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## Longitudinal changes in well-being of parents of individuals with developmental or mental health problems

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#### ABSTRACT

Rationale: A large body of work demonstrates the impact of caregiving burden on the well-being of parents of individuals with developmental conditions or mental health problems. However, a relative dearth of research examines this impact longitudinally into parents' older age. Objective. The current study examines (1) longitudinal changes in the effect of having a child with a developmental or mental health problem on parental negative affect, psychological well-being, and somatic symptoms, (2) age and gender moderations on these effects, and (3) the unique impact of factors related to the child's condition. Method. This study employs hierarchical linear regression models to examine longitudinal survey data from midlife adults (N=1,101) from two waves of the National Study of Midlife in the United States (MIDUS). Results. Models revealed some evidence for age attenuation of the impact of caregiving stress. Parents of children with developmental problems still had higher negative affect, poorer psychological well-being, and more somatic symptoms on average than parents in a comparison sample, whereas parents of children with mental health problems only showed evidence of higher negative affect compared to this sample. Within-group analyses also revealed differences between each parenting group into later adulthood. Conclusions. Parents of individuals with developmental or mental health problems may be at risk for poorer well-being late in life. Yet, age and gender differences as well as diagnostic group differences nuance these findings.

#### 1. Introduction

Parenting a child with a developmental or mental health problem can be a significant source of stress. The effects of caring for a child with one of these diagnoses on parental well-being have been documented across both parental age groups and domains of well-being. Compared to parents of children without such conditions, parents of children with developmental or mental health problems experience poorer psychological health, increased daily and global negative affect, and increased daily and global physical symptoms (Ha et al., 2008; Seltzer et al., 2009). Additionally, parents of children with developmental and mental health problems experience greater caregiving burden, such as more restrictions on their time (Smith and Grzywacz, 2014) and more negative parenting experiences (Song et al., 2016) compared to parents of children without such conditions. For instance, parents of children with

developmental conditions or mental health problems have reported a greater burden associated with caregiving (Greenberg et al., 1997), attributing more stress to their child with special needs than to other siblings (Baxter et al., 2000). Furthermore, this type of caregiving has been associated with physiological dysregulation (Barker et al., 2012; Seltzer et al., 2009), accelerated cognitive aging (Song et al., 2016), and being more vulnerable during periods of economic downturn (Song et al., 2018). In general, providing care for a child with these conditions can contribute to a feeling of chronic stress for parents (Baxter et al., 2000; Masefield et al., 2020), which presents a particularly troubling problem, as children with such conditions are likely to reside in the home longer than their typically-developing peers (Seltzer et al., 2001).

This study presents a longitudinal extension of a previous crosssection study of examining the potential age-attenuation of the stress of caring for a child with disabilities on the well-being of parental

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caregivers (Ha et al., 2008). Ha et al. (2008) found that midlife parents of children with developmental or mental health problems had significantly higher negative affect and more somatic symptoms than a comparison sample of parents. Furthermore, those with children with developmental conditions also had poorer psychological well-being than the comparison sample. Additionally, among those with children with developmental or mental health problems, older parental age of onset of the child's condition was protective of parental well-being, and longer duration of the child's condition also predicted better health outcomes, suggesting that parents may adapt to the stress of their caregiving role over time.

Although these findings provide initial evidence of potential adaptation among parents, they are limited by cross-sectional designs. Longitudinally, parents of individuals with developmental conditions have shown declines in some aspects of physical and psychological wellbeing into old age, with parents whose child still resided at home during adulthood at greatest risk (Namkung et al., 2018). Therefore, there is still much to be learned about how the impact of caregiving stress changes over time, especially for parents of children with mental health problems, who may be less likely than individuals with developmental conditions to continue residing at home into adulthood. Additionally, longitudinal data provides the opportunity to examine within-person change, which more accurately assesses whether parents truly adapt to this role over time.

## 1.1. Developmental trends in well-being

Normative samples of adults generally evidence increases in wellbeing across adulthood. For example, older adults show reduced negative affect, greater well-being, and fewer negative emotional experiences compared to younger adults (Carstensen and Charles, 1998). This trend has multiple explanations. For one, older adults, having lived longer, have access to a wider range of experiences and behavioral skills. Therefore, older adults have more practice with interpreting social situations and regulating their emotions, as well as more varied exposure to such experiences (Hess et al., 2005). This improvement in emotion regulation helps explain general improvement in affective well-being (Charles, 2010). Furthermore, Socioemotional Selectivity Theory (Carstensen et al., 2003) posits that because of a perceived decrease in the time remaining in life, older adults increasingly prioritize emotion-related goals, such as family and interpersonal relationships. Not only do emotions themselves become more salient through the lifespan (Carstensen et al., 2003), but older adults also cognitively attend more to positive and less to negative emotional material, and negative experiences are more easily forgotten for older adults (Charles, 2010).

