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Age-related trajectories of health and cognition in mothers of children with developmental disabilities: Longitudinal findings from two independent studies

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ABSTRACT

Developmental disabilities are a heterogenous group of disorders characterized by impairments in physical functioning, learning, language, behavior, and self-care (Zablotsky et al., 2019). Parenting a child with a developmental disability can be a profound source of stress, particularly for mothers. This atypical parenting experience can begin with the birth of the child, or soon thereafter, and continues over the life course, often extending six decades or more. However, there is limited research on the impact of this parenting role across the full adult life course – from mothers' early years of parenting through older age. Here we draw on data from two separate studies, one a national study of mothers of children with a range of developmental conditions (n = 96) and the other a community study of mothers of children with autism (n = 391). We used an accelerated longitudinal design to estimate mothers' trajectories of health, mental health, and cognitive functioning beginning in their 20s and extending until their 80s or beyond, and conducted a series of cohort and sensitivity analyses. Together, the results of analyses of these two studies revealed very similar patterns across a number of important outcomes. The inclusion in one of the studies of a nationally representative comparison group of mothers whose children did not have disabilities (n = 1,181) indicated that after around age 65, aging in mothers of children with developmental disabilities differed from the norm, suggesting the 'wear-and-tear' effects of this common form of stressful parenting.

1. Introduction

In the United States, approximately 1 in 6 children has a developmental disability, a heterogenous group of disorders characterized by impairments in physical functioning, learning, language, behavior, and self-care (Zablotsky et al., 2019). Developmental disabilities include autism, Down syndrome, and intellectual disability, among others. Parenting a child with a developmental disability can be a profound source of stress, particularly for mothers (Miodrag and Hodapp, 2010; Dembo et al., 2022). This atypical parenting role can begin with the birth of the child, or soon thereafter, and continues into parents' old age. As developmental disabilities last a lifetime, most parents continue to provide care and support even as their children reach adulthood, often extending as long as six decades (Chamak and Bonniau, 2016). However, there is little research examining the impacts of parenting a child with a developmental disability over the life course, particularly in contrast to parents of children without developmental disabilities. In the present study, we analyze data from a national sample to assess differences in the age-related health trajectories of mothers of children with a diverse range of developmental disabilities, as well as those of a comparison group, over six decades. We also present the results of an independent study from a separate longitudinal cohort of mothers of autistic sons and daughters to assess whether there are similar patterns of life course health trajectories as observed in the national sample.

While it is normative for aspects of parenting to be difficult, those who have children with developmental disabilities face many unique stressors. Challenges include managing persistent physical and behavioral symptoms (Miodrag and Hodapp, 2010), navigating educational (Burke and Hodapp, 2014) and health care service systems (McManus et al., 2011), experiencing stigma and discrimination (Song et al., 2018), and planning for uncertain futures (Marsack-Topolewski and Graves, 2020). Past research has

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documented that mothers tend to be the primary family member filling these unique caregiving roles (Woodman, 2014; Roper et al., 2014) and therefore we focus on mothers of children with developmental disabilities in the present research. Prior studies, most of which focused on the early decades of parenting, have found that parents of children with developmental disabilities are more likely to experience depression (Scherer et al., 2019), psychological distress (Keenan et al., 2016), anxiety (Jones and Reilly, 2016), and a greater number of physical health symptoms (Lovell et al., 2021) and chronic conditions (Gallagher and Hannigan, 2014) compared to parents of children without developmental disabilities. These findings, based on both self-reported and biomarker data, are consistent with a wear-and-tear process, wherein the exposure to this type of chronic stress results in physical and mental health problems (Miodrag et al., 2011).

Narratives of adaptation by parents of children with developmental disabilities (Beighton and Wills, 2019) and cross-sectional age group comparisons (Barker et al., 2014) describe how coping and social support may moderate the stresses that emanate from the challenges of caregiving. However, very limited research has demonstrated that patterns of adaptation are the dominant or prevalent response to parenting a child with a developmental disability. The potential for both wear-and-tear and adaptive processes to occur may result from the varying effects of stress at different points in the lifespan. Longitudinal data are needed to characterize such complex and nuanced trajectories in parents' health over the life course. This is especially important because the needs and challenges of individuals with developmental disabilities change over time (Smith et al., 2012; Fisher et al., 2016).

To date, research concerning parents of children with developmental disabilities remains largely cross-sectional, and longitudinal studies tend to either focus on changes over a short duration (Gallagher et al., 2018), changes among cohorts of parents at single life stages (usually those with young children) (Cheng et al., 2015), or changes indexed by chronological time rather than by parental age (Sloan et al., 2020). Furthermore, because prior studies rarely include comparison groups of parents drawn from the general population, it is unclear whether the longitudinal changes in parents' health that have been reported are a function of normative aging or due to the impacts of chronic parenting stress – or the interaction between the two.

The present research is guided by a stress process theoretical model (Pearlin et al., 2005; Folkman and Lazarus, 1986) whereby the experience of parenting a child with a developmental disability is characterized by stress, which in turn contributes to compromised parental health. We begin with a study that uses nationally representative data to estimate differences in maternal well-being longitudinally across six decades of parenting. The key hypothesis, guided by the stress process model and past research on the types of stress experienced by these parents, is that mothers of children with developmental disabilities will manifest poorer well-being across the decades of parenting, particularly during midlife and older age, than mothers whose children do not have disabilities. We then conduct a second study to delve into child-related sources of stress (behavioral, cognitive, and health challenges) that may contribute to mothers' health over the life course.

Other theoretical models inform this research, including theories of stress proliferation (Pearlin et al., 1997; Thoits, 2010) and cumulative disadvantage (Ferraro et al., 2009; Dannefer, 2003). Studies have shown that the challenges of parenting a child with a developmental disability may proliferate and lead to other stressors, such as material hardship due to high financial costs of care (Stabile and Allin, 2012) and reduced participation in the workforce (Cidav et al., 2012), ultimately affecting parental well-being. Furthermore, prior research suggests that the stressors which emanate from parenting a child with a developmental disability may result in subsequent disadvantages that accumulate over the life course (Houle and Berger, 2017), posing increasing threats to parents' health. These theoretical models underscore the need to extend beyond prior research to trace the longitudinal health trajectories that result from long-term parenting stress, particularly through midlife and older age.

