American Journal on Intellectual and Developmental Disabilities

Improving Retention of Diverse Samples in Longitudinal Research on Developmental Disabilities

--Manuscript Draft--

Manuscript Number:	AJIDD-D-22-00001R2
Article Type:	Research Report
Keywords:	retention in longitudinal research, diversity and inclusion, developmental disabilities research
Corresponding Author:	Jieun Song, PhD University of Wisconsin-Madison Madison, WI UNITED STATES
First Author:	Jieun Song, PhD
Order of Authors:	Jieun Song, PhD
	Robert S Dembo, PhD
	Leann E DaWalt, PhD
	Carol D Ryff, PhD
	Marsha R Mailick, PhD
Manuscript Region of Origin:	UNITED STATES
Abstract:	Developmental disabilities (DD) research has depended on volunteer and clinical samples, with limited racial/ethnic diversity. This study focused on improving diversity and retention in DD research. The sample included 225 parents with a child with DD and 4,002 parents without children with DD from diverse racial/ethnic groups, drawn from MIDUS, a national longitudinal study. Unexpectedly, parents of children with DD from diverse racial/ethnic groups were more likely to participate longitudinally than other groups. Relative participant payment was a factor that enhanced their likelihood of retention. This research illustrates how large national studies can be leveraged to increase representativeness and ongoing participation of diverse racial/ethnic groups, especially in combination with other factors, such as parenting a child with DD.

Improving Retention of Diverse Samples in Longitudinal Research on Developmental Disabilities

Abstract

Developmental disabilities (DD) research has depended on volunteer and clinical samples, with limited racial/ethnic diversity. This study focused on improving diversity and retention in DD research. The sample included 225 parents with a child with DD and 4,002 parents without children with DD from diverse racial/ethnic groups, drawn from MIDUS, a national longitudinal study. Unexpectedly, parents of children with DD from diverse racial/ethnic groups were *more likely* to participate longitudinally than other groups. Relative participant payment was a factor that enhanced their likelihood of retention. This research illustrates how large national studies can be leveraged to increase representativeness and ongoing participation of diverse racial/ethnic groups, especially in combination with other factors, such as parenting a child with DD.

Keywords: retention in longitudinal research, diversity, developmental disabilities research

Improving Retention of Diverse Samples in Longitudinal Research on Developmental Disabilities

Across the fields of science, it is increasingly evident that research samples need greater diversity to adequately represent the population (*New England Journal of Medicine*, 2021). This is especially important in research on developmental disabilities (DD), a category which encompasses a heterogeneous range of disorders that manifest before age 22 and often last over the life course. Some definitions of DD focus only on conditions that limit adaptive functioning (e.g., Havercamp et al., 2019; Schalock et al., 2021), while others are broader and include a range of conditions that have more specific impacts (e.g., Zablotsky et al., 2019). Many DD conditions result from a complex interaction of risk factors (e.g., autism spectrum disorders; attention-deficit/hyperactivity disorder), though some have a specific genetic etiology (e.g. Down syndrome, fragile X syndrome) (Grether et al., 2009; Mackay et al., 2016; Roten et al., 2021; Sagiv et al., 2010; Von Ehrenstein et al., 2021).

Epidemiological studies have found that there are racial and ethnic biases in diagnostic practices related to which DD conditions are included in various definitions (e.g., Durkin et al., 2015; Patrick et al., 2021). Notably, according to recent prevalence estimates, nearly 18% of children in the U.S. has a DD, broadly defined by the Centers for Disease Control and Prevention (CDC) as "lifelong conditions due to an impairment in physical, learning, language, or behavior areas." Defined as such, more than 1-in-6 children in the U.S. are reported to have a DD (Zablotsky et al., 2019). For the present investigation of diversity in DD research, we adopt the CDC's broader definition.

With few exceptions, DD research is based on samples that do not reflect the racial and ethnic diversity of the full population with DD diagnoses, and this is particularly true for

longitudinal studies. Nearly all U.S. studies start with volunteer samples of their parents, recruit from clinical settings, or utilize convenience sampling approaches such as internet surveys (e.g., Gotham et al., 2015), resulting in under-representation of racially and ethnically diverse participants. Other countries maintain national registries of individuals with disabilities (e.g., Sweden), thereby facilitating the inclusion of representative cohorts in research. However, there are no comparable national datasets within the U.S. An additional challenge is the low prevalence of specific DD conditions, further underscoring the need for large representative study populations, as well as longitudinal data that can be used to track developmental changes and life course transitions. Some nationally representative surveys have been used for research on DD, including the Midlife in the United States (MIDUS) study (e.g., Dembo et al., 2022) and the Panel Study of Income Dynamics (PSID) (e.g., Hoyle et al., 2021). Studies that draw samples from these large, national surveys often identify parents of children with DD based on a heterogeneous set of diagnoses (e.g., Down syndrome, autism spectrum disorder, ADHD, learning disabilities), guided by the CDC's broad definition of developmental disabilities.

Parents of children with DD are known to differ from parents of non-disabled children on factors previously linked with retention in longitudinal studies, such as being married (Jacobson et al., 2021; Watson & Wooden, 2009). Many past studies have shown that parents of individuals with DD have higher rates of divorce than parents of individuals without DD (Hartley et al., 2010; Namkung et al., 2015; Seltzer et al., 2011). Poor physical and mental health have also been associated with lower rates of retention in longitudinal studies (Radler & Ryff, 2010), and studies have shown that parents of individuals with DD have more stress-related physical and mental health problems than parents of non-disabled individuals (Miodrag & Hodapp, 2010; Scherer, Verhey, & Kuper, 2019; Smith et al., 2012). Parents of individuals with DD also have lower

household incomes and fewer assets, on average, than other parents (Seltzer et al., 2011), and higher socioeconomic status tends to be associated with greater retention in longitudinal studies (Heid et al., 2021). However, no studies to date have directly evaluated retention rates of parents of individuals with DD compared to rates of retention among parents of non-disabled children in longitudinal, population-based research.