The Strengths and Vulnerability Integration model (i.e., Charles, 2010) is based in Socioemotional Selectivity Theory, but additionally posits that along with age-related strengths such as emotion regulation and salience of positive events, aging can also be accompanied by certain vulnerabilities that make dealing with emotional experiences more difficult. One such vulnerability occurs in the presence of chronic stress. When chronic stressors persist over long periods, negative experiences become unavoidable: despite advanced emotion regulation skills, adults may not have the option of reappraising or directing attention away from the source(s) of certain stressors. For example, empirical studies have found that compared to younger adults, older adults are less reactive to daily stress that was avoided, but equally reactive to stress when it does occur (Charles et al., 2009). In other words, unavoidable stressors present a meaningful threat to well-being, even for older adults. Over time, persistent exposure to unavoidable stressors may reduce the actual capacity for emotion regulation (Charles, 2010). That is, chronic stress may work to cancel out the normative age-related benefits of emotion regulation.

As a chronic stressor, caring for a child with developmental or mental health problems may alter trajectories of age-related patterns in well-

being for this subset of parents. For example, the finding that older parental age at onset of the child's disorder is associated with better health (Ha et al., 2008), suggests that older parents have built up emotional resources throughout the lifespan that can help alleviate the stress associated with caregiving. However, little is known about how patterns of chronic stress may change as children themselves grow older and become less likely to live at home. In general, interactions between parents and their adult children get more positive with time, and parent-child dyads tend to engage in behaviors that maximize positive feelings in the tie and minimize dissent as children age (Birditt et al., 2009). However, this may be less true of parent-child dyads characterized by stressful relationships, such as when the adult child has a disability or other chronic condition. For instance, parents report more negative than positive interactions with children experiencing various physical and emotional problems (Birditt et al., 2016), which have been shown to negatively impact physiological stress responses (Birditt et al., 2016; Seltzer et al., 2009). Utilizing longitudinal data will allow us to evaluate whether these negative patterns persist or attenuate over time for parents whose adult child has developmental or mental health conditions.

#### 1.2. Diagnostic differences in the impact of parenting stress

The stress associated with parenting a child with developmental or mental health problems affects parents differentially depending on both personal characteristics of the parent and those associated with the diagnosis itself. For instance, previous work has suggested that mothers are particularly vulnerable to the impacts of parenting a child with such problems, in terms of both subjective well-being and physical health (see Pinquart and Sörensen, 2006 for meta-analysis). For instance, mothers' economic situations may be more heavily impacted by caregiving burden than that of fathers, resulting in lower earnings and less time spent working (Parish et al., 2004; Seltzer et al., 2001). Additionally, they may be at risk for more physical symptoms associated with caregiving burden than fathers (Namkung et al., 2018), as well as poorer mental health outcomes (Homan et al., 2020; Penning and Wu, 2016; Smith and Grzywacz, 2014), and cognitive functioning (Song et al., 2016). However, other work has suggested that gender does not moderate the effects of parental caregiving stress (Ha et al., 2008), and that mothers potentially benefit more from the positive aspects of caregiving compared to fathers (Homan et al., 2020). Therefore, further investigation into gender differences in caregiving stress is needed.

Additionally, parents of children with developmental conditions display different patterns of well-being than parents of children with mental health problems (Greenberg et al., 1997; Ha et al., 2008; Seltzer et al., 2001). For example, parents of individuals with mental health problems may face more unpredictability in daily experiences with their child, whereas parents of individuals with developmental conditions tend to adapt family routines more sustainably, especially given the typically younger age of onset of these conditions (Seltzer et al., 2001). Furthermore, parents of children with mental health problems may be at greater risk for financial problems such as unexpected costs and barriers to services (Song et al., 2018). Therefore, one must consider each group individually, asking whether parents of children with developmental and mental health problems adapt such that they reach more normative levels of well-being in older adulthood, or if this type of parenting presents as a chronic stressor with lasting impact over the lifespan.

## 1.3. The current study

The current study used data from a representative sample of midlife-to-older adults who have at least one child with a developmental condition or mental health problem and from a comparison group of parents to better understand how health and well-being change throughout the lifespan. Some models implemented in the current study were previously tested by Ha et al. (2008) using cross-sectional data that were

collected between 2004 and 2006. The current study extended these analyses by incorporating a second wave of data from the same respondents, collected approximately 10 years after the previous wave. Based on the cross-sectional findings from this sample (i.e., Ha et al., 2008) and theoretical propositions, our hypotheses are:

- Having a child with a developmental or mental health problem will
  predict higher negative affect, lower psychological well-being, and a
  greater number of somatic symptoms, at both a baseline time point
  and a 10-year follow-up, compared to parents of children without
  these problems.
- Having a child with a developmental condition or mental health problem will be associated with net increases in negative affect, decreases in psychological well-being, and increases in somatic symptoms from the first time point to the second.
  - a. Parental age will moderate these effects such that older parents of children with developmental or mental health problems will not show elevated negative affect.
  - Parental gender will moderate these effects such that mothers will experience greater detrimental effects on well-being compared to fathers.
- 3. Within groups, longer duration of the child's condition and older parental age will be related to better parental well-being for parents of children with developmental or mental health problems.

