethnic populations.

Furthermore, although the NCI-IPS provides a structured way to assess choice and control, its scope is limited to a relatively narrow set of decision domains. Many other meaningful areas of autonomy, such as romantic relationships, healthcare decisions, transportation options, and how to participate in the broader community, are not included. Thus, the findings presented here

likely provide an incomplete picture of how adults with autism experience autonomy across diverse aspects of their lives and point to the need for future data collection efforts, including qualitative data, that capture a broader spectrum of decisions relevant to individuals with autism.

Lastly, we explored the impact of proxy status on choice but were likely unable to account for the full implication of proxy status in the analysis. Having proxies available to answer questions provides data from some people for whom data otherwise might not be available. The approach of dichotomizing high versus low proxy involvement was a necessity for data dimensionality reduction, as there were more than 20 questions that could have been answered by a proxy. However, the relationship between the proxy and the surveyed individual remains unknown. Future work may further examine proxy involvement on a per-question basis to fully explore the impact on responses and incorporate information about proxy identity (e.g., family vs. staff) to refine these estimates.

Conclusion

This study highlights critical disparities in the autonomy and choice-making of autistic adults, particularly emphasizing the role of racial and ethnic backgrounds. The findings reveal that autistic adults often have limited choices in major life decisions, a situation exacerbated for those from minority racial and ethnic groups. These insights suggest a hypothesis that adopting more inclusive, culturally responsive approaches to supporting autistic individuals could potentially reduce racial and ethnic differences, which warrants further investigation in future research. Recognizing and addressing these disparities is crucial for enhancing the quality of life and independence of autistic adults. Future research and practice should focus on developing targeted strategies that acknowledge and bridge these gaps, ensuring equitable access to choice and control for all autistic adults. The study underscores the importance of prioritizing the voices and

choices of autistic adults from diverse backgrounds to enhance their quality of life and independence.

Supplementary Materials

Supplementary Tables S1-S3 are available at <https://atrproject.org/wp-content/uploads/2025/06/Supplementary-Material-Table-1-3.pdf> or upon request from the corresponding author, W.S.

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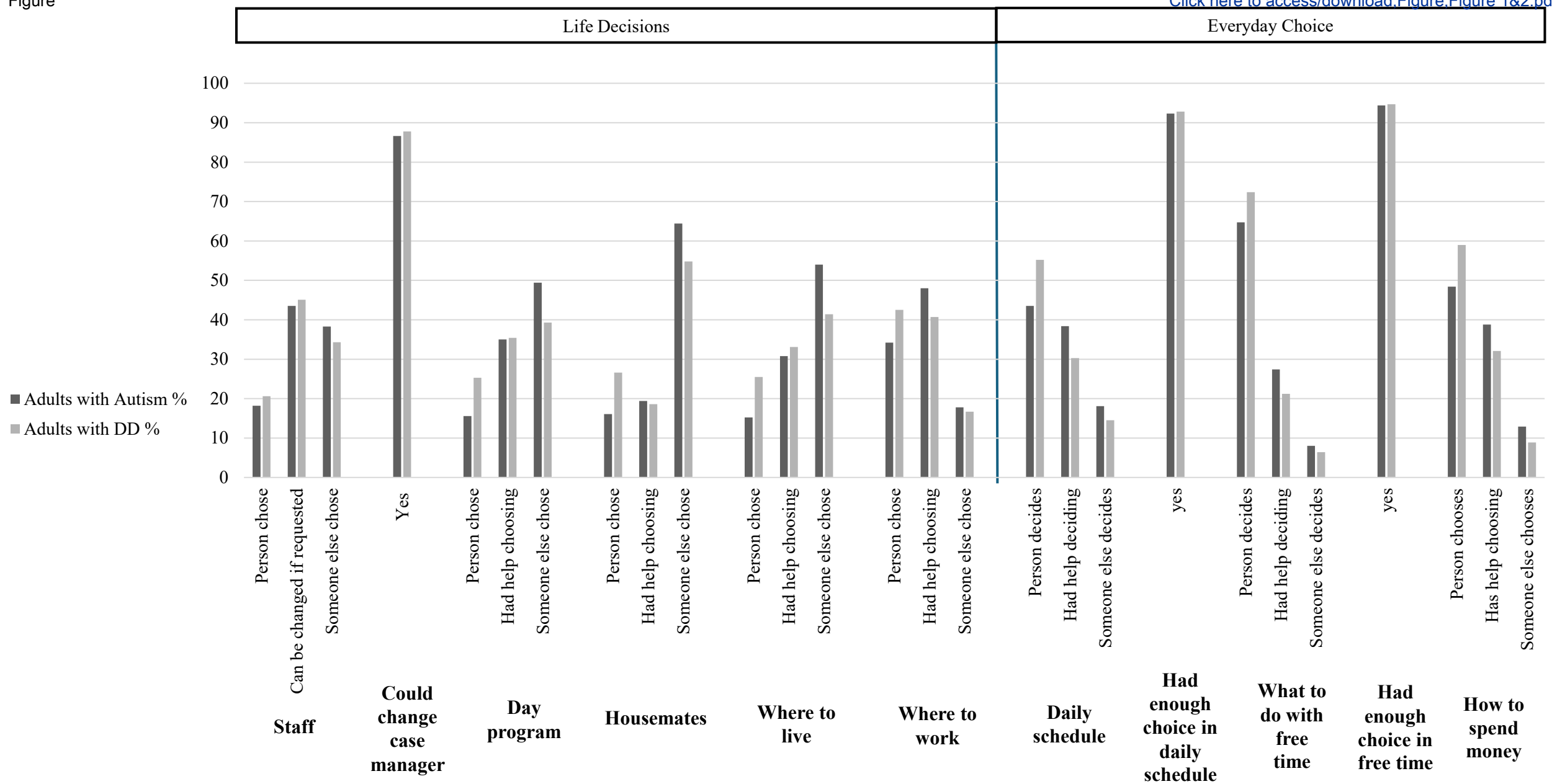