Importantly, racial/ethnic differences in study participation and retention also contribute to the non-representativeness of DD (Johnson, Bogenschutz, & Peak, 2021; Maye et al., 2021). Whites are known have higher rates of participation and retention in population research than members of other racial groups (Bambs et al., 2013; Radler & Ryff, 2010). Substantial health disparities between Whites with DD, and their families, and those from other racial groups have been well-documented (Magana et al., 2016; Scott & Havercamp, 2014), further jeopardizing research participation. Thus, identifying factors that promote retention in longitudinal studies is critical to advancing DD research. Past research on participant retention in population studies often included controls for age, gender, education, and employment status (Jacobsen et al., 2021; Song et al., 2021), and thus these characteristics were included as control variables in the present analysis.

In the present study, we used data from the MIDUS study, a large three-wave longitudinal NIH-funded national probability sample of non-institutionalized, English-speaking adults (midus.wisc.edu/). Based on the identification of participants who had children with DD as well as the self-reported race/ethnicity of participants, we compared rates of longitudinal retention over a 9-year period between the second and third waves of the MIDUS study in sub-groups defined by parental status and race/ethnicity. We focused on retention in longitudinal research because DD conditions are, by definition, developmental and as such multiple data

points reflecting developmental trajectories are particularly valuable. Drawing on the above literature, we hypothesized that (a) parents of individuals who have DD would be less likely to be retained in longitudinal studies than parents of non-disabled individuals, and further that (b) parents from diverse racial and ethnic groups who have a son or daughter with DD would have the lowest rate of retention. We also sought to discover factors that might underlie patterns of non-retention linked with parenting a son or daughter with DD and race/ethnicity. The overarching goal was to identify potential strategies that might be incorporated into future research to enhance the diversity of participants in longitudinal research on DD.

Additionally, we examined the effects of payments used to incentivize recruitment and retention. Past research suggests that such participant payments tend to improve rates of engagement in research, although the effect is non-linear (response rates increase as the size of the payment increases, but do so at a declining rate) (Singer & Ye, 2013). We sought a more nuanced understanding of the effect of participant payments on retention by calculating the ratio of the participant payment to the participant's household income. So doing would clarify whether such incentives matter differentially, depending on each participant's income.

Methods

Data and Sample

The data for the present study were taken from waves 2 and 3 of the three-wave MIDUS study. MIDUS began in 1995-1996 with a national sample of 7,108 adults aged 25 to 74 (Radler & Ryff, 2010). Participants were studied again in 2004-2006 when they were aged 35 to 84 (MIDUS 2, n = 4,963) and in 2013-2014 when they were aged 44 to 94 (MIDUS 3, n = 3,294). The mortality-adjusted retention rate between MIDUS 2 and MIDUS 3 was 77% (Ryff, Almeida, Ayanian, Binkley, et al., 2018a).

The percentages of participants from racial and ethnic groups other than non-Hispanic Whites were 10.9% at MIDUS 2 and 9.4% at MIDUS 3. To increase inclusion of Blacks, MIDUS 2 was expanded to include a stratified (by age, gender, and SES) sample of households (n = 592) from Milwaukee, WI (Ryff, Almeida, Ayanian, Carr, et al., 2018), with longitudinal follow-up at MIDUS 3 (n = 389) (Ryff, Almeida, Ayanian, Binkley, et al., 2018b). The mortality-adjusted retention rate between the two waves of the Milwaukee sample was 78% (Ryff, Almeida, Ayanian, Binkley, et al., 2018c). In total, 1,130 participants from racial and ethnic groups other than non-Hispanic Whites were included in MIDUS 2, drawing from both the national and the Milwaukee samples.

It was at MIDUS 2 that the disability status of the children of participants was first obtained. The analytic sample consists of two groups of MIDUS 2 participants: parents with a child with DD (n = 226) and parents who did not have children with DD or a mental health condition and who did not provide personal care to family or friends or experienced the death of a child (n = 3,461). Both groups were further divided by race/ethnicity.

Data Collection Procedures and Measures

All participants in the national sample of MIDUS 2 and MIDUS 3 (including non-Hispanic Whites and those from other racial and ethnic groups) completed telephone interviews. The Milwaukee participants completed in-person interviews. Although the different interview modes might have had an influence on participation and retention, in-person interviews for the Milwaukee Black sample were used by the MIDUS study to maximize response rates and increase data quality.

At MIDUS 2, parents responded to a question about each of their children asking

whether the child had a DD, such as autism, cerebral palsy, epilepsy, or other intellectual or developmental disability. Those who answered affirmatively were asked to report their child's specific condition (Table 1).

[Table 1]

Participants self-reported their race (White, Black/African American, Native American or Alaska Native/Eskimo, Asian, Native Hawaiian or Pacific Islanders, other) and ethnicity (non-Hispanic, Hispanic). The majority of participants other than non-Hispanic Whites were Black (68.8%). Due to the small number of participants from other specific racial/ethnic groups, we combined all participants other than non-Hispanic Whites into a single non-White group for the present analysis, which is a limitation of the present research.

The participant payment was $25 for respondents in the national sample (whether non-Hispanic White or members of other racial/ethnic groups). For the Milwaukee sample, the participant payment was $50. *Relative participant payment* was defined as the participant payment in the MIDUS 2 interview as a percentage of the participants' average monthly household income: (participant payment)*100/average monthly household income.

Other variables found in prior research to be associated with retention were included in the analyses as covariates: age, gender, education (in years), marital status (1 = currently married, 0 = unmarried), employment status (1 = working, 0 = not working), and physical and mental health (each coded as 1 = poor to 5 = excellent) (Jacobsen et al., 2021; Radler & Ryff, 2010; Song et al., 2021).

Analysis Plan

Characteristics of the four study groups were descriptively compared using one-way analysis of variance, with Duncan post-hoc tests for between-group contrasts. Subsequently,

logistic regression was used to evaluate parenting status and race/ethnicity as predictors of retention from MIDUS 2 to MIDUS 3. We examined a parenting status × race/ethnicity interaction term, controlling for factors that might have affected retention rates. Logistic regression was also used to evaluate the effects of the relative participant payment on retention in MIDUS 3. Specifically, we examined the interaction between the relative participant payment and parenting status, and the interaction between the relative participant payment and race/ethnicity. It was not possible to test a three-way interaction (i.e., relative participant payment × parenting status × race/ethnicity) due to sample size constraints.