#### 2. Method

#### 2.1. Participants

Participants were drawn from the Study of Midlife in the United States (MIDUS), a national sample of adults between the ages of 25 and 74 at the first point of data collection (MIDUS I) in 1995–96. These participants were followed through two additional data collection times, MIDUS II (beginning in 2004) and MIDUS III (beginning in 2013). For this study, data from MIDUS II and MIDUS III are examined, as MIDUS II was the first time when information regarding child disability or other conditions was collected. Therefore, Time 1 refers to MIDUS II, and Time 2 refers to MIDUS III. At each time point, respondents participated in a computer-assisted telephone survey and a mail-back questionnaire. Participants must have completed both of these portions of the overall study to have the data necessary for inclusion in this study.

At the first time point, 430 respondents were identified as having a child with any developmental, mental health, or other diagnosis; 55 of these had only children with other conditions such as injuries, health problems like diabetes and heart conditions, or vision/hearing impairments, that were not included in this study. Of the remaining respondents, 305 had completed the data necessary for inclusion. Inclusion was contingent upon having participated in both a structured phone interview and a battery of questionnaires, which included the questions used in the following analyses. The comparison sample was drawn from respondents who reported having at least one child, but who did not have any children with a developmental or mental health diagnosis, or other chronic condition. Additionally, this group must not have provided care for more than one month to a family member or friend who, "because of a long-term, physical or mental condition, illness, or disability was not able to take care of him- or herself." These criteria left a sample of 2,024 participants in the comparison sample.

Of 2,329 eligible participants (305 parents of individuals with disabilities or mental health problems and 2,024 comparison respondents), 1,656 participated in MIDUS III. Of these, 11.7% (n=194) were excluded from the present analyses because they completed the telephone interview but did not return the self-administered questionnaire mailer, which contained the outcome variables of interest for this study. Additionally, some parents in the comparison sample no longer met the inclusion criteria at MIDUS III. A group of 108 parents had a child diagnosed with a developmental condition or mental health problem

between MIDUS II and III. Furthermore, 285 parents had reported caregiving responsibilities between MIDUS II and III that would preclude them from being in the comparison sample; 32 of these were those who also had a child with a new diagnosis; thus, 361 respondents were dropped to retain a true comparison sample. Therefore, the total sample consisted of 108 parents of children with developmental conditions, 86 parents of children with mental health problems, and 907 comparison parents (N = 1,101).

Attrition due to death accounted for 31.7% of all attrition (30 respondents from the samples of parents of children with developmental or mental health problems and 245 from the comparison group). Compared to the longitudinal sample, those who completed MIDUS II but did not complete MIDUS III (including the deceased) had a lower income and education level, were less likely to be employed, and were less likely to be married. Considering those who survived until MIDUS III (i.e., those who could have participated but did not), those who remained in the longitudinal sample were older by 4.10 years. Respondents with children with developmental or mental health problems were no more likely to drop out than those in the comparison sample. Attrition was higher for parents of children with developmental conditions (38.6%) versus those with children with mental health problems (33.3%). Table 1 gives the breakdown of conditions and age of onset for the conditions included in the analytic sample, which is comparable in proportions to the sample analyzed in Ha and colleagues' (2008) analysis of the sample.

#### 2.2. Measures

#### 2.2.1. Negative affect

The scale for negative affect (Mroczek and Kolarz, 1998;  $\alpha_{Time\ 1}=0.83$ ,  $\alpha_{Time\ 2}=0.85$ ) consisted of six items that assessed how often in the past 30 days the respondent felt: so sad nothing could cheer you up, nervous, restless or fidgety, hopeless, that everything was an effort, and worthless. Responses were on a Likert-type scale from 1 (all of the time) to 5 (none of the time) and were reverse coded so that higher responses indicated more negative affect. The total negative affect score was the sum of these six items. This sum was calculated when at least half (3 or more) of the items had been completed and when this was true, individual mean imputation was used.

**Table 1**Age of onset by condition.

	Child Age of Onset			Parent Age of Onset		
	n	M	SD	N	M	SD
Developmental Conditions						
ADD/ADHD	28	6.25	5.92	30	33.87	7.14
Learning Disabilities	19	5.89	6.79	21	32.62	8.96
Intellectual Disability	14	5.71	6.31	14	31.29	8.86
Cerebral Palsy	7	.14	.38	7	30.29	9.09
Epilepsy	7	6.71	6.82	7	37.29	9.38
Down Syndrome	4	.25	.50	4	33.00	6.38
Multiple Developmental Conditions	1	4.00		1	26.00	
Other Developmental Condition	13	3.31	5.72	14	29.86	7.11
Totals	93	4.03	4.06	98	31.78	7.12
Mental Health Problems						
Bipolar	20	19.65	8.14	23	47.48	7.06
Depression	18	17.66	9.06	18	43.61	11.2
Schizophrenia	9	20.44	3.05	9	48.44	5.85
Anxiety Disorder	8	19.25	10.51	8	47.00	8.52
Drug/Alcohol problem	7	19.28	5.47	7	43.29	7.87
Multiple Mental Health Problems	4	18.50	5.69	5	43.60	7.27
Other Mental Health Problem	7	15.00	1.63	7	44.86	3.98
Totals	73	18.54	6.22	77	45.47	7.40

*Note.* M = Mean; SD = Standard Deviation; Child Age of Onset could not be calculated if the parent did not report the child's current age. Therefore, some group sizes for child age of onset are smaller.