Figure 1. Percentages of adults with autism report having choices in life and everyday decisions compared to adults with other developmental disabilities (DD)

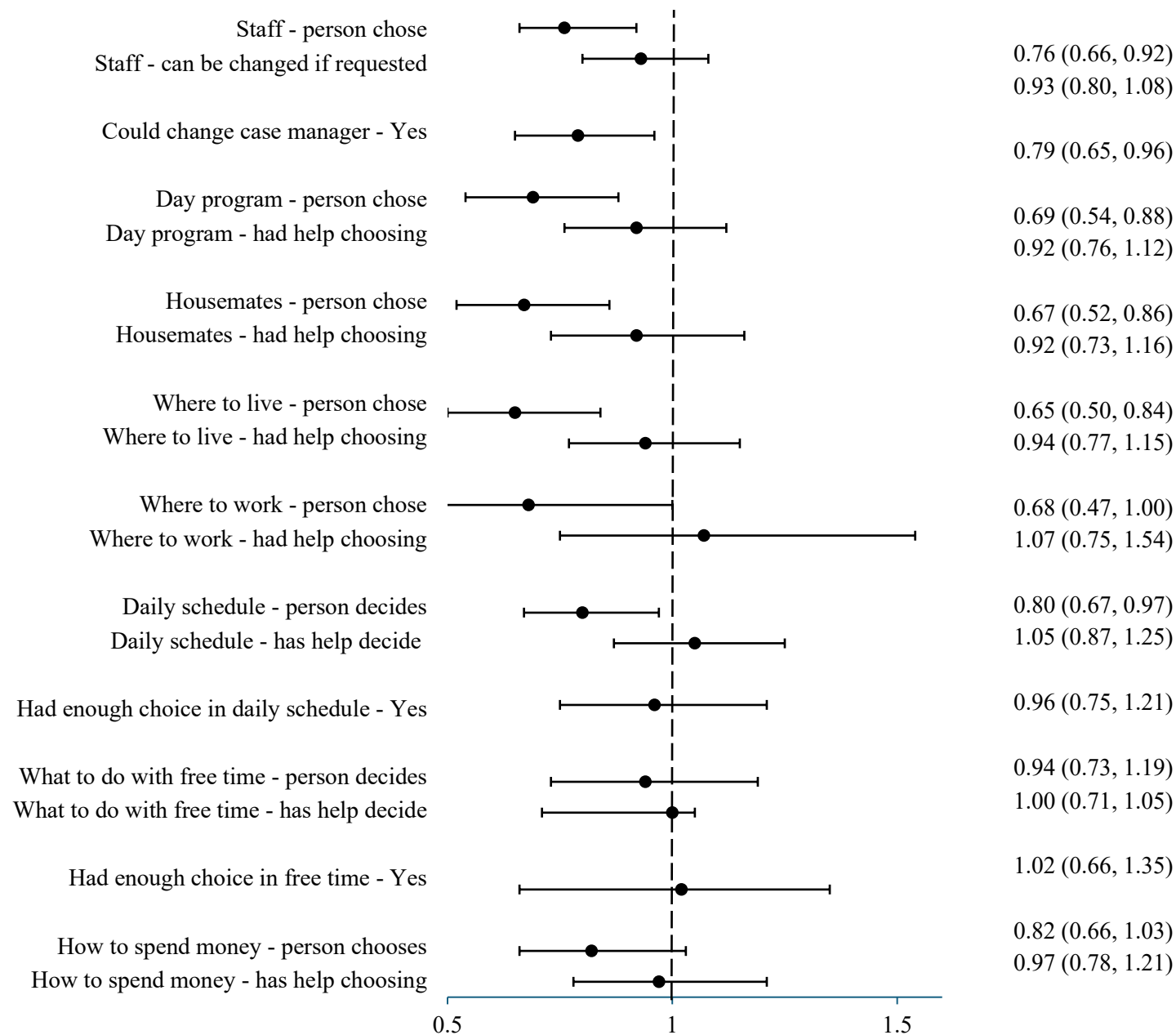


Figure 2. The adjusted relative risk ratios or odds ratios and 99% confidence interval of choices by disability groups (autism or other DD) by controlling for gender, race/ethnicity, age, ID, and proxy status.

Table 1 Background variables of adults with autism in comparison with adults with other DD in 2018-2019 NCI-IPS

Variables	Adults with autism (N= 4,253)		Adults with other DD (N= 16,625)		P values
	%	99%CI	%	99%CI	
Age (years)					
18-30	52.8	50.3, 55.2	21.9	20.9, 22.9	*
31-45	29.2	27.0, 31.5	30.5	29.4, 31.7	
46-65	15.2	13.4, 17.1	35.9	34.7, 37.1	*
66 and older	2.9	2.1, 3.8	11.7	10.9, 12.6	*
Gender					
Male	75.3	73.1, 77.3	53.5	52.3, 54.8	*
Female	24.7	22.6, 26.8	46.4	45.2, 47.7	*
Other	0.1	0.0, 0.3	0.1	0.0, 0.2	
Race					
White, non-Hispanic	72.9	70.7, 75.1	73.3	72.2, 74.4	
Black, non-Hispanic	14.4	12.7, 16.2	16.2	15.3, 17.1	