Results

Descriptive Comparisons among Parent Groups

As shown in Table 2, the participants from diverse racial/ethnic groups whose children had DD (group B in Table 2) were significantly different on all study variables other than employment status – they were younger, more likely to be mothers, had less education, lower income, less likely to be married, and in poorer physical and mental health (see Table 2 for specific group differences). The participant payment was a higher proportion of income for parents of children of DD from diverse racial/ethnic groups compared to the other groups. Participants from racial/ethnic groups other than non-Hispanic Whites who had a child with DD had significantly *higher* rates of retention in MIDUS 3 (82%) than the other groups (for whom retention rates ranged from 68% to 73%).

[Table 2]

Prediction of Retention

Table 3 presents results of logistic regression models predicting MIDUS 3 retention. Model 1 shows that participants who were older, mothers, employed, and who had higher levels

of education and better physical health were more likely to participate in MIDUS 3, which was nine years after MIDUS 2, on average. Notably, race/ethnicity was not a significant predictor of retention. Controlling for these factors, there was a trend for parents of children with DD to be *more likely* to remain in the study at MIDUS 3 compared to parents whose children did not have disabilities ($p = .079$), which was counter to our first hypothesis.

[Table 3]

Model 2 in Table 3 presents results of a logistic regression that examined the moderating effects of race/ethnicity. There was a significant parenting status × race/ethnicity interaction effect ($p = .048$). Figure 1 illustrates that, among parents of children with DD, those from diverse racial/ethnic groups had a significantly *higher probability* of retention in MIDUS 3 than non-Hispanic White parents ($p = .03$), but among parents of children without disabilities, the two racial/ethnicity groups did not differ in retention over the 9-year study period ($p = .52$), counter to our second hypothesis.

[Figure 1]

Models 3 to 5 in Table 3 examine the *relative participant payment* as a predictor of retention at MIDUS 3. Although there was no significant main effect of the relative participant payment on the likelihood of retention (Model 3), results in Models 4 and 5 showed that this variable was a significant predictor of retention once parenting status and race/ethnicity were taken into account. In Model 4, the interaction between the relative participant payment and *parenting status* was a significant predictor of retention ($p = .013$). As illustrated in Figure 2A, among parents of children with DD, the greater the relative participant payment, the higher the probability of retention ($p = .01$). However, for parents of children without DD, there was no association between the relative participant payment and retention ($p = .62$). In Model 5, the

interaction between the relative participant payment and *race/ethnicity* also was a significant predictor of retention ($p < .001$). As illustrated in Figure 2B, a higher relative participant payment was a significant predictor of retention among parents from diverse racial/ethnic groups ($p = .01$). However, unexpectedly, among non-Hispanic White parents, the relative participant payment had the opposite pattern; there was a trend indicating that the higher the relative participant payment, the *lower* the probability of retention ($p = .09$).

[Figure 2]

Discussion

Unlike much past research that documented the substantial health disparities of individuals with DD associated with racial/ethnic group membership (e.g., Magana et al., 2016), the present study focused on an important precursor to such inquiries – namely, disparities in retention of racially and ethnically diverse participants in longitudinal DD research. Parents of children with DD from diverse racial/ethnic groups were found to have unexpectedly higher rates of retention than their counterparts who differed in race/ethnicity and parenting status. Although the size of this sub-group was small, this finding is notable for research in the field of DD. It also has relevance for the general research community by underscoring the need to jointly evaluate effects of multiple factors in understanding participants' motivations to participate in longitudinal studies.

We offer several possible explanations for these unexpected patterns. Certainly, the relative value of the participant payment was a factor that enhanced the likelihood of retention among some (but not all) sub-groups. Importantly, parents of children with DD with more limited financial resources were more likely to be retained over the nearly decade-long study period, a pattern not observed among parents of non-disabled children. Past research has shown

that parents of children with DD have lower incomes and fewer assets than other parents (Seltzer et al., 2011), and often have higher out-of-pocket costs for their child with DD (Buescher et al., 2014; Chevreul et al., 2015; Kogan et al., 2008), further contributing to the value of the participant payment, and motivating continued participation.

The impact of the relative participant payment also mattered for those from diverse racial and ethnic groups. For these parents, the greater the relative value of the participant payment, the higher the rate of retention. In contrast, among non-Hispanic White parents, the pattern tended to be in the opposite direction– the greater the relative value of the participant payment, the *lower* the likelihood of retention. Additional research is needed to better understand the complex effects of participant payments among various sub-groups of potential research participants, especially when sub-groups are defined by the intersection of multiple factors.

We also emphasize another potentially important factor in understanding how to maximize representativeness in DD research. A key point is that the MIDUS study recruited participants who were representative of the larger U.S. population, without consideration of whether a potential participant was a parent of a child with DD. In contrast, most studies of parents of children with DD rely on volunteer or clinical samples where those who consent to participate are aware that the study will focus on their child. Although this focus might be a positive motivating factor for some parents, it is possible that others may choose not to participate or remain in the study specifically because of the focus on their child's DD condition. Thus, recruitment into the MIDUS study, which was not based on whether participants had any children with disabilities, may have removed a barrier to ongoing participation for some parents. That is, ongoing participation in a general research study may be perceived as less stigmatizing for some families than in research focused on their child's DD condition. This possibility may be

particularly salient for parents of children with DD from diverse ethnic and racial groups, who may feel blamed by the medical professionals who diagnose and treat their children. A previous study revealed that parents of children with disabilities reported significantly higher levels of stigma related to embarrassment/shame and daily discrimination than parents who had non-disabled children (Song et al., 2018). Such feelings may negatively affect ongoing participation in studies explicitly focused on children with DD.

Together, these findings and observations point to future strategies for increasing ongoing participation in longitudinal research of parents of children with DD from diverse racial and ethnic groups. Provision of sufficient financial incentives to motivate ongoing participation among families who have less financial security and who often have greater out-of-pocket costs for their child with DD is a first step. Of critical importance is that what mattered in the present study was the amount of the payment relative to one's own household income (for all sub-groups except for non-Hispanic White parents of non-disabled children), even after controlling for other factors. Additionally, messages about the value of participation in future studies could be framed in the context of emphasizing positive aspects of research participation such as supporting research and contributing to the development of interventions and social policy.