#### 2.2.2. Psychological well-being

The measure for psychological well-being was the sum of six domains of well-being: autonomy, environmental mastery, purpose in life, positive relations with others, personal growth, and self-acceptance (Ryff, 1989). Each domain is assessed on seven items, for a total of 42 items ( $\alpha=0.89$  at Times 1 and 2). Responses were on a Likert-type scale from 1 (strongly disagree) to 7 (strongly agree). Items were coded so that higher scores indicate greater psychological well-being. As with the measure of negative affect, mean imputation was used for those who had scores on more than half (four or more) of the items for each domain, and sums were calculated.

#### 2.2.3. Somatic symptoms

The measure of somatic symptoms ( $\alpha_{Time\ 1}=0.70,\,\alpha_{Time\ 2}=0.73$ ) was a count of up to seven physical symptoms: headaches, backaches, sweating a lot, aches/joint stiffness, trouble falling or staying asleep, leaking urine, or aches/pain in extremities. These particular symptoms were chosen in order to maintain consistency from Ha et al. (2008) analyses of this sample. Respondents reported how often they had experienced these symptoms in the last 30 days, from 1 (not at all) to 6 (almost every day). The cutoff score was 4 (several times a month) or greater for a symptom to be counted.

#### 2.2.4. Parenting type

Parenting type was coded as a categorical variable, based on whether the respondent was a parent of a child with a developmental condition (coded 1), mental health problem (coded 2), or a child without these diagnoses (coded 0). Some respondents (n = 13) qualified for both parenting type categories, as they had either one child who would fit into both the developmental and mental health problem categories, or one child in each category. These respondents were categorized into either the developmental or mental health groups based on criteria determined by Ha et al. (2008) in their previous examination of this sample. These were (1) which condition was more chronic, and (2) which had the longer duration. Therefore, if the child had both a chronic developmental condition and a chronic mental illness, the decision was that they should be placed in the developmental condition group as these problems begin earlier in life than mental health diagnoses. This resulted in four respondents being placed in the developmental conditions group, and nine in the mental health problems group.

#### 2.2.5. Sociodemographic variables

Responses from Time 2 were used to measure all sociodemographic variables, to capture respondents' current situation. Age and sex were included as predictors in this study. Age was measured in years, based on the respondent's birthdate. Sex was assessed with one item during the telephone interview, with response options, "male," "female," and "don't know." Sex was measured at time point 1. The following were also included as control variables: race (1 = non-Hispanic white, 0 = others), education (in years), income, employment status (1 = working for pay, 0 = not working for pay), marital status (1 = married, 0 = unmarried), number of children, and number of co-resident children.

### 2.3. Analytic strategy

To address between-group differences in the outcome variables of interest (Hypothesis 1), Analyses of Variance (ANOVAs) were used with parenting group (developmental condition, mental health problem, or comparison group) as the grouping factor. Post-hoc tests for individual group differences used Dunnett's T3 t-tests, which account for unequal variances across groups. Power analyses based on the smallest sample size (n=86 for the mental health parent group) suggested that these ANOVAs had sufficient power to detect small-to-medium effect sizes (Cohen's f of 0.19 or greater).

To measure change from Time 1 to Time 2 (Hypothesis 2), we used hierarchical linear regressions with time one levels as predictors of time

two outcomes to examine the effects of parental group, age, and sex on change in the outcome variables, as well as their interaction effects, while controlling for potentially confounding variables. Due to different patterns of missingness across the outcome variables of interest, we conducted a sensitivity analysis running the models with only those with complete data for all outcome variables (n=1,073). The pattern of results remained the same for this sample, therefore we decided to use the models with the most possible data. Power analyses suggested that the full models were well-powered to detect even small effect sizes (based on a *Cohen's f*<sup>2</sup> of 0.02; Cohen, 1988). Specifically, the model for negative affect had a power of .83, the model for psychological well-being had a power of .84, and the model for somatic symptom had a power of .83 to detect a small effect size.

Finally, we used multiple linear regressions to examine within-group effects of condition-related variables on the well-being of parents of individuals with developmental and mental health problems separately at time two (Hypothesis 3). Due to the smaller sample sizes, these models were sufficiently powered to detect medium effect sizes (*Cohen's f*<sup>2</sup> of 0.15 or greater) but not smaller. The models for the developmental conditions parent group had sufficient power (above 80%) to detect effect sizes of *Cohen's f*<sup>2</sup> of 0.12 or greater, while the models for the mental health parent group had sufficient power to detect effect sizes of *Cohen's f*<sup>2</sup> of 0.16 or greater. For within-group comparisons of these outcomes at time one, see Ha et al. (2008).