Hispanic	6.9	5.7, 8.3	6.3	5.7, 6.9	
Multiple/other, non-Hispanic	5.8	4.8, 7.0	4.2	3.7, 4.7	
Types of residence					
Specialized institutional facility	3.5	2.7, 4.5	4.4	3.9, 5.0	
Group living setting	29.0	26.7, 31.4	33.2	32.0, 34.5	*
Own home/apartment	13.7	12.1, 15.4	19.1	18.2, 20.2	*
Parent/relative home	47.5	45.0, 49.9	35.3	34.2, 36.5	*
Foster care/host home	5.9	4.9, 7.0	6.9	6.4, 7.5	
Other (e.g., homelessness)	0.5	0.2, 0.9	1.0	0.7, 1.3	
Received Medicare	41.6	39.1, 44.1	58.4	57.1, 59.7	*
Had a paid job in the community	30.9	28.1, 33.8	28.3	27.0, 29.6	
Level of Intellectual disability					
No ID	20.6	18.6, 22.8	7.4	6.7, 8.1	*
Mild ID	23.4	21.4, 25.6	39.2	37.9, 40.4	*
Moderate ID	21.8	19.9, 23.8	27.3	26.2, 28.4	*
Severe ID	14.9	13.2, 16.7	10.5	9.7, 11.3	*
Profound ID	6.8	5.6, 8.2	7.2	6.6, 7.9	
Unspecified	12.5	11.0, 14.1	8.5	7.8, 9.3	*
Mental health condition					
Anxiety disorder	41.1	38.6, 43.6	24.9	23.8, 26.0	*
Mood disorder	33.7	31.4, 36.2	32.8	31.7, 34.1	
Behavioral challenges	49.5	47.0, 52.0	28.4	27.3, 29.6	*