As recently noted in the *New England Journal of Medicine* (*NEJM*, 2021) "solving this problem [representing racial diversity] will require changes throughout the research enterprise." Multiple changes may have separate or synergistic effects, and future research is needed to determine which approaches are most effective. All changes will involve trade-offs and choices that reflect the goals and values of the researchers, and together they affect what can be learned from a given study.

An important caveat is that studies of populations with specific DD diagnoses might not be well-served by trying to identify potential participants via national population studies because an insufficient number of parents of children with a specific diagnosis would be identified. In such contexts, an alternative is to recruit potential participants through specialty medical practices or from electronic health records (EHRs) (see, for example: Mailick et al., 2021; Movaghar et al., 2021). By proactively reaching out to potential participants who have children with DD diagnoses that are noted in the EHR, it may be possible to reduce some of the bias that emanates from relying on volunteers to come forward. This recruitment strategy might be particularly effective for including parents from diverse racial and ethnic groups, those who have limited finances, and those who feel stigmatized by their child's condition.

Nonetheless, recruiting potential participants who have specific DD diagnoses via EHRs or from specialty medical practices will not likely be feasible for all research, given bureaucratic and privacy constraints on access to such data. Additionally, not all DD diagnoses have specific codes that appear in the EHR. An alternative in such instances would be to compare volunteer and clinical samples with socio-demographically matched sub-groups in population data sets (see, for example: Seltzer et al., 2010; Smith et al., 2010). Data for matching sub-groups can be accessed via population studies such as MIDUS, thereby maximizing the opportunities that come from studying clinical groups within a population-based framework.

Overall, the patterns revealed in this study warrant confirmation in other research. A significant limitation was that all DD conditions were grouped together due to limited sample size, obscuring the factors that differentiate specific diagnoses and that might differentially affect research participation. An additional important limitation was that non-English speakers were excluded from the MIDUS study, limiting the linguistic diversity of the sample. Further, all

parents other than non-Hispanic Whites were grouped together, thus obscuring well-documented differences between the racial and ethnic groups. This approach was necessitated by the limited number of participants in the MIDUS study who had children with DD *and* who self-identified as members of specific diverse groups. Future research should strive for more fine-grained analysis of how various racial and ethnic groups might differ in research participation patterns. Yet it is important to recognize that racial and ethnic group membership is a social construct, not a biological variable (Burton et al., 2010; Johnson, Bogenschutz, & Peak, 2021). In a summary of numerous studies, Williams and Mohammed (2013) emphasized the significance of race independent of SES in accounting for health disparities; the patterns in the present study emerged even after controlling for education and employment status. It should be also noted that the current study examined the longitudinal retention of parents of individuals with disabilities in various racial/ethnic groups. These parents were initially recruited in 2004-2006 and their retention was evaluated in 2013-2014. Thus, the findings could reflect period effects related to those time points of data collection, such as the Great Recession that began in 2008.

It is noteworthy that different interview modes were used for Black participants (telephone and in-person interviews). Although these different modes might have yielded different participation and retention rates, which could have impacted the findings, our exploratory analyses showed that among Black parents who had children with disabilities, the retention rates were comparable across the interview modes (in-person and telephone). Data are available from the first author.

In interpreting these patterns, we note that the main effect of race/ethnicity was not in and of itself a significant predictor of research participation. It was only when the race/ethnicity variable was examined in interaction with parenting status that the sub-group with the highest

levels of research participation was identified, namely parents of children with DD from diverse racial and ethnic groups. Johnson and colleagues (2021) warned against treating each social marker variable separately in DD research, without evaluating the intersectionality of multiple markers, reflected in the patterns observed here.

Ultimately, the success of the MIDUS study in recruiting and retaining diverse parents of individuals who have DD emerged from a confluence of factors – beginning with a national sample that was actively designed to represent the U.S. population (and as such included participants from diverse racial and ethnic groups from the start), intentionally augmenting the core sample by over-recruitment of Blacks, and crucially for the present study, identifying parents of children with DD diagnoses as part of the data collection (Maye et al., 2021). Future research can build on these strategies and thus better fulfill the imperative of diversifying longitudinal research samples of individuals with DD and their families. The present research thus serves as an example of how large representative samples such as MIDUS can be leveraged to broaden our understanding of factors motivating the ongoing participation of diverse racial/ethnic groups, especially in combination with other factors, such as parenting a child with DD.

References

Bailey, D. B. Jr., Raspa, M., Bishop, E., Mitra, D., Martin, S., Wheeler, A., & Sacco, P. (2012). Health and economic consequences of fragile X syndrome for caregivers. *Journal of Developmental and Behavioral Pediatrics, 33*(9), 705-712. https://doi.org/10.1097/DBP.0b013e318272dcbc

Bambs, C. E., Kip, K. E., Mulukutla, S. R., Aiyer, A. N., Johnson, C., McDowell, L. A., Matthews, K., & Reis, S. E. (2013). Sociodemographic, clinical, and psychological factors associated with attrition in a prospective study of cardiovascular prevention: The Heart Strategies Concentrating on Risk Evaluation Study. *Annals of Epidemiology, 23*(6), 328-333. https://doi.org/10.1016/j.annepidem.2013.02.007

Buescher, A. V. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States, *JAMA Pediatrics, 168*(8), 721-728. https://doi.org/10.1001/jamapediatrics.2014.210

Burton, L. M., Bonilla-Silva, E., Ray, V., Buckelew, R., & Hordge Freeman, E. (2010). Critical race theories, colorism, and the decades' research on families of color. *Journal of Marriage and Family, 72*(3), 440-459. https://doi.org/10.1111/j.1741-3737.2010.00712.x

Chevreul, K., Berg Bringham, K., Brunn, M., des Portes, V., & BURQOL-RD Research Network. (2015). Fragile X syndrome: Economic burden and health-related quality of life of patients and caregivers in France. *Journal of Intellectual Disability Research, 59*(12), 1108-1120. https://doi.org/10.1111/jir.12215

Dembo, R. S., Huntington, N., Mitra, M., Rudolph, A. E., Lachman, M. E., & Mailick, M. R. (2022). Social network typology and health among parents of children with developmental disabilities: Results from a national study of midlife adults. *Social Science*

& Medicine, 292, Advance online publication. https://doi.org/10.1016/j.socscimed.2021.114623.