#### 3. Results

#### 3.1. Group comparisons

Table 2 displays mean comparisons of each of the three family types at the second occasion of measurement. One-way ANOVAs revealed group differences on age  $(F_{(2, 1098)} = 8.70, p < .001)$ , parent sex  $(F_{(2, 1098)} = 8.70, p < .001)$  $_{1098)} = 13.09, p < .001)$ , household income ( $F_{(2, 1016)} = 7.13, p = .001)$ , employment status ( $F_{(2, 1098)} = 13.11, p < .001$ ), marital status ( $F_{(2, 1097)}$ = 10.80, p < .001), number of children ( $F_{(2, 1098)} = 18.02, p < .001)$ , and number of co-resident children ( $F_{(2, 1098)} = 4.91, p = .008$ ). Dunnett's T3 tests were used to probe these interactions, to account for unequal variances between the three groups. Specifically, parents of children with mental health problems were older than those in the comparison group (p < .001) and developmental disabilities parent group (p = .001). They were also less likely to be employed than those in both the comparison (p < .001) and developmental disabilities parent group (p < .001) .001), and less likely to be married than those in the comparison group (p = .001). Those with children with developmental conditions had more children than the comparison group (p = .001) and more children who resided at home compared to the group with children with mental health problems (p = .034). Additionally, the percentage of female respondents (i.e., mothers) was lower in the comparison group than in both samples of parents whose children had disabilities (p = .001compared to parents of individuals with developmental disabilities, *p* < .001 compared to parents of individuals with mental health problems).

Among the groups of parents with children with developmental or mental health problems, there were group differences in condition-related variables. Specifically, the duration of the condition was longer among those with children with developmental disabilities compared to parents of children with mental health problems ( $t_{(179)} = 3.72, p < .001$ ). Additionally, their children were older ( $t_{(165)} = -3.74, p < .001$ ), and less likely to be female than those in the mental health group ( $t_{(192)} = -2.76, p = .006$ ).

Table 2 presents group by timepoint ANOVAs as well as the results of post-hoc Dunnett's T3 tests probing specific between-group differences, which test Hypothesis 1. There was an omnibus effect of time on increased somatic symptoms across the three groups ( $F_{(1, 2183)} = 7.07 p = .01$ ), as well as a downward trend in negative affect over time ( $F_{(1, 2164)} = 3.44$ , p = .06). Of interest, there were also omnibus effects of parenting group on negative affect ( $F_{(2, 2164)} = 40.71$ , p < .001),

**Table 2**Mean comparisons by parenting type at time 2.

	Comparison (n = 907)		Developme	Developmental Group ( $n = 108$ )		alth Group $(n = 86)$	Significance Test
	M	SD	M	SD	M	SD	
Predictor Variables							
Parent's Age (years)	63.47	11.24	62.43	11.61	68.50	10.81	$F = 8.70^{***b,c}$
Parent's Sex $(1 = female)$	.46		.64		.67		F = 13.09 ****a,b
Demographic Variables							
Race (non-Hispanic white = 1)	.92		.88		.92		F = 1.06
Education (years)	14.71	2.61	14.31	2.66	14.78	2.92	F = 1.20
Income (thousands of \$)	100.49	75.15	87.24	75.18	69.67	57.84	$F = 7.13^{***}^{b}$
Employment Status	.46		.44		$.17^{ m b,c}$		F = 13.11***b,c
Marital Status	.78		.70		.57 <sup>b</sup>		$F = 10.80 ***^{b}$
Number of Children	2.65	1.31	3.57	2.61	2.88	1.66	F = 18.02****
Co-resident Children	.48	.86	.73	1.38	.35	.63	$F = 4.91**^{c}$
Condition-Related Variables							
Multiple disabled children			.13		.14		$t_{192} = -0.20$
Child co-resides with parent			.19		.20		$t_{192} = -0.22$
Duration of Condition			29.58	14.01	22.76	9.48	$t_{179} = 3.72 ***^{c}$
Target child age			34.15	12.84	41.22	11.15	$t_{165} = -3.74***$
Target child sex $(1 = female)$			.29		.48		$t_{192} = -2.76 **^{c}$
Outcome Variables							
Negative Affect, Time 1	8.38	2.74	10.17	4.25	9.48	3.46	F = 20.91 ***a,b
Negative Affect, Time 2	8.13	2.83	9.93	4.53	9.34	3.73	F = 19.86 ***a,b
Well-Being, Time 1	234.54	32.59	223.30	39.91	228.94	38.53	$F = 6.00^{**a}$
Well-Being, Time 2	232.78	33.24	224.12	33.66	225.39	39.98	$F = 4.61^{*a}$
Somatic Symptoms, Time 1	2.85	1.75	3.61	1.92	3.54	1.87	$F = 12.79^{***a,b}$
Somatic Symptoms, Time 2	3.08	1.81	3.75	1.85	3.52	1.91	$F = 8.54^{***a,d}$

*Note.* M = Mean; SD = Standard Deviation; A Group x Time ANOVA was conducted for the Outcome Variables; F-values reported here are within-timepoint; One-Way ANOVAs were conducted for all other variables; Dunnett's T3 Tests were used to probe specific effects and account for unequal variance between groups; two-tailed significance tests were used with an alpha level of 0.05; total degrees of freedom for F-tests ranged from 1,016 to 1,098.