1.1. The present research

Fig. 1 presents a graphic description of the workflow of the present research. We investigate the same overarching research question in two separate studies. First, we draw upon data from the Midlife in the United States (MIDUS) study (Brim et al., 2020) to examine the longitudinal age-related trajectories in health and cognition in mothers of children with developmental disabilities and a comparison group of mothers of children without developmental disabilities. We then augment the MIDUS study with a separate analysis of data drawn from a different longitudinal cohort of mothers participating in the Adolescents and Adults with Autism study (Hong et al., 2023; Seltzer et al., 2003). The two current studies share the same over-arching goal, namely to characterize age-related trajectories of physical and mental health over the decades of adulthood in mothers of individuals with developmental disabilities. However, the two studies differ in some methodological factors, such as heterogeneity of specific conditions of children of participating mothers, the number of waves of data collection, and the measures operationalizing the outcomes. Additionally, the MIDUS study offers the inclusion of a comparison group of parents of children without developmental disabilities, while the Adolescents and Adults with Autism study provides data on the effects of child behavioral, cognitive, and health challenges on maternal well-being. The present research makes it possible to determine if the overall patterns of age-related trajectories in the two studies are similar, particularly during midlife and older age, despite these methodological differences.

2. Methods

2.1. Study 1: Midlife in the U.S. (MIDUS) study

Study 1 analyzed data from MIDUS (Brim et al., 2020), a longitudinal study that began in 1995–1996 with a national probability sample of 7,108 non-institutionalized, English-speaking adults. Participants were aged 25–74 years at MIDUS 1. Data were collected via telephone interviews and self-administered questionnaires. Follow-up studies were conducted in 2004–2006 (MIDUS 2, n = 4,963) and in 2013–2014 (MIDUS 3, n = 3,294) when participants were aged 35–84 years and 44–94 years, respectively (Ryff et al., 2017, 2019). The mortality-adjusted retention was 75% from MIDUS 1 to MIDUS 2 and 77% from MIDUS 2 to MIDUS 3.

For the present research, we compared MIDUS mothers of children with developmental disabilities (n = 96) to a comparison group of mothers (n = 1,181), defined below. With repeated measurements, the mothers of children with developmental disabilities and the comparison group contributed 262 and 2,960 observations to the analysis, respectively. Mothers ranged in age from 25 to 91 years across the three MIDUS waves. At MIDUS 1, mothers of children with developmental disabilities and comparison group mothers did not differ in age (M = 45.63 years, SD = 10.97 and M = 46.91 years, SD = 12.19, respectively; p = .32). Mothers of children with developmental disabilities were more likely to be retained through MIDUS 3 than comparison group mothers (78% vs. 67%, $\chi^2 = 6.08$, p = .014) (Song et al., 2023).

2.1.1. Sample ascertainment

Child developmental disability status was first ascertained at MIDUS 2 when mothers were asked whether each of their children had a developmental disability and, if so, to specify the condition and age of symptom onset. Notably, mothers indicated the age when symptoms were first evident, not age of clinical diagnosis; this was important because the "diagnostic odyssey" between symptom onset and obtaining a specific diagnosis often takes years (Lappé et al., 2018; Okoniewski et al., 2019). Only mothers who were parenting a child with a

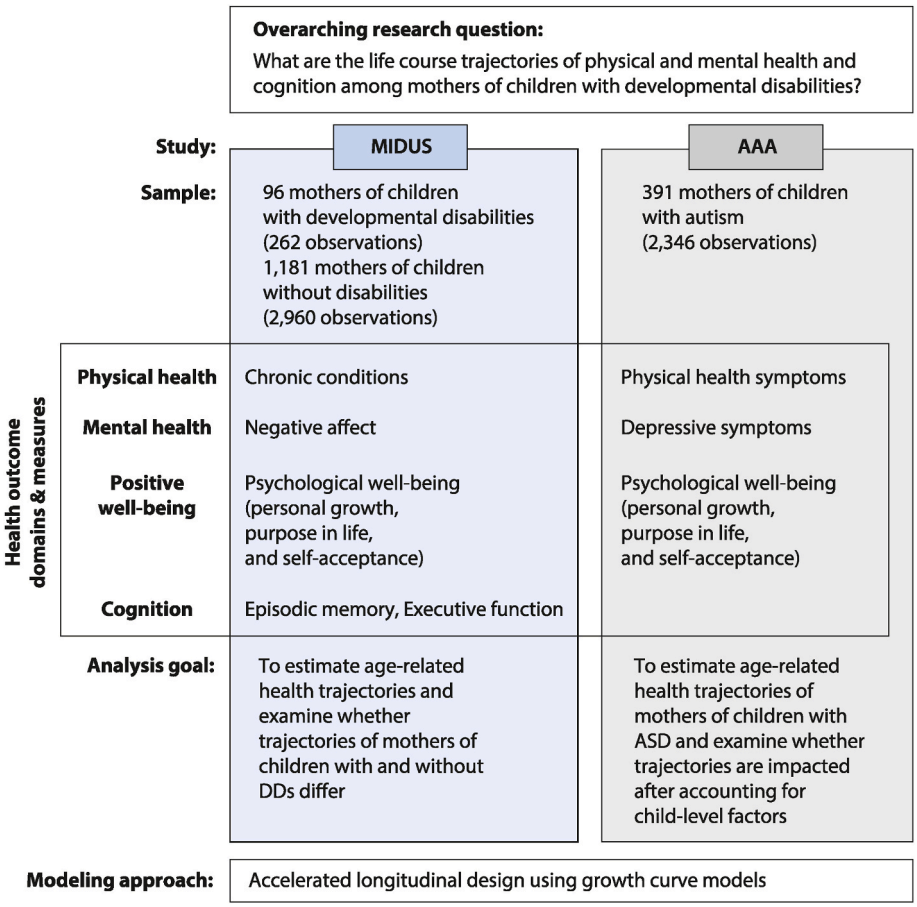

Fig. 1. Study design and workflow.
Note: MIDUS - Midlife in the United States; AAA - Adolescents and Adults with Autism.

developmental disability prior to their participation in MIDUS 1 were included in the developmental disability group.

Similarly, the comparison group only included mothers who became parents prior to MIDUS 1. From the comparison group, we excluded mothers of any children who had a developmental disability or mental health condition, those who had ever provided disability-related care to a family member for one month or longer, and those who had experienced the death of any children, similar to past research (Song et al., 2023).

