

Improving Retention of Diverse Samples in Longitudinal Research on Developmental Disabilities

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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 Midlife in the United States, 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

Across the fields of science, it is increasingly evident that research samples need greater diversity to adequately represent the population (The Editors, 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., Haverkamp et al., 2019; Schalock et al., 2021), whereas 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 [ASD]; attention-deficit/hyperactivity disorder [ADHD]), 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 United States have 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” (Zablotsky et al., 2019, p. 2). Defined as such, more than 1-in-6 children in the U.S. are reported to have a DD. 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 underrepresentation 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 United States. 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, ASD, ADHD, learning disabilities), guided by the CDC's broad definition of DD.

Parents of children with DD are known to differ from parents of nondisabled 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 nondisabled individuals (Miodrag & Hodapp, 2010; Scherer et al., 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 nondisabled children in longitudinal, population-based research.

Importantly, racial/ethnic differences in study participation and retention also contribute to the nonrepresentativeness of DD (Johnson et al., 2021; Maye et al., 2021). Whites are known to 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 National Institute on Health-funded national probability sample of noninstitutionalized, 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 subgroups 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 previous literature, we hypothesized that (a) parents of individuals who have DD would be less likely to be retained in longitudinal studies than parents of nondisabled 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 nonretention 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 nonlinear (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 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 socioeconomic status [SES]) sample of households ($n = 592$) from Milwaukee, WI (Ryff et al., 2018), with longitudinal follow-up at MIDUS 3 ($n = 389$) (Ryff 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: (a) parents with a child with DD ($n = 226$) and (b) 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).

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.

Table 1
Diagnoses of Children With Developmental Disabilities

Variables	Non-Hispanic White	Other Race/Ethnicity
	<i>n</i> (%)	<i>n</i> (%)
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)
<i>n</i>	176	50

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

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 \times 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 \times parenting status \times 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%).

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 9 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.

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 \times 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.

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

Table 2

Descriptive Statistics of Parents of Children With Developmental Disabilities and Comparison Parents Across Racial/Ethnic Groups in MIDUS 2 (2004–2006) and MIDUS 3 (2013–2014) Surveys

Variables	Parents of children with DD		Comparison parents		Group Difference ^b
	Non-Hispanic White (A) <i>M (SD) or %</i>	Other Race/Ethnicity (B) <i>M (SD) or %</i>	Non-Hispanic White (C) <i>M (SD) or %</i>	Other Race/Ethnicity (D) <i>M (SD) or %</i>	
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
<i>n</i>	176	50	2,837	624	

Note. DD = developmental disabilities; MIDUS = Midlife in the United States.

^aRelative participant payment was calculated for the full sample: (Participant payment)*100/average monthly household income.

^bOne-way ANOVA and Duncan post-hoc tests were conducted for the group comparisons.

****p* ≤ .001.

a trend indicating that the higher the relative participant payment, the lower the probability of retention (*p* = .09).

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 subgroup 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) subgroups. 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 nondisabled 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; Chevreur et al., 2015; Kogan et al., 2008), further contributing to the

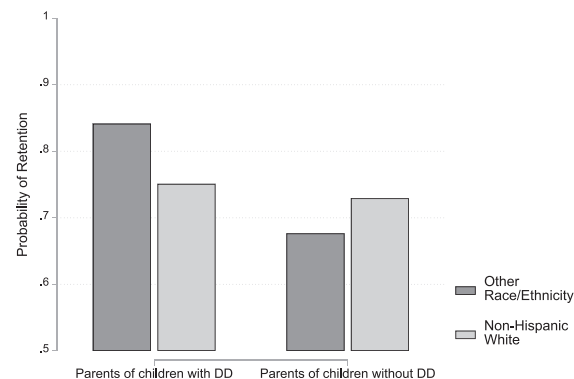
Table 3
Logistic Regression Models Predicting Retention Between MIDUS 2 (2004–2006) and MIDUS 3 (2013–2014) by Parenting Status and Race/Ethnicity

Variables	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

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

^aRelative 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.

Figure 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; MIDUS = Midlife in the United States.

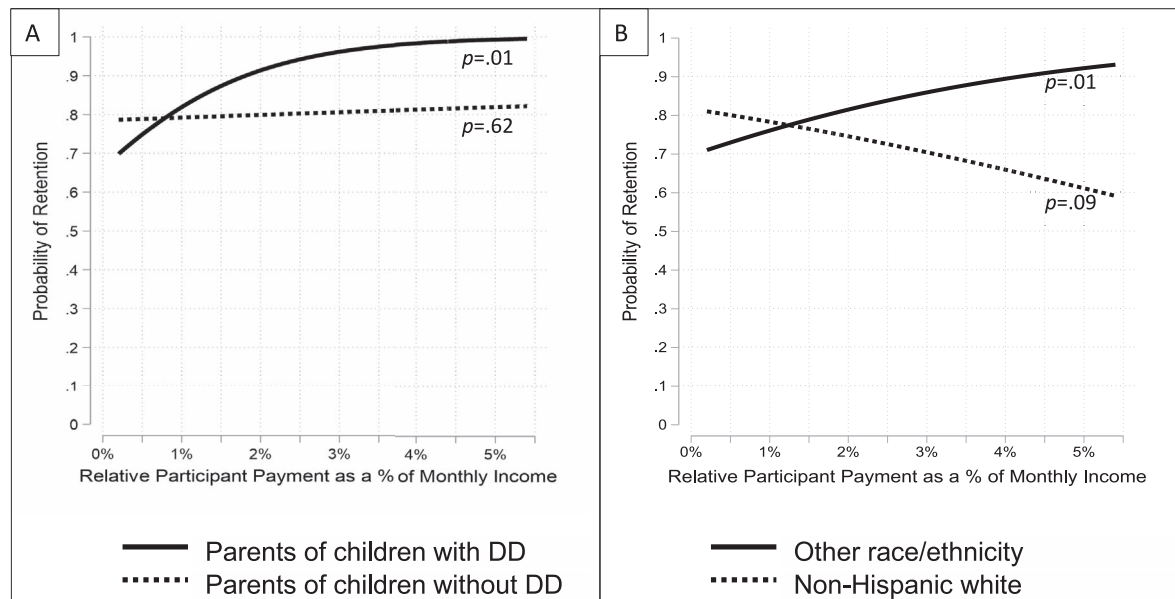
value of the participant payment and motivating continued participation.

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 subgroups of potential research participants, especially when subgroups 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

Figure 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; MIDUS = Midlife in the United States.

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 nondisabled 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 subgroups except for non-Hispanic White parents of nondisabled 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* (The Editors, 2021) “solving this problem [representing racial diversity] will require changes throughout the research enterprise” (p. 1429). 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 e.g., 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 subgroups in population data sets (see e.g., Seltzer et al., 2010; Smith et al., 2010). Data for matching subgroups 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 et al., 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 subgroup 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.

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