- <sup>a</sup> Indicates a significant mean difference between the Comparison and Developmental groups.
- <sup>b</sup> Indicates a significant difference between the Comparison and Mental Health groups.
- <sup>c</sup> Indicates a significant difference between the Developmental and Mental Health groups.

psychological well-being ( $F_{(2, 2196)} = 10.39$ , p < .001), and somatic symptoms ( $F_{(2, 2183)} = 21.02$  p < .001) across timepoints. Specifically, at Time 1, our results repeated the previous cross-sectional analyses conducted by Ha et al. (2008), with parents of individuals with developmental conditions having higher negative affect (p < .001), poorer psychological well-being (p = .017), and more somatic symptoms (p < .001) compared to a comparison sample of parents. Additionally, parents of individuals with mental health problems had higher negative affect (p = .015) and more somatic symptoms (p = .004) than comparison parents at Time 1, which was also consistent with the previous analysis of a similar sample (Ha et al., 2008). This is in line with Hypothesis 1. There was not evidence for Group by Time interaction effects

for any of the three outcomes, indicating that group differences present at Time 1 largely persisted at Time 2, but failing to support the specific trajectories predicted in Hypothesis 2.

At Time 2, parents with children with developmental conditions had higher negative affect (p < .001), lower psychological well-being (p = .037), and more somatic symptoms than those in the comparison group (p = .001), supporting Hypothesis 1. In contrast, parents of children with mental health problems had higher negative affect that the comparison group (p = .013), but did not differ in terms of psychological well-being (p = .269) or somatic symptoms (p = .120), partially supporting Hypothesis 1. Parents of children with developmental conditions and mental health problems did not differ from each other on any of the

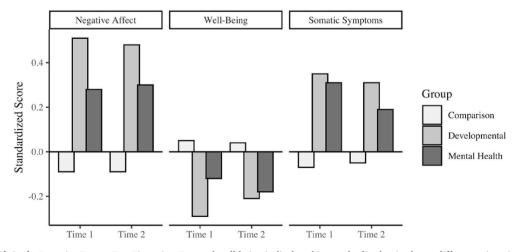


Fig. 1. Parental Well-being by Parenting Type at Two Timepoints. Parental well-being is displayed in standardized units due to differences in units between scales. Raw values for group means and standard deviations are displayed in Table 2. Specific results of a Group × Time ANOVA for each outcome are displayed in Table 2.

 $<sup>^{\</sup>rm d}\,$  Indicates a difference between Time 1 and Time 2 scores across groups.

measured outcomes. Mean levels of each outcome variable at each timepoint are displayed in Fig. 1.

# 3.2. Effects of having a child with a developmental or mental health problem

Table 3 displays results of hierarchical regressions assessing longitudinal change in parental well-being, which tested Hypothesis 2a and 2b. Model 1 includes only parenting group and demographic variables, Model 2 includes moderating effects of age by parenting group, and Model 3 includes moderating effects of sex by parenting group. All models control for Time 1 outcomes.

In Model 1, there was a significant main effect of having a child with either a developmental condition ( $\beta=0.65$ ,  $t_{(979)}=2.36$ , p=.019) or mental health problem ( $\beta=0.70$ ,  $t_{(979)}=2.36$ , p=.019) in predicting elevated negative affect. These results partially support Hypothesis 2. Older age was associated with declining psychological well-being ( $\beta=-0.22$ ,  $t_{(1002)}=-2.41$ , p=.016), but not the other two outcomes. Additionally, being female was predictive of increases in psychological well-being ( $\beta=3.51$ ,  $t_{(1002)}=2.31$ , p=.021).

Age and sex moderations were partially supported for parents' negative affect. A significant age by condition interaction was found for the effect of parenting a child with a developmental condition on negative affect ( $\beta = -0.05$ ,  $t_{(977)} = -1.98$ , p = .048). A simple slopes test was used to probe this interaction, which revealed that the effect of parenting a child with developmental conditions on negative affect was only observed for younger parents (-1 SD;  $\beta$  = 1.09,  $t_{(977)}$  = 3.09, p = .002) but not older parents (+1 *SD*;  $\beta$  = 0.03,  $t_{(977)}$  = 0.06, p = .952). The region of significance test showed that the slope was significant and positive for those under 63.12 years old. This effect was not significant for parents of individuals with mental health problems. In other words, these results provide some support for age attenuation of the effect of caring for a child with a developmental disability on negative affect. This interaction is consistent with Hypothesis 2a, and is reflected in Fig. 2. Age did not moderate the effect of parenting a child with a developmental disability or mental health problem on parents' psychological well-being or somatic symptoms. Additionally, a gender by condition interaction was found at the trend level such that the effect of caring for a child with a mental health problem had a greater impact on the negative affect for fathers than for mothers ( $\beta = -1.16$ , p = .054). A simple slopes test confirmed that the effect of having a child with a

mental health condition was associated with increased negative affect for fathers ( $\beta = 1.43$ ,  $t_{(977)} = 2.96$ , p = .003) but not for mothers ( $\beta = 0.27$ ,  $t_{(977)} = 0.74$ , p = .459). This is depicted in Fig. 3. This finding is in contrast to the hypothesized effect (Hypothesis 2b), in which we predicted effects would be stronger for mothers than fathers. There were no main or interaction effects of sex on the other two outcome variables.