Durkin, M. S., Maenner, M. J., Benedict, R. E., Van Naarden Braun, K., Christensen, D., Kirby, R. S., Wingate, M., & Yeargin-Allsopp, M. (2015). The role of socio-economic status and perinatal factors in racial disparities in the risk of cerebral palsy. *Developmental medicine and child neurology*, *57*(9), 835–843. https://doi.org/10.1111/dmcn.12746

Gotham, K., Marvin, A. R., Taylor, J. L., Warren, Z., Anderson, C. M., Law, P. A., Law, J. K., & Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from the Interactive Autism Network data. *Autism, 19*(7), 794-804. https://doi.org/10.1177/1362361315583818

Grether, J. K., Anderson, M. C., Croen, L. A., Smith, D., & Windham, G. C. (2009). Risk of autism and increasing maternal paternal age in a large north American population. *American Journal of Epidemiology*, *170*(9), 1118-1126. https://doi.org/10.1093/aje/kwp247

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, *24*(4), 449–457. https://doi.org/10.1037/a0019847

Havercamp, S. M., Krahn, G. L., Larson, S. A., Fujiura, G., Goode, T. D., Kornblau, B. L., & National Health Surveillance for IDD Workgroup. (2019). Identifying people with intellectual and developmental disabilities in national population surveys. *Intellectual and Developmental Disabilities*, *57*(5), 376-389.

Heid, A. R., Cartwright, F. P., Wilson-Genderson, M., & Pruchno, R. (2021). Understanding attrition and bolstering retention in a longitudinal panel of older adults: ORANJ BOWL. *Innovation in Aging, 5*(2), igab010. https://doi.org/10.1093/geroni/igab010

Hoyle, J. N., Laditka, J. N., & Laditka, S. B. (2021). Mental health risks of parents of children with developmental disabilities: A nationally representative study in the United States. *Disability and Health Journal, 14*(2), 101020. https://doi.org/10.1016/j.dhjo.2020.101020

Jacobsen, E., Ran, X., Liu, A., Chang, C. C. H., & Ganguli, M. (2021). Predictors of attrition in a longitudinal population-based study of aging. *International Psychogeriatrics, 33*(8), 767-778. https://doi.org/10.1017/S1041610220000447

Johnson, K. R., Bogenschutz, M., & Peak, J. (2021). Propositions for race-based research in intellectual and developmental disabilities, *Inclusion, 9*(3), 156-169. https://doi.org/10.1352/2326-6988-9.3.156

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics, 122*(6), e1149–e1158. https://doi.org/10.1542/peds.2008-1057

Mackay, D. F., Smith, G. C., Cooper, S. A., Wood. R., King, A., Clark, D. N., & Pell, J. P. (2016). Month of conception and learning disabilities: A record-linkage study of 801,592 children. *American Journal of Epidemiology, 184(7),* 485-493. https://doi.org/10.1093/aje/kww096

Magaña, S., Parish, S., Morales, M. A., Li, H., & Fujiura, G. (2016). Racial and ethnic health disparities among people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 54*(3), 161-172. https://doi.org/10.1352/1934-9556-54.3.161

Mailick, M. R., Hong, J., Movaghar, A., DaWalt, L., Berry-Kravis, E. M., Brilliant, M. H., Boero, J., Todd, P. K., & Hall, D. (2021). Mild neurological signs in FMR1 premutation women in an unselected community-based cohort. *Movement Disorders, 36*(10), 2378-2386. https://doi.org/10.1002/mds.28683

Maye, M., Boyd, B. A., Martínez-Pedraza, F., Halladay, A., Thurm, A., & Mandell, D. S. (2021). Biases, barriers, and possible solutions: Steps towards addressing autism researchers under-engagement with racially, ethnically, and socioeconomically diverse communities. *Journal of Autism and Developmental Disorders*. Advance online publication. https://doi.org/10.1007/s10803-021-05250-y

Miodrag, N., & Hodapp, R. M. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current Opinion in Psychiatry, 23*(5), 407-411. https://doi.org/10.1097/YCO.0b013e32833a8796

Movaghar, A., Page, D., Scholze, D., Hong, J., DaWalt, L. S., Kuusisto, F., Stewart, R., Brilliant, M., & Mailick, M. (2021). Artificial intelligence-assisted phenotype discovery of fragile X syndrome in a population-based sample. *Genetics in Medicine, 23*(7), 1273-1280. https://doi.org/10.1038/s41436-021-01144-7

Namkung, E. H., Song, J., Greenberg, J. S., Mailick, M. R., & Floyd, F. J. (2015). The relative risk of divorce in parents of children with developmental disabilities: Impacts of lifelong parenting. *American Journal of Intellectual and Developmental Disabilities, 120*(6), 514-526. https://doi.org/10.1352/1944-7558-120.6.514

New England Journal of Medicine (2021). Striving for diversity in research studies. *New England Journal of Medicine, 385*(15), 1429-1430. https://doi.org/10.1056/NEJMe2114651

Patrick, M. E., Shaw, K. A., Dietz, P. M., Baio, J., Yeargin-Allsopp, M., Bilder, D. A., Kirby, R. S., Hall-Lande, J. A., Harrington, R. A., Lee, L. C., Lopez, M., Daniels, J., & Maenner, M. J. (2021). Prevalence of intellectual disability among eight-year-old children from selected communities in the United States, 2014. *Disability and health journal*, *14*(2), 101023. https://doi.org/10.1016/j.dhjo.2020.101023

Radler, B. T., & Ryff, C. D. (2010). Who participates? Accounting for longitudinal retention in the MIDUS national study of health and well-being. *Journal of Aging and Health*, *22*(3), 307-331. https://doi.org/10.1177/0898264309358617

Roten, R. S., Chodick, G., Davidovitch, M., Bellavita, A., & Weisskopf, M. G. (2021). Maternal thyroid anomalies and attention-deficit hyperactivity disorders in progeny. *American Journal of Epidemiology.* Advance online publication. https://doi.org/10.1093/aje/kwab272