Mothers in MIDUS who had a child with a developmental disability reported a range of conditions, including learning disability (22.92%), ADD/ADHD (19.79%), autism spectrum disorder (10.42%), cerebral palsy (8.33%), epilepsy and seizure disorder (7.29%), intellectual disability (7.29%), and Down syndrome (5.21%). Other less prevalent developmental disabilities together accounted for 18.75% of cases.

At MIDUS 1, mothers ranged in age from 25 to 75 years (M = 46.81, SD = 12.10). They had a median household income of $54,750; more than one-third of mothers (34.18%) had incomes below the 1995 poverty threshold for a family of four ($15,569) (Baugher and Lamison, 1996). Mothers were primarily white, non-Hispanic (89.01%) and most were married (74.31%).

2.1.2. Measures

Outcomes. All outcomes were assessed at MIDUS 1, 2, and 3 except measures of cognition which were assessed at MIDUS 2 and 3 only (see https://midus.wisc.edu). Regarding *chronic health conditions*, mothers reported on whether they experienced or had been treated for 28 chronic conditions in the last year (e.g., hypertension, diabetes) (Agrigoroaei et al., 2017). A count of the conditions was used in the present analysis. *Negative affect* was measured as the mean of six items, each referring to a negative affective state experienced in the past 30 days (i.e., so sad nothing could cheer you up; nervous; restless or fidgety; hopelessness; everything was an effort; worthlessness) (Mroczek and Kolarz, 1998). Higher scores on the scale indicate greater negative affect. *Psychological well-being* was measured via three subscales drawn from Ryff's eudaimonic framework (Ryff, 1989): personal growth, purpose in life, and self-acceptance, each comprised of 3 items. We analyzed these subscales to align with the data available in the Adolescents and Adults with Autism study (described below). We constructed the psychological well-being scale by taking the mean of the 3 subscales, with higher scores reflecting greater well-being. *Episodic memory* and *executive functioning* were separate measures of cognition assessed via the Brief Test of Adult Cognition by Telephone (BTACT) (Lachman et al., 2014). For both measures, higher scores reflect better cognitive functioning.

Key Predictor. Maternal age, measured at each MIDUS wave, was the key predictor in the analysis.

Characteristics of mothers. Three characteristics of mothers were included as covariates. *Educational attainment* (0 = less than college degree, 1 = college degree or more) is an indicator of socioeconomic status and has robust associations with physical and mental health across the life course (Cohen et al., 2020; Johnson-Lawrence et al., 2017). Two additional variables were included to address the possibility that poor health in earlier life may have predisposed mothers to worse physical and mental health trajectories. At MIDUS 1, respondents retrospectively rated their *physical* and *mental health at age 16* on separate five-point scales (0 = Poor to 4 = Excellent). 'Physical health at 16' was included as a covariate in the chronic conditions model and 'mental health at 16' was included as a covariate in the negative affect and

psychological well-being models.

2.2. Study 2: Adolescents and adults with autism study

Study 2 analyzed data from an ongoing longitudinal study of families of autistic adolescents and adults. The study began in 1998 with families of 406 autistic adolescents and adults in Wisconsin (n = 202) and Massachusetts (n = 204). Participating families met three criteria upon recruitment: (1) the family had a son or daughter who had received a diagnosis on the autism spectrum from a health or educational professional; (2) the autistic son or daughter was at least 10 years old; and (3) a researcher-administered Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994) profile was consistent with the diagnosis. The key respondent in the present analysis was the mother of the autistic son or daughter (n = 391, 96.31%); fathers or other family respondents were not included in this analysis, as it focuses on mothers.

The present research used repeated measures of data collected from mothers over nine waves (Time 1–9), between 1998 and 2022. On average, waves of data collection occurred 18 months apart, with the exceptions of Time 4 and 5 (42 months apart) and Time 8 and 9 (96 months apart). During each wave of data collection, mothers were interviewed and completed questionnaires. The 391 mothers contributed 2,346 observations to the analysis.

At Time 1, the autistic sons and daughters ranged in age from 10 to 52 years (M = 21.45, SD = 9.47) and their mothers ranged in age from 32 to 81 years (M = 50.67, SD = 10.44). Mothers had a median household income of between $45,000 and $50,000 at Time 1. Notably, 14.47% earned less than $20,000 per year, when the US federal poverty level was $17,050 for a family of four (Office of the Federal Register, 2000). Mothers were primarily white, non-Hispanic (92.35%) and most were married (78.29%).

2.2.1. Measures

Outcomes. As in the MIDUS study, the outcomes measured for mothers in the Adolescents and Adults with Autism study included physical and mental health indicators, although no repeated measure of cognition was available. At Times 2–7, mothers in the Adolescents and Adults with Autism study reported whether they experienced 18 *physical health symptoms* in the past six months (e.g., headaches, dizziness). A count of the number of symptoms was used in the analysis. Maternal *depressive symptoms* was measured at Times 1–9 using the 20-item Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). Higher scores indicate greater levels of depressive symptoms. *Psychological well-being* was measured at Times 1, 3, 5, 7, and 9. The mean of items in three of Ryff's subscales (Ryff, 1989) (personal growth, 4 items; self-acceptance, 4 items; purpose in life, 5 items) were summed to create the measure of psychological well-being analyzed in the Adolescents and Adults with Autism study.

Key Predictor. Maternal age, measured at each wave, was the main predictor variable in the analysis for Study 2.

Characteristics of mothers and autistic individuals. Educational attainment of the mother was reported at Time 1 (0 = less than college degree, 1 = college degree or more). In addition, we examined whether five characteristics of the autistic sons and daughters were associated with maternal outcomes. *Sex* (0 = male, 1 = female) was reported at Time 1. *Intellectual disability* (ID) *status* was measured by the Wide Range Intelligence Test (Glutting et al., 2000) and the Vineland Screener (Sparrow et al., 1993). Based on diagnostic guidelines (Luckasson et al., 2002), individuals with scores of 70 or below on these measures were classified as having ID (0 = no ID, 1 = ID).