## 3.2.1. Prediction of outcomes among parents of children with disabilities

The final set of analyses examined factors predicting well-being using within-group analyses for each type of parent (having a child with a developmental condition or mental health problem). To examine effects of caregiving stress that persisted over time, these analyses focus on Time 2 outcomes. Three condition-related factors that may be related to well-being were examined: duration of the child's condition, having multiple children with disabilities or mental health problems, and whether or not the target child co-resided with the parent at Time 2. A summary of results appears in Table 4.

Among parents of individuals with developmental conditions, mothers had a higher number of somatic symptoms than fathers ( $\beta=0.84,\ t=2.10,\ p=.038$ ). Additionally, a trend-level effect emerged suggesting that having a child who remained in the parental household was associated with poorer psychological well-being for parents of individuals with developmental conditions ( $\beta=-15.34,\ t=-1.81,\ p=.074$ ). Among those with children with mental health problems, longer duration of the child's condition was associated with elevated negative affect ( $\beta=0.14,\ t=2.42,\ p=.018$ ), whereas parent's current age was associated with lower levels of negative affect ( $\beta=-0.17,\ t=-3.22,\ p=.002$ ). These results provide mixed support for Hypothesis 3.

#### 4. Discussion

The results of this longitudinal study paint a bittersweet picture for the change in the well-being of parents of individuals with developmental and mental health problems, similar to evidence suggested by previous longitudinal work (e.g., Baxter et al., 2000; Namkung et al., 2018). Parents in both of these groups showed normative decreases in negative affect over time that were in line with those experienced by the sample as a whole (See Table 2 for time effects). This was especially true for older parents. However, the experience of normative age-related changes in well-being also suggests that group differences present at earlier timepoints persisted into later life. For instance, average levels of

**Table 3**Parenting group, age, and sex predicting change in well-being among parents.

	Negative Affect			Psychological Well-Being			Somatic Symptoms		
	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3	Model 1	Model 2	Model 3
(Intercept)	3.51***	3.55***	3.51***	57.57***	56.94***	57.40***	1.64***	1.64***	1.64***
Time 1 Level	.58***	.58***	.58***	.70***	.70***	.70***	.57***	.57***	.57***
Dev. Problem	.65*	$.50^{+}$	$.72^{+}$	80	-1.43	3.49	.25	.25	20
MH Problem	.70*	.82*	1.43**	-3.55	-3.80	-11.47	.06	.07	.28
Parent Age	01	.00	01	22*	19 <sup>+</sup>	22*	.00	.00	.00
Parent Sex $(1 = female)$	32*	31 <sup>+</sup>	22	3.51*	3.56*	3.40*	.01	.01	01
Dev. x Age		05*			30			.00	
MH x Age		04			.03			.00	
Dev. x Sex			15			-2.60			.27
MH x Sex			$-1.16^{+}$			4.83			13
Race (1 = Non-Hispanic White)	.07	.08	.07	-2.28	-2.05	-2.35	05	05	04
Education (years)	01	01	02	.73*	.72*	.75*	01	01	01
Income	12	12	12	3.14***	3.13***	3.12***	11*	11*	11*
Employment $(1 = Employed)$	10	07	09	-2.55	-2.47	-2.60	16	16	16
Marital Status ( $1 = Married$ )	31	33 <sup>+</sup>	30	2.80	2.70	2.75	.16	.16	.16
Number of Children	.08	.08	.08	.79	.80	.79	03	03	03
Number Co-Resident Children	.05	.07	.05	-2.61**	-2.70**	-2.66**	.05	.05	.05
Adjusted R <sup>2</sup>	.361	.364	.362	.526	.526	.526	.330	.329	.329
$\Delta R^2$		.004+	.002		.001	.001		.000	.001
Significance	$F_{(12, 979)} = 47.7***$	$F_{(14, 977)} = 41.5^{***}$	$F_{(14, 977)} = 41.2^{***}$	$F_{(12, 1002)} = 94.9^{***}$	$F_{(14, 1000)} = 81.5^{***}$	$F_{(14, 1000)} = 81.4^{***}$	$F_{(12, 992)} = 42.2^{***}$	$F_{(14, 990)} = 36.1***$	$F_{(14, 990)} = 36.2^{***}$

Note. Dev. = Developmental; MH = Mental Health; all coefficients reported are unstandardized; +p < .10; \*=p < .05; \*\*=p < .01; \*\*\*=p < .001.