Ryff, C. D., Almeida, D., Ayanian, J., Binkley, N., Carr, D. S., Coe, C., Davidson, R., Grzywacz, J. G., Karlamangla, A., Krueger, R. F., Lachman, M. E., Love, G., Mailick, M., Mroczek, D. K., Radler, B., Seeman, T. E., Sloan, R. P., Thomas, D., Weinstein, M., & Williams, D. (2018a). *Midlife in the United States (MIDUS 3), 2013-2014: Disposition codes codebook* (No. 36346). Inter-university Consortium for Political and Social Research. https://www.icpsr.umich.edu/web/NACDA/studies/36346/datadocumentation#

Ryff, C. D., Almeida, D., Ayanian, J., Binkley, N., Carr, D. S., Coe, C., Davidson, R., Grzywacz, J. G., Karlamangla, A., Krueger, R. F., Lachman, M. E., Love, G., Mailick, M., Mroczek, D. K., Radler, B., Seeman, T. E., Sloan, R. P., Thomas, D., Weinstein, M., & Williams, D. (2018b). *Midlife in the United States (MIDUS 3): Milwaukee African American*

sample, 2016-2017. Inter-university Consortium for Political and Social Research [distributor]. https://doi.org/10.3886/ICPSR37120.v2

Ryff, C. D., Almeida, D., Ayanian, J., Binkley, N., Carr, D. S., Coe, C., Davidson, R., Grzywacz, J. G., Karlamangla, A., Krueger, R. F., Lachman, M. E., Love, G., Mailick, M., Mroczek, D. K., Radler, B., Seeman, T. E., Sloan, R. P., Thomas, D., Weinstein, M., & Williams, D. (2018c). *Midlife in the United States (MIDUS 3): Milwaukee African American sample, 2016-2017: MIDUS DDI Codebook: Aggregate data*. Inter-university Consortium for Political and Social Research [distributor]. https://www.icpsr.umich.edu/web/NACDA/studies/37120/datadocumentation

Ryff, C. D., Almeida, D., Ayanian, J., Carr, D. S., Cleary, P. D., Coe, C., Davidson, R., Kruger, R. F., Lachman, M. E., Marks, N. F., Mroczek, D. K., Seeman, T. E., Mailick, M., Singer, B. H., Sloan, R. P., Tun, P. A., Weinstein, M., & Williams, D. (2018). *Midlife in the United States (MIDUS 2): Milwaukee African American sample, 2005-2006*. Inter-university Consortium for Political and Social Research [distributor]. http://doi.org/10.3886/ICPSR22840.v5

Sagiv, S. K., Thurston, S. W., Bellinger, D. C., Tolbert, P. E., Altshul, L. M., & Korrick, S. A., (2010). Prenatal organochlorine exposure and behaviors associated with attention deficit hyperactivity disorder in school-aged children. *American Journal of Epidemiology, 171*(5), 593-601. https://doi.org/10.1093/aje/kwp427

Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An Overview of Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports. *American Journal on Intellectual and Developmental Disabilities, 126*(6), 439-442.

Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLOS ONE*, *14*(7), e0219888. https://doi.org/10.1371/journal.pone.0219888

Scott, H. M., & Havercamp, S. M. (2014). Race and health disparities in adults with intellectual and developmental disabilities living in the United States. *Intellectual and Developmental Disabilities*, *52*(6), 409–418. https://doi.org/10.1352/1934-9556-52.6.409

Seltzer, M. M., Floyd, F., Song, J., Greenberg, J., & Hong, J. (2011). Midlife and aging parents of adults with intellectual and developmental disabilities: Impacts of lifelong parenting. *American Journal on Intellectual and Developmental Disabilities*, *116*(6), 479-499. https://doi.org/10.1352/1944-7558-116.6.479

Seltzer, M. M., Greenberg, J. S., Hong, J., Smith, L. E., Almeida, D. M., Coe, C., & Stawski, R. S. (2010). Maternal cortisol levels and behavior problems in adolescents and adults with ASD. *Journal of Autism and Developmental Disorders*, *40*(4), 457-469. https://doi.org/10.1007/s10803-009-0887-0

Singer, E., & Ye, C. (2013). The use and effects of incentives in surveys. *The ANNALS of American Academy of Political and Social Sciences*, *645,* 112-141. https://doi.org/10.1177/0002716212458082

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *40*(2), 167-178. https://doi.org/10.1007/s10803-009-0844-y

Smith, L. E., Seltzer, M. M., & Greenberg, J. S. (2012). Daily health symptoms of mothers of adolescents and adults with fragile X syndrome and mothers of adolescents and adults

with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *42*(9), 1836-1846. https://doi.org/10.1007/s10803-011-1422-7

Song, J., Mailick, M. R., & Greenberg, J. S. (2018). Health of parents of individuals with developmental disorders or mental health problems: Impacts of stigma. *Social Science & Medicine*, *217*, 152–158. https://doi.org/10.1016/j.socscimed.2018.09.044

Song, J., Radler, B. T., Lachman, M. E., Mailick, M. R., Si, Y., & Ryff, C. D. (2021). Who returns? Understanding varieties of longitudinal participation in MIDUS. *Journal of Aging and Health*, *33*(10), 896-907. https://doi.org/10.1177/0898264309358617

Von Ehrenstein, O. S., Cui, X., Yan, Q., Aralis, H., & Ritz, B. (2021). Maternal prenatal smoking and autism spectrum disorder in offspring: A California statewide cohort and sibling study. *American Journal of Epidemiology*, *190*(5), 728-737. https://doi.org/10.1093/aje/kwaa182

Watson, N., & Wooden, M. (2009). Identifying factors affecting longitudinal survey response. In P. Lynn (Ed.), *Methodology of Longitudinal Survey* (pp. 157-181). John Wiley & Sons, Ltd.

Williams, D. R., & Mohammed, S. A. (2013). Racism and health I: Pathways and scientific evidence. *American Behavioral Scientist*, *57*(8), 1152–1173. https://doi.org/10.1177/0002764213487340

Zalotsky, B., Black, L.I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. et al. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. *Pediatrics*, *144*(4), e20190811. https://doi.org/10.1542/peds.2019-0811

Table 1. Diagnoses of Children with Developmental Disabilities

	Non-Hispanic White	Other Race/Ethnicity
	n (%)	*n* (%)
Autism	9 (5.1)	4 (8.0)
Cerebral palsy	14 (8.0)	5 (10.0)
Down syndrome	7 (4.0)	1 (2.0)
IDD	44 (25.0)	13 (26.0)
Learning disability	33 (18.8)	8 (16.0)
ADD/ADHD	53 (30.1)	14 (28.0)
Epilepsy/seizure disorder	16 (9.1)	5 (10.0)
n	176	50

Notes. IDD = Intellectual and developmental disabilities; ADD = Attention deficit disorder; ADHD = Attention deficit hyperactive disorder.