Psychotic disorders	11.3	9.8, 13.0	11.8	11.0, 12.7	
Other	15.0	13.3, 16.9	11.6	10.8, 12.5	*
Any of above	75.7	73.6, 77.8	58.5	57.2, 59.7	*
Physical health condition (either vision or hearing impairment)	8.3	7.1, 9.6	14.9	14.0, 15.8	*
Amount of paid support					
24-hr on-site	48.8	46.2, 51.4	51.9	50.6, 53.3	*
Daily on-site	18.2	16.4, 20.3	16.2	15.3, 17.2	
Scheduled, less than daily	15.0	13.3, 16.8	14.5	13.6, 15.4	
As needed and phone contact	2.9	2.2, 3.9	2.7	2.3, 3.1	
None of the above	15.1	13.4, 17	14.7	13.8, 15.7	
Use of verbal communication	69.5	67.2, 71.7	81.9	80.9, 82.8	*
Mobility (Use of a mobility aid)					
Moves self around without aids	91.6	90.2, 92.9	72.5	71.3, 73.6	*
Moves self around with aids or uses wheelchair independently	5.3	4.4, 6.6	16.5	15.5, 17.4	*
Non-ambulatory, always need assistance	3.0	2.3, 4.0	11.0	10.3, 11.9	*
General health status					
Excellent	23.8	21.7, 25.9	17.4	16.5, 18.4	*
Very good	49.5	47.0, 51.9	47.8	46.6, 49.1	
Fairly good/Poor	26.8	24.7, 29	34.7	33.5, 35.9	*

Note. Survey weights were applied to estimate the percentages. * p<0.001

Table 2. Results of logistic regression of choice of adults with autism by race and ethnicity

	Black	Hispanic	Other
Staff	RRR (99% CI)	RRR (99% CI)	RRR (99% CI)
Person chose	0.70 (0.43, 1.13)	0.82 (0.45, 1.50)	0.94 (0.52, 1.72)
Staff assigned but can be changed if requested	0.83 (0.59, 1.17)	0.60 (0.36, 1.00)	0.71 (0.42, 1.18)
Someone else chose	ref	ref	ref
Change case manager			
Yes	0.80 (0.48, 1.29)	0.41 (0.24, 0.71)	0.51 (0.28, 0.92)
Day program			
Person chose	0.64 (0.36, 1.17)	0.98 (0.38, 2.51)	0.48 (0.19, 1.17)
Had help choosing	0.60 (0.39, 0.92)	0.55 (0.27, 1.12)	0.73 (0.39, 1.41)
Someone else chose	ref	ref	ref
Housemates			
Person chose	0.60 (0.28, 1.27)	0.66 (0.23, 1.98)	0.91 (0.39, 2.11)
Had help choosing	0.99 (0.55, 1.77)	0.64 (0.24, 1.68)	1.00 (0.44, 2.25)
Someone else chose	ref	ref	ref
Where to live			
Person chose	0.57 (0.25, 1.31)	0.85 (0.31, 2.34)	1.00 (0.38, 2.62)
Had help choosing	0.75 (0.44, 1.28)	0.73 (0.33, 1.61)	1.19 (0.51, 2.78)
Someone else chose	ref	ref	ref
Where to work			
Person chose	0.78 (0.26, 2.34)	1.16 (0.24, 5.52)	0.45 (0.10, 1.96)
Had help choosing	0.79 (0.31, 2.04)	0.47 (0.10, 2.18)	0.66 (0.19, 2.26)
Someone else chose	ref	ref	ref
Daily schedule			
Person decides	0.58 (0.39, 0.88)	0.39 (0.23, 0.66)	0.42 (0.23, 0.74)
Had help deciding	0.51 (0.35, 0.76)	0.31 (0.18, 0.52)	0.63 (0.37, 1.07)
Someone else decides	ref	ref	ref
Had enough choice in daily schedule			
yes	0.81 (0.47, 1.39)	0.49 (0.25, 0.96)	0.55 (0.28, 1.08)
What to do with free time			
Person decides	0.59 (0.36, 0.97)	0.20 (0.11, 0.37)	0.41 (0.20, 0.87)
Had help deciding	0.53 (0.31, 0.89)	0.17 (0.09, 0.31)	0.45 (0.20, 1.01)
Someone else decides	ref	ref	ref
Had enough choice in free time			
yes	0.82 (0.44, 1.52)	0.50 (0.24, 1.04)	0.79 (0.34, 1.85)
How to spend money			
Person chooses	0.77 (0.47, 1.25)	0.44 (0.24, 0.80)	0.67 (0.35, 1.28)
Has help choosing	1.01 (0.64, 1.59)	0.45 (0.25, 0.81)	0.68 (0.35, 1.30)
Someone else chooses	ref	ref	ref

Note. RRR=Relative risk ratio, controlling for gender, age, ID, and proxy status. Non-Hispanic White as the reference group