Three other characteristics of the autistic individuals that were found in past research to be associated with the health of their mothers (Namkung et al., 2018; Valicenti-McDermott et al., 2015; Dembo et al., 2023) were included, and modeled as time-varying covariates. *Maladaptive behavior* was measured at Times 1–9 using the Scales of Independent Behaviors-Revised (SIB-R) (Bruininks et al., 1996). The General Maladaptive Behavior Index of the SIB-R captures the frequency and severity of internalized, externalized, and asocial behaviors exhibited during the past 6 months, with higher scores reflecting more severe behavior challenges. *Health status* (1 = Poor to 4 = Excellent) and *residential status* (0 = co-residing with the mother, 1 = living elsewhere) of the autistic individuals were reported by mothers at Times 1–9.

2.3. Statistical analysis for studies 1 and 2

Although Study 1 and Study 2 differed in several dimensions, the overall approach to the data analysis for the two studies was similar. For both studies, we used an accelerated longitudinal design (Galbraith et al., 2017) (ALD) to estimate trajectories. For each outcome, multiple short-term longitudinal trajectories from each mother were combined to estimate a single long-term longitudinal trajectory for the sample. In doing so, the ALD enables the estimation of a growth trajectory that covers a wider age range than the duration of the longitudinal study, i.e., from the age of the youngest mother at the start of the longitudinal period to the age of the oldest mother at the end (Hong et al., 2023; Galbraith et al., 2017). Specifically, for Study 1, mothers were aged 25–75 years at MIDUS 1 and 41–91 years at MIDUS 3. Thus, while mothers in the analytic sample from MIDUS were followed for an average of 15 years, we modeled trajectories over a 66-year period. In Study 2, mothers were aged 32–81 years at the first wave of data collection and 55–91 years at the last. Mothers in the Adolescents and Adults with Autism study were followed for an average of 22 years, and we modeled their age-related trajectories over a 59-year period. Each dependent variable was modeled separately to estimate its distinct age-related trajectory and to identify its unique associations with predictors. Graphs were generated to illustrate the estimated age-related trajectories and are presented in Fig. 2, with trajectories of common constructs in the MIDUS and Adolescents and Adults with Autism studies

Table 1
MIDUS: Baseline descriptive statistics of mothers of children with and without developmental disabilities.

	Mothers of Children with Developmental Disabilities % or M (SD)	Mothers of Children without Developmental Disabilities % of M (SD)
N	96	1,181
Characteristics of Mothers		
Age[1]	45.63 (10.97)	46.91 (12.19)
College degree	22.92	26.59
Physical health at 16 (0 = Poor, 4 = Excellent)	3.27 (0.90)	3.43 (0.81)
Mental health at 16 (0 = Poor, 4 = Excellent)	2.97 (1.03)	3.09 (1.03)
Outcomes		
Number of chronic conditions[1]	2.5 (2.59)	2.30 (2.31)
Negative affect[1]	1.76 (0.85)	1.54 (0.61)
Psychological well-being[1]	16.07 (2.69)	16.68 (2.33)
Episodic memory[2]	0.24 (1.01)	0.21 (1.00)
Executive function[2]	−0.14 (1.11)	−0.10 (0.98)

Notes: (1) At MIDUS 1; (2) At MIDUS 2.

plotted side by side.

To test cohort effects, we assessed whether age-related trajectories differed depending on the age of the mother at baseline. In both the MIDUS and Adolescents and Adults with Autism analyses, we included interactions between maternal age at the first wave of data collection and the maternal age trajectory term in the final model. A significant interaction would indicate differences in trajectories between those who were younger versus older when the study began. There were no cohort effects detected for any outcome for either study (see Supplemental Materials).

As a final step, sensitivity analyses were conducted in both studies to further probe whether additional characteristics of the mother potentially confounded the age-related patterns tested in the ALD models. In both studies, the original model included a variable measuring college degree attainment, and in the sensitivity analyses variables measuring household income and marital status were also included, all of which were sociodemographic factors that could potentially impact the age-related trends tested here. Additionally, we included two measures of stress exposure in the sensitivity analysis. Specifically, in the MIDUS study, a measure of childhood disadvantage was included (in addition to the measures of maternal health at age 16, which were estimated in the original models); in the Adolescents and Adults with Autism study, a measure of stressful life events that occurred during the decades of parenting was included (in addition to the measures of potentially stressful child characteristics that were estimated in the original models). In the MIDUS study, we also controlled for the educational attainment of the mothers' parents as a further attempt to reduce potential historical confounders. Finally, another set of sensitivity analyses included estimates based on subsets of the participants to probe whether attrition altered the results. Even with these robust sensitivity analyses, there were no changes to any of the estimated significant age effects in the ALD models in either of the studies. See the Supplemental Materials for tables presenting the sensitivity analyses.

Analyses were conducted in Stata 17 (StataCorp, 2021). All outcomes were treated as continuous variables. As ALD uses Maximum Likelihood (ML) estimation, mothers who participated in a greater number of time points had a greater influence on the age-related trajectory estimates.

3. Results

3.1. Study 1: MIDUS descriptive results

Table 1 presents descriptive characteristics of the MIDUS sample. Mothers of children with developmental disabilities did not significantly differ from comparison group mothers in their age, rates of college degree attainment (approximately one-quarter completed college), retrospective appraisals of physical health at age 16 (averaging between a rating of good and excellent), or mental health at age 16 (averaging a rating of good). With regard to the outcome measures at baseline, mothers of children with developmental disabilities had significantly higher levels of negative affect ($t = 3.23$, $p = .001$) and significantly lower levels of psychological well-being ($t = 2.35$, $p = .019$) than the comparison group. The two groups did not differ in baseline levels of chronic conditions, episodic memory, or executive function.

3.2. Study 1: MIDUS longitudinal results

Statistical Analysis. In addition to the general approach to the data analysis described above, for MIDUS, our specific approach involved fitting a series of mixed-effects growth curve models with polynomial functions of age. For the chronic conditions, negative affect, and psychological well-being models, age was centered at 25, the youngest age of sample members at MIDUS 1. For the cognition models, however, age was centered at 33, corresponding with the youngest age of sample members at MIDUS 2 when the BTACT was first administered.