Table 2. Descriptive Statistics of Parents of Children with DD and Comparison Parents across Racial/Ethnic Groups in MIDUS 2 (2004-2006) and MIDUS 3 (2013-2014) surveys

	Parents of children with DD		Comparison parents		Group Difference [b]	
	Non-Hispanic White (A)	Other Race/Ethnicity (B)	Non-Hispanic White (C)	Other Race/Ethnicity (D)		
	M (SD) or %	M (SD) or %	M (SD) or %	M (SD) or %		
Age	52.3 (11.6)	47.8 (10.7)	55.2 (12.0)	51.4 (11.6)	***	B<A,D<C
Gender: Mother, %	57.4	84.0	52.4	57.4	***	B>A,C,D
Education (years)	13.9 (2.7)	12.9 (3.0)	14.3 (2.5)	13.6 (2.6)	***	B<C
Household income (annual)	74169 (55336)	42626 (35957)	76912 (62980)	52625 (47080)	***	B,D<A,C
Marital Status: Married, %	79.0	38.0	79.5	49.8	***	B<D<A,C
Employment Status: Working, %	66.9	53.1	67.1	69.5	ns	--
Physical health	3.4 (1.0)	2.8 (1.1)	3.6 (1.0)	3.4 (1.0)	***	B<C
Mental health	3.6 (0.9)	3.2 (1.1)	3.9 (0.9)	3.8 (1.0)	***	B<C
Relative participant payment [a]	1.6 (6.3)	5.8 (14.5)	1.3 (7.1)	3.0 (7.1)	***	B>A,C,D
Retention MIDUS2−MIDUS3, %	72.7	82.0	73.0	67.8	***	B>A,C>D
n	176	50	2,837	624		

Notes. DD = developmental disabilities; MIDUS = Midlife in the United Status.

[a] Relative participant payment was calculated for the full sample: (Participant payment)*100/average monthly household income.

[b] One-way ANOVA and Duncan post-hoc tests were conducted for the group comparisons.

+ $P \leq .10$, ** $P \leq .01$, *** $P \leq .001$.

Table 3. Logistic Regression Models Predicting Retention between MIDUS 2 (2004-2006) and MIDUS 3 (2013-2014) by Parenting Status and Race/Ethnicity

	Retention									
	Full sample				80% sample (household income 10% to 90%)					
	Model 1		Model 2		Model 3		Model 4		Model 5	
	OR	*P*	OR	*P*	OR	*P*	OR	*P*	OR	*P*
Age	1.017	<.001	1.017	<.001	1.010	.045	1.011	.028	1.014	.009
Gender (1=mother)	1.317	<.001	1.310	<.001	1.182	.122	1.176	.135	1.190	.108
Education	1.111	<.001	1.111	<.001	1.122	<.001	1.123	<.001	1.119	<.001
Employment status (1=working)	1.280	.007	1.288	.006	1.366	.015	1.393	.010	1.336	.025
Marital status (1=married)	1.124	.197	1.128	.184	1.295	.052	1.290	.056	1.237	.111
Physical health	1.097	.045	1.099	.043	1.200	.005	1.207	.004	1.200	.005
Mental health	1.035	.487	1.036	.473	1.080	.266	1.084	.246	1.068	.343
Race/ethnicity (1=non-Hispanic white)	1.020	.847	1.069	.516	1.160	.308	1.155	.323	1.986	.001
Parenting status (DD=1)	1.332	.079	2.604	.014	1.041	.850	0.522	.040	1.021	.921

Parenting status (DD=1) × Race	---	---	0.431	.048	---	---	---	---	---	---
Relative participant payment [a]	---	---	---	---	1.120	.195	1.046	.616	1.400	.004
Relative participant payment [a] × Parenting status	---	---	---	---	---	---	2.291	.013	---	---
Relative participant payment [a] × Race	---	---	---	---	---	---	---	---	0.575	<.001

Notes. DD = developmental disabilities; MIDUS = Midlife in the United States; OR = Odds ratio.

[a] Relative participant payment = (Participant payment)*100/average monthly household income. Participants whose household income was below 10% and above 90% were excluded in the analysis due to extreme values.