We built the models as follows. First, we fit a main effects model (Model 1) to estimate the effect of maternal group (child with a developmental disability versus comparison), a linear age term, and covariates to assess whether there was a main effects difference in the age-related trajectories between mothers of children with developmental disabilities and the comparison group. Next, in Model 2, we assessed whether the shape of the trajectories in the outcomes differed for mothers of children with developmental disabilities versus the comparison group. To do so, we tested the interactions between the maternal group variable and linear, quadratic, and cubic age terms; we interpret the results of the model with the highest-order age term interaction that was statistically significant. Model 1, the main effects model, is

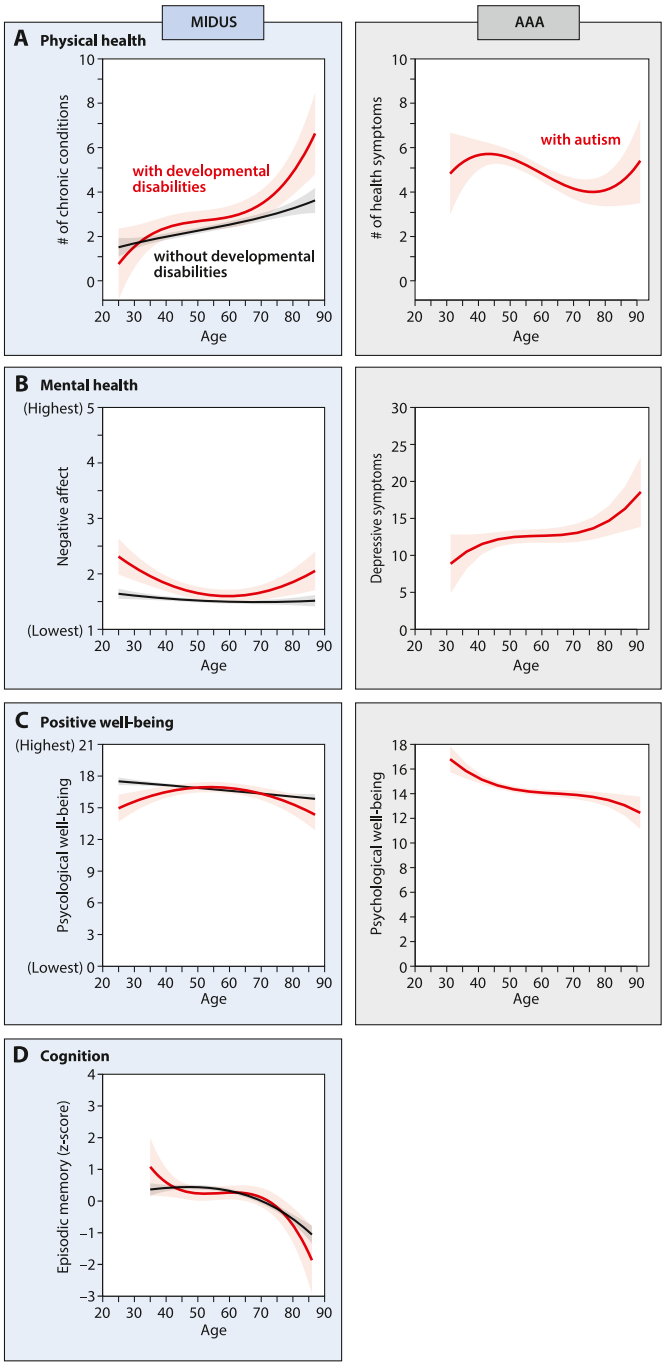

Fig. 2. Health trajectories of mothers of children with and without developmental disabilities (MIDUS) and mothers of children with autism (AAA).
Note: MIDUS - Midlife in the United States.
Note: AAA - Adolescents and Adults with Autism.

Table 2
MIDUS: Trajectories of chronic conditions, negative affect, psychological well-being, and cognition in mothers of children with and without developmental disabilities.

	A: Chronic Conditions		B: Negative Affect		C: Psychological Well-Being		D. Episodic Memory		E. Executive Function
	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1	Model 2	Model 1
Fixed Effects									
Maternal group (1 = has child with developmental disability)	0.44* (0.19)	−0.58 (0.79)	0.19*** (0.05)	0.67*** (0.003)	−0.23 (0.23)	−2.55*** (0.67)	−0.03 (0.09)	1.00 (0.63)	−0.05 (0.08)
Age	0.03*** (0.004)	0.06* (0.03)	−0.002** (0.001)	−0.01* (0.003)	−0.02*** (0.004)	0.02 (0.01)	−0.02*** (0.002)	0.01 (0.02)	−0.03*** (0.002)
Age^2	–	−0.001 (0.001)	–	0.0001 (0.00005)	–	−0.0001 (0.0002)	–	−0.0002 (0.001)	–
Age^3	–	0.00001 (0.00001)	–	–	–	–	–	−0.00001 (0.00001)	–
Maternal group X Age	–	0.15 (0.10)	–	−0.03** (0.01)	–	0.16*** (0.04)	–	−0.16* (0.08)	–
Maternal group X Age^2	–	−0.006 (0.003)	–	**0.001**** **(0.0002)**	–	**−0.002**** **(0.001)**	–	0.01* (0.003)	–
Maternal group X Age^3	–	**0.0001* (0.00004)**	–	–	–	–	–	**−0.0001* (0.00004)**	–
College degree	−0.36** (0.11)	−0.37** (0.11)	−0.15*** (0.03)	−0.15*** (0.03)	1.46*** (0.14)	1.45*** (0.14)	0.38*** (0.06)	0.35*** (0.06)	0.47*** (0.05)
Physical health at age 16	−0.20** (0.06)	−0.19** (0.06)	–	–	–	–	–	–	–
Mental health at age 16	–	–	−0.12*** (0.01)	−0.12*** (0.01)	0.41*** (0.06)	0.41*** (0.06)	–	–	–

Notes. ***p < .001, **p < .01, *p < .05. Standard errors in parentheses.

informative of overall age-related patterns with respect to the dependent variables, and separately, whether there are maternal group differences in these variables assuming a linear effect of age. In Model 2, using interaction terms, we explore nonlinear age effects (i.e., quadratic, cubic) and whether they differ by maternal group. Then, for illustrative purposes, we plotted the results of the interaction terms (see Fig. 2) to depict patterns of stability and change separately for the two groups of mothers in this study. For each model, the significance of the random intercept variance and random slope variance was tested.

Chronic Conditions. Table 2A presents the results of the chronic conditions analysis. As shown in Model 1, mothers of children with developmental disabilities had a significantly greater number of chronic conditions than comparison group mothers (b = 0.44, p = .021). There was also a significant main effect of age on the number of chronic conditions, with older age associated with a greater number of conditions (b = 0.03, p < .001).

As shown in Model 2, the two groups differed in their longitudinal trajectories of chronic conditions; the differential age effects were cubic (maternal group X age^3: b = 0.0001, p = .041). Visual inspection of Fig. 2A (left panel) illustrates that, for mothers of children with developmental disabilities, the trajectory was characterized by an early increase in chronic conditions until around age 40, a gradual upward slope through the subsequent 30 years, followed by a sharp increase beginning at around age 70.

Negative Affect. Table 2B presents the results of the negative affect analysis. As shown in Model 1, mothers of children with developmental disabilities had significantly higher levels of negative affect than comparison group mothers (b = 0.19, p < .001). There was also a significant main effect of age (b = −0.002, p = .005), such that younger mothers had greater negative affect. Model 2 shows that there was a quadratic age-related trajectory in negative affect that differed between mothers of children with developmental disabilities and the comparison group (maternal group X age^2: b = 0.001, p = .003). Visual inspection of Fig. 2B (left panel) shows that, for mothers of children with developmental disabilities, the longitudinal trajectory resembled a U-shape, characterized by a decline in negative affect between ages 25 and 55 which preceded a decade of minimal change. Mothers of children with developmental disabilities then exhibited an increase in negative affect beginning at around age 65.

Psychological Well-being. Table 2C presents the results of psychological well-being analysis. As shown in Model 1, age was negatively associated with psychological well-being (b = −0.02, p < .001) but maternal group was not significantly associated with this outcome (b = −0.23, p = .31). However, as shown in Model 2, there was a quadratic differential age effect between the two maternal groups (maternal group X age^2: b = −0.002, p = .001). Visual inspection of Fig. 2C (left panel) shows that, for mothers of children with developmental disabilities, psychological well-being was initially lower than the comparison group, but increased between the approximate ages of 25 and 55. Psychological well-being subsequently plateaued for a decade, followed by a decline at around age 65.

Cognition. Table 2D presents the results of the analysis of episodic memory. As shown in Model 1, the main effect of the maternal group variable was not significant (b = −0.03, p = .77), but there was a significant main effect of age (b = −0.02, p < .001), with worsening memory with advancing age. As shown in Model 2, there was a cubic differential age effect between mothers with developmental disabilities and comparison group mothers (maternal group X age^3: b = −0.0001, p = .028). Visual inspection of Fig. 2D (left panel) suggests that mothers of children with developmental disabilities exhibited a decline in episodic memory during their 30s and early 40s, with subsequent stability between approximately age 45 and 65, followed by an accelerating decline beginning between ages 70 and 75.

The analysis of executive functioning showed a different pattern than the other outcomes. In Model 1 (Table 2E), the main effect of the maternal group variable was not significant (b = −0.05, p = .59) but there was a significant main effect of age (b = −0.03, p < .001), with a decline in executive functioning associated with advancing age. We do not present Model 2, as there were no significant interactions between the maternal group variable and any age polynomials in predicting executive functioning.

Covariates. College education was a significant predictor of each outcome; mothers with a college degree had significantly fewer chronic conditions, lower negative affect, greater psychological well-being, and better episodic memory and executive functioning as compared to those without a college degree. Mothers who had better physical health at age 16 had significantly fewer chronic conditions, while those who had better mental health at age 16 had lower negative affect and greater psychological well-being.

Table 3
Adolescents and Adults with Autism: Baseline descriptive statistics of mothers and autistic individuals.

	% or M (SD)
N	391
Characteristics	
College degree (mother)	45.48%
Child sex (female)	28.17%
Intellectual disability	68.73%
Behavior problems general score (Time 1)	115.58 (11.33)
Health (Time 1) (0 = Poor, 4 = Excellent)	3.19 (0.73)
Living outside family home (Time 1)	34.88%
Outcomes	
Number of health symptoms[1]	5.83 (3.50)
Depressive symptoms (CES-D)[2]	12.60 (9.99)
Psychological well-being[1]	14.56 (2.37)

Note: (1) At Time 1; (2) At Time 2.

3.3. Study 2: Adolescents and adults with autism descriptive results

Table 3 presents descriptive information about the mothers and their autistic adolescent or adult children. Nearly half of mothers had a college degree, a substantially higher proportion than in the MIDUS study. At Time 1, mothers reported an average of nearly 6 health symptoms and an average of just under 15 on the psychological well-being scale. With regard to depression, mothers had an average of 12.60 on the CES-D and one-third had scores ≥16, the threshold indicating risk for clinically significant depressive symptoms (Lewinsohn et al., 1997). With regard to characteristics of the autistic individuals, approximately one-quarter were female and about two-thirds had an intellectual disability. At Time 1, autistic individuals had between good and excellent health, on average. The mean behavior problem score was 115.58; 60% of autistic individuals had scores on the SIB-R ≥ 110, the threshold for clinically significant maladaptive behavior. About one-third of the autistic individuals were living outside of the family home at Time 1.

3.4. Study 2: Adolescents and adults with autism longitudinal results

Statistical Analysis. A similar ALD approach as employed in the MIDUS analyses was used to test for change in outcomes over time among mothers in the Adolescents and Adults with Autism study. The primary distinctions from the MIDUS analyses are that the Adolescents and Adults with Autism study does not include a comparison group but includes the estimation of models that covary key child-related factors. For each outcome, we first estimated a growth curve model with a linear age term and controlling for maternal education (Model 1). We then fit a series of growth curve models with linear, quadratic, and cubic age terms (modeled separately), to determine the shape of the trajectories. We interpreted the model with the highest-order age term that was statistically significant as Model 2. We also estimated a third model, Model 3, that evaluated whether the maternal age trajectories identified in Model 2 were altered by the inclusion of the autistic child's characteristics. As in the MIDUS analyses, maternal age was centered at the lower bound of the age range of the sample at the first point of measurement of each outcome (32 or 33 years of age). The significance of the random intercept variance and random slope variance was tested for each model.