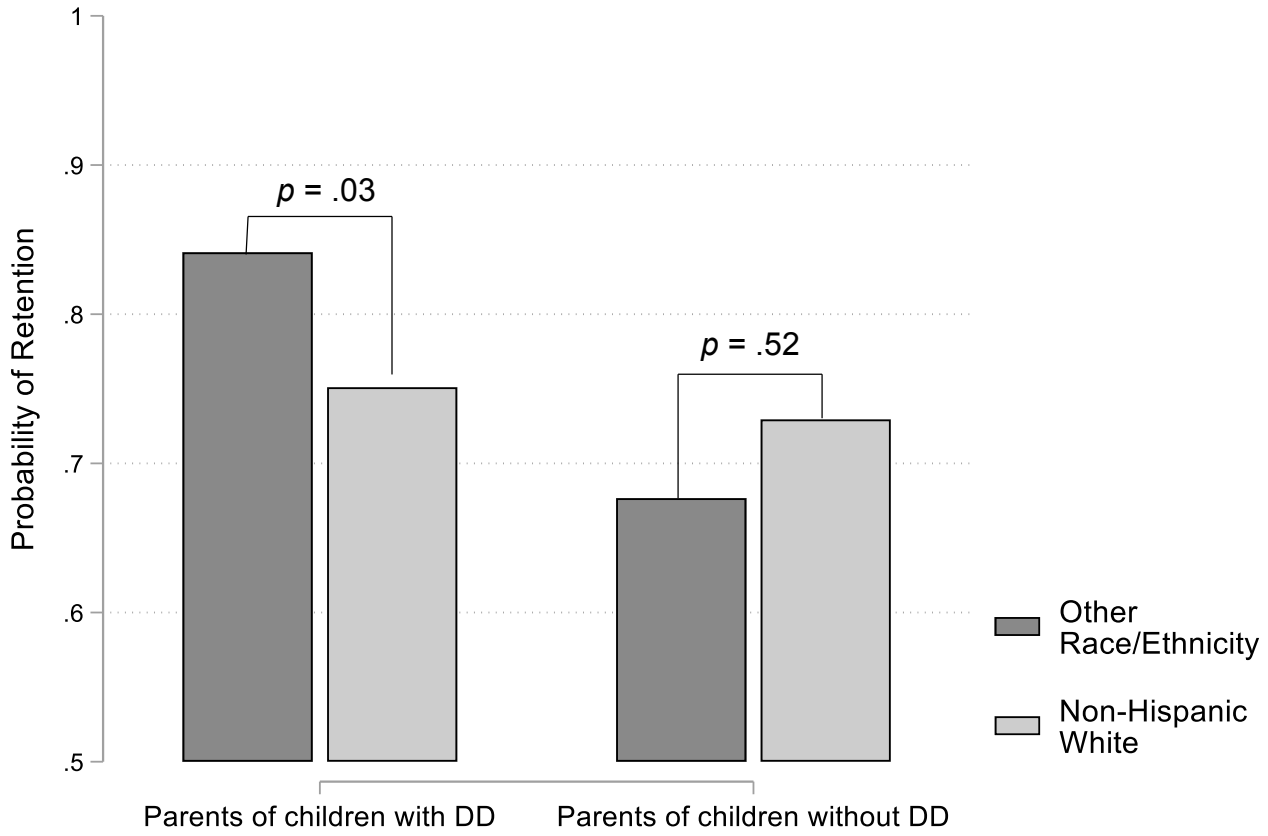

Fig. 1. Probability of Retention between MIDUS 2 (2004-2006) and MIDUS 3 (2013-2014) by DD Parenting Status and Race/Ethnicity (Note: DD = Developmental disabilities).

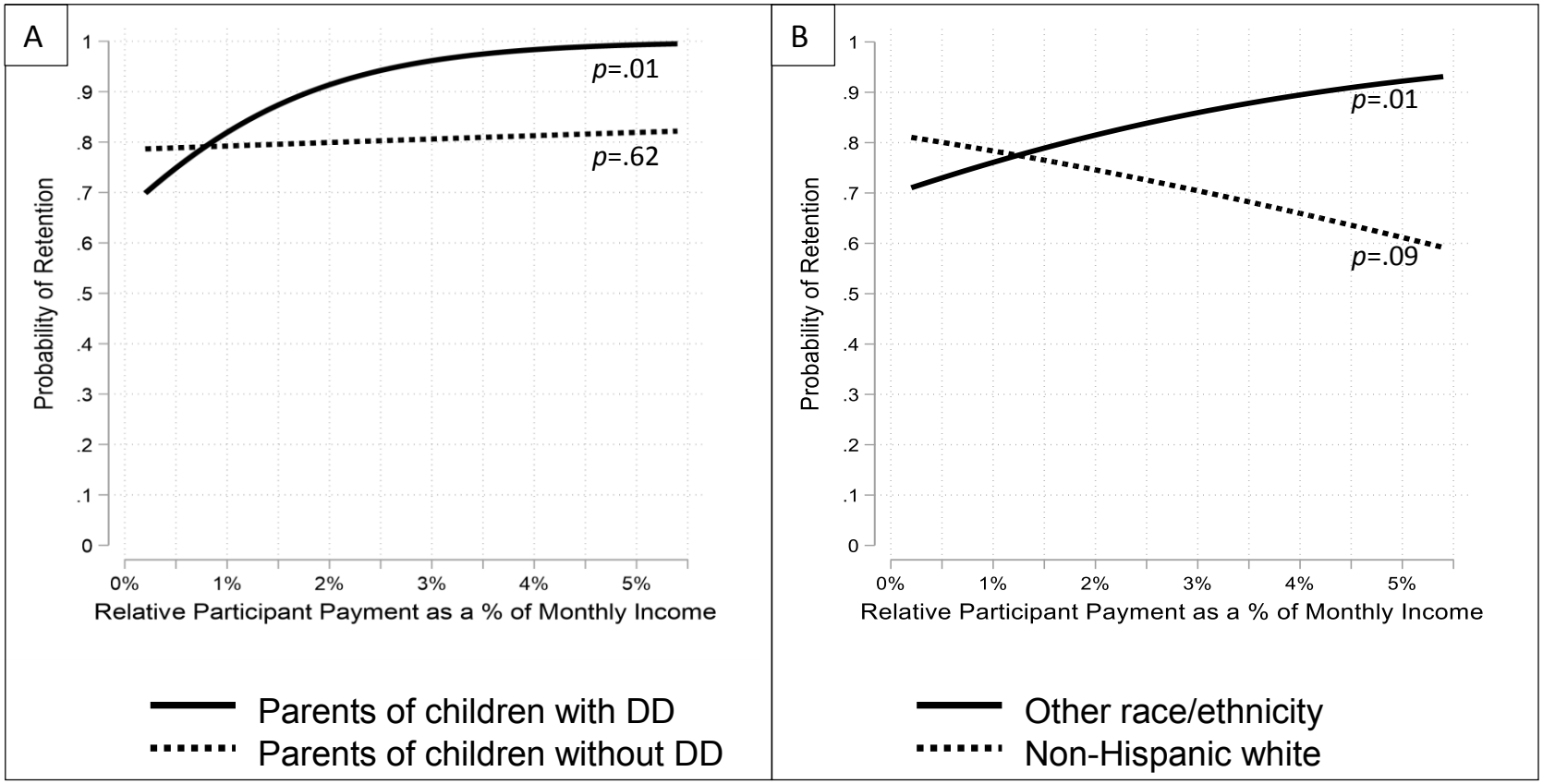

Fig. 2. Probability of Retention between MIDUS 2 (2004-2006) and MIDUS 3 (2013-2014) by DD Parenting Status and Relative Participant Payment (A) and by Race/Ethnicity and Relative Participant Payment (B) (Note: DD = Developmental disabilities).