Health Symptoms. Table 4 presents the results of the health symptoms analysis. As shown in Model 1 (Table 4A), the linear age term in predicting number of health symptoms was significant (b = −0.07, p < 0.001), indicating greater health symptoms in older age. The functional form of the age-related trajectory, which was assessed in Model 2, was cubic (b = 0.001, p = 0.003). This age term remained significant in Model 3 after inclusion of the characteristics of the autistic son or daughter (b = 0.0001, p = 0.014). Behavior problems and co-residence were significant child predictors. Visual inspection of Fig. 2A (right panel) suggests that the trajectory in number of health symptoms in these mothers was characterized by a small increase until around age 45, followed by a decline over the next three decades, and a subsequent increase again at around age 75.

Depressive Symptoms. Results of the depressive symptoms analysis are presented in Table 4B. The linear age term was not significant in Model 1 (b = 0.004, p = 0.87). However, as shown in Model 2, the functional form of the age-related trajectory was cubic (b = 0.0002, p = 0.035) and remained a strong trend in Model 3 after controlling for the characteristics of the autistic child (b = 0.0002, p = .052); notably, behavior problems and health status were significant child predictors. Visual inspection of Fig. 2B (right panel) suggests that maternal depressive symptoms increased until around age 45, followed by relative stability over the subsequent 25 years, and another increase at around age 70.

Psychological Well-being. Table 4C presents the results of the psychological well-being analysis. The linear age term was significant in Model 1 (b = −0.03, p < 0.001), indicating lower psychological well-being among younger mothers. As shown in Model 2, the functional form of the age trajectory was cubic (b = −0.0001, p = 0.01). The cubic age effect remained significant in Model 3 with the inclusion of the

Table 4
Adolescents and Adults with Autism: Trajectories of health symptoms, depressive symptoms, and psychological well-being among mothers of autistic individuals.

	A. Number of Health Symptoms			B. Depressive Symptoms			C. Psychological Well-Being		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
Fixed Effects (mothers)									
College degree	−0.46 (0.33)	−0.48 (0.33)	−0.56 (0.32)	−0.62 (0.88)	−0.58 (0.88)	−0.95 (0.86)	0.37 (0.23)	0.43 (0.23)	0.50* (0.23)
Age	−0.07*** (0.01)	0.14 (0.09)	0.13 (0.09)	0.004 (0.025)	0.23 (0.19)	0.34 (0.19)	−0.03*** (0.01)	−0.17** (0.05)	−0.20*** (0.05)
Age^2	–	−0.01** (0.00)	−0.01** (0.00)	–	−0.01 (0.01)	−0.01 (0.01	–	0.005** (0.002)	0.006** (0.002)
Age^3	–	0.0001** (0.0000)	**0.0001*** **(0.0000)**	–	0.0002* (0.0001)	**0.0002**† **(0.00001)**	–	−0.0001** (0.00002)	**−0.0001**** **(0.00002)**
Fixed Effects (autistic individual)									
Female	–	–	0.64 (0.36)	–		0.06 (0.96)	–	–	−0.23 (0.26)
Intellectual disability	–	–	0.06 (0.35)	–	–	−1.72 (0.93)	–	–	0.38 (0.25)
Behavior problems	–	–	0.03*** (0.01)	–	–	0.14** (0.02)	–	–	−0.02** (0.01)
Health (0 = Poor, 4 = Excellent)	–	–	−0.20 (0.11)	–	–	−0.97*** (0.27)	–	–	0.08 (0.08)
Resides outside of family home	–	–	−0.58** (0.21)	–	–	−0.87 (0.50)	–	–	0.11 (0.15)

Notes. ***p < .001, **p < .01, *p < .05, †p = .052. Standard errors in parentheses.

characteristics of the autistic son or daughter (b = −0.0001, p = 0.01), where behavior problems was the only significant child-related covariate. Visual inspection of Fig. 2C (right panel) suggests that mothers exhibited a decline in psychological well-being until around age 50, followed by stability over two decades, and a subsequent decline again beginning at around age 75. With respect to maternal characteristics, educational attainment was significantly associated with greater psychological well-being; educational attainment was not associated with the other outcomes.

4. Discussion

This research investigated age-related health trajectories among a national sample of mothers of children with a range of developmental conditions and among a separate cohort of mothers who had a child with autism. Using an accelerated longitudinal design, we estimated trends in mothers' physical and mental health over a 60-year period of time. Together, the analyses of these two samples revealed consistent patterns of stability and change in midlife and old age across a number of important outcomes.

Using MIDUS data, we examined whether there were differences in the average level of health, mental health, and cognition between mothers of individuals with developmental disabilities and comparison group mothers, and whether the shape of the trajectories differed between the two groups. We found that the trajectories of the two groups of mothers differed with respect to chronic conditions, negative affect, psychological well-being, and episodic memory. For these outcomes, there was a discernible acceleration in age-related decline in functioning for mothers of children with developmental disabilities beginning at around age 65–75, whereas for mothers in the comparison group, age-related change was more gradual. The reported trajectories illustrate the dynamic impacts of exceptional parenting, how these impacts unfold over the life course, and how they are patterned by lifelong caregiving responsibilities.

For Study 2, we used longitudinal data drawn from a community-based volunteer cohort to conduct a similar analysis focused solely on mothers of autistic adolescent and adult children. The two studies differed in several respects. The Adolescents and Adults with Autism study followed mothers for a longer period of time, had more frequent waves of data collection, and measured outcomes using similar though not identical indicators as the MIDUS study. In addition, the Adolescents and Adults with Autism study focused on the life course impacts of parenting an autistic child, whereas the sample ascertained in MIDUS included mothers of children with a diverse range of developmental conditions of varying severity. Despite these differences, the age-related trajectories for mothers in the Adolescents and Adults with Autism study were very similar to the findings from the MIDUS analysis, particularly during the mothers' midlife and older years. Importantly, both studies indicated accelerating vulnerability for mothers of children with developmental disabilities beginning at around age 65–75.

The results of cohort and sensitivity analyses demonstrated the robustness of the age-related findings. The patterns observed did not differ by the age of the mother at the start of the study, which ruled out cohort effects. The patterns also did not change when additional variables (both historical and concurrent) were included in the models to attempt to further reduce the possibility of confounding factors. Nor did the patterns change when subsets of the participants were included to model potential attrition effects. Thus, the conclusions regarding the aging of mothers of children with developmental disabilities remained strong and stable. Given the robustness of the results and the similarity of accelerated aging effects observed across two independent studies, strategies for supporting the health and well-being of these parents remain an unmet public health challenge.

One alternative explanation for the results, offered by some prior studies, is that physical and mental health challenges experienced by mothers of children with developmental disabilities may not only result from the impacts of caregiving, but possibly also from genetic vulnerability shared with the child (Fairthorne et al., 2014; Hodge et al., 2011). Given the heterogeneity of developmental disability diagnoses in the MIDUS analysis, the results of the present research do not lend support to this theory. Instead, the patterns of physical and mental health, psychological, and cognitive declines experienced by the mothers more likely reflect the cumulative effects of years of stressful parenting. While the impacts of parenting stress have been described previously (Barker et al., 2011; Masefield et al., 2020), the present research details a wear-and-tear process in mothers of children with developmental disabilities extending over six decades – a much longer period of time than has been previously reported. As the results of the growth curve models reveal, the effects of stressful parenting become most evident starting late in midlife, as mothers approach older age, marking a period of particular vulnerability for mothers of children with various developmental conditions. The results of the Adolescents and Adults with Autism study indicated that these cumulated effects were observed even when child characteristics known to affect the mental and physical health of their mothers were controlled.

In contrast, earlier in midlife, mothers of children with developmental disabilities exhibited relative stability in their health, and even periods of resilience in some outcomes. These variations and non-linearities are particularly important given that prior research often tends to portray the lives of parents of children with developmental disabilities dichotomously, as *either* burdensome and deleterious (Miodrag and Hodapp, 2010; Song et al., 2018) *or* as adaptive and resilient (Maul and Singer, 2009; McConnell et al., 2014). The results of the present research suggest a more nuanced picture. Here, we extend research results based on the Wisconsin Longitudinal Study (Seltzer et al., 2001, 2011) which found that, while in their early 50s, parents of children with developmental disabilities had similar physical health and psychological well-being as parents without exceptional caregiving responsibilities. However, by the time they reached their mid-60s, the normative health profiles had begun to fray, and parents of children with developmental disabilities exhibited worsening health relative to the comparison group. The present research builds upon this line of work by leveraging an accelerated longitudinal design with national and community samples, extending across a broader age range, implementing sensitivity and cohort analyses, and revealing converging patterns across different measures of physical and mental health.

The present research speaks to the need to strengthen policy and service delivery. Currently, family-focused supports and interventions are primarily targeted toward parents of younger children or those whose adolescent children are transitioning out of educational systems. Parenting, however, does not end after an individual with a developmental disability enters adulthood. Parents of children with developmental disabilities continue to provide significant care and assistance as their sons and daughters age, and this is also the case for parents whose adult children with developmental disabilities are no longer living with them (Marsack-Topolewski et al., 2024). As the results of the present analyses show, the chronic strain of stressful parenting accumulates over multiple decades. Policies and services are needed that can flexibly support families of children with developmental disabilities of all ages.

Interventions and services should also account for family-wide aging that includes the individuals who have developmental disabilities, their siblings, as well as their parents. Recent research has identified accelerated health declines for adults with developmental disabilities, including those with autism, fragile X syndrome, and Down syndrome (Hong et al., 2023; Bayen et al., 2018; Usher et al., 2020), that begins approximately in their 40s. The timing of these midlife health challenges in individuals with developmental disabilities corresponds to the point at which mothers in our study begin a more rapid decline across several outcomes. Investments are critically needed to strengthen the safety net and service system for older parents who have midlife children with developmental disabilities and who are themselves experiencing elevated health problems.

4.1. Limitations, Strengths, and Future Research

The present research has a number of limitations, including limited racial and ethnic diversity, especially in the Adolescents and Adults with Autism study, and limited disability-related information about the sons and daughters with developmental disabilities in the MIDUS study. The MIDUS study had a relatively small sample of 96 mothers of children with developmental disabilities, although these mothers contributed 262 observations across multiple time points. Replication is needed with larger studies to verify the age-related patterns reported here. Additionally, as the data used in the present research are observational, causal relationships and direction of effects should be interpreted with caution. Finally, it is important for future research to examine the role of additional individual, family, and life course factors, particularly as potential mediators.

Counterbalancing these limitations are the extensive longitudinal study periods that extend further into the mothers' aging years than prior research, the ALD statistical approach that leverages the longitudinal data across multiple decades, the identification of behavior problems as the primary child-related factor contributing to heterogeneity in maternal outcomes, and, importantly, the convergence of results across the two unique cohorts. Trajectories reflecting positive as well as negative outcomes were estimated, with consistent results about the timing of observed accelerated aging. Additionally, testing for cohort effects and the inclusion of sensitivity analyses were strengths of the present research.

The findings of these studies point to several opportunities for future research. First, fathers remain significantly underrepresented in developmental disability family research, and there is a need to understand their long-term trajectories. Additionally, future studies should consider investigating the specific health conditions, as well as their timing, that differentiate mothers of children with developmental disabilities from mothers of children without such conditions. Such evidence could inform targeted treatment and prevention efforts. There is a need for future research to expand analyses of the factors that may account for heterogeneity in age-related health changes in mothers of individuals with developmental disabilities.

In conclusion, the present research reported accelerations in vulnerabilities in physical health, mental health, and cognitive functioning after mothers reach approximately age 65 that reveal the wear-and-tear effects of parenting a child with a developmental disability. The service system relies on families to provide care across their child's life course, with public supports very often being inadequate. Were it not for the efforts of families, the cost to society would be enormous and the quality of life of individuals with developmental disabilities would suffer substantially. There is thus an urgent need to buttress the health and well-being of these parents as they age.

CRediT authorship contribution statement

Robert S. Dembo: Writing – original draft, Visualization, Methodology, Formal analysis, Data curation, Conceptualization. **Jinkuk Hong:** Writing – original draft, Visualization, Methodology, Formal analysis, Data curation, Conceptualization. **Leann Smith DaWalt:** Writing – review & editing, Resources, Project administration, Funding acquisition, Conceptualization. **Marsha R. Mailick:** Writing – original draft, Supervision, Resources, Project administration, Methodology, Funding acquisition, Conceptualization.

Declaration of competing interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.socscimed.2025.117912.

Data availability

The MIDUS dataset analyzed in this study is free and publicly available. Information about accessing the data can be found on the MIDUS website: https://midus.wisc.edu/.

The AAA dataset analyzed in this study is not publicly available per IRB. Due to the sensitive nature of the study, participants were assured raw data would not be shared.

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