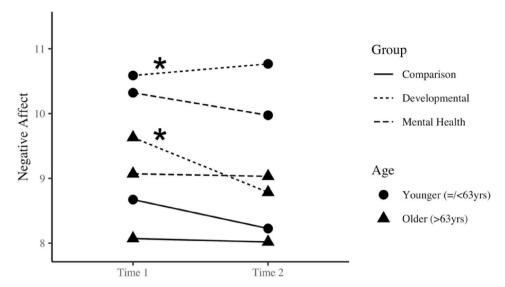


Fig. 2. Negative Affect by Parenting Type and Age. Older parents experienced declines in negative affect over time, while younger parents did not experience this benefit. Slopes that contributed to a significant interaction effect are denoted with an asterisk (\*). Simple slopes test revealed that there was a positive association between parenting a child with a developmental condition and negative affect for parents 63.12 years and younger.

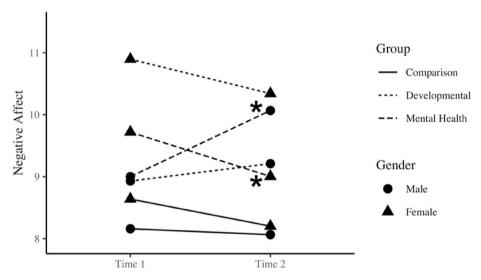


Fig. 3. Negative Affect by Parenting Type and Gender. Fathers of individuals with mental health problems experienced increases in negative affect, while mothers did not. Slopes that contributed to a significant interaction effect are denoted with an asterisk (\*). Simple slopes test revealed that the association between parenting a child with a mental health problem and negative affect was significant and positive for fathers but not mothers.

**Table 4**Condition-related predictors of well-being among parents of individuals with disabilities.

	Child Has Develop	mental Condition	ı	Child Has Mental Health Problem			
	Negative Affect	Well-Being	Somatic Symptoms	Negative Affect	Well-Being	Somatic Symptoms	
(Intercept)	12.43**	212.91***	$2.35^{+}$	17.62***	192.49***	5.89***	
Condition-Related Variables							
Duration of Condition (Time 2)	0.00	-0.21	0.00	0.14*	-0.95	0.02	
R has multiple children with Disabilities (Time 2)	1.58	-3.32	0.41	1.85	-12.67	-0.91	
Target child Co-Resides with Parent (Time 2)	1.46	$-15.32^{+}$	-0.03	1.39	-13.64	-0.18	
Demographic Variables							
Parent Sex $(1 = female)$	1.21	-8.56	0.84*	-1.16	2.03	0.50	
Parent Age at Time 2	-0.06	0.42	0.01	-0.17**	0.86	04	
Adjusted R <sup>2</sup>	.014	.010	.016	.138	.002	.018	
Significance	F <sub>(5, 92)</sub>	F <sub>(5, 96)</sub>	F <sub>(5, 96)</sub>	F <sub>(5, 72)</sub>	$F_{(5, 73)}$	$F_{(5, 73)}$	
	= 1.27	= 1.21	= 1.32	= 3.47**	= 1.04	= 1.29	

 $\textit{Note.} \ \ R = \text{Respondent; all coefficients reported are unstandardized;} \\ += p < .10; \ ^*=p < .05; \ ^{**}=p < .01; \ ^{***}=p < .001.$ 

negative affect were higher among both parents of children with developmental problems and mental health conditions compared to parents of non-disabled children, even into late life, which provided support for Hypothesis 1. Interaction probes revealed that the significance was driven by the younger age group, who showed a blunted decrease in negative affect over time compared to older parents (see Fig. 2), which supports Hypothesis 2a. Although not statistically significant, younger parents (<65 years old) were more likely to still reside with their child with a developmental condition (23%) compared to older parents (12%) at the second wave of data collection. Therefore, these parents may experience a more active caregiving role compared to older parents. Parents of children with developmental conditions also retained poorer psychological well-being and physical symptoms compared to parents of children without these conditions.

In contrast, parents of children with mental health problems no longer differed from the sample of comparison parents in terms of psychological well-being or somatic symptoms by the second time point (see Table 2). Contrary to previous findings (e.g., Herring et al., 2006; Homan et al., 2020; Parish et al., 2004; Smith and Grzywacz, 2014) and Hypothesis 2b, a sex interaction showed that the negative affect of fathers was more vulnerable to impacts of caregiving stress than that of mothers (see Fig. 3). It is possible that fathers have fewer sources of social support compared to mothers, and therefore have fewer buffers against the stress of these unique caregiving situations. Examining the reasons why change in well-being may differ for aging fathers and mothers will be an important area of future study.

Within-group analyses of parents of children with developmental and mental health problems revealed potential differences in how time impacts the effect of caregiving burden (see Table 4). Specifically, having a child with a developmental disability was particularly harmful for mothers' negative affect, and may impact negative affect levels more if the child still resides at home. These findings are consistent with gender differences discussed in other literature (Namkung et al., 2018; Penning and Wu, 2016; Pinquart and Sörensen, 2006), as well as the idea that parents whose child resides at home into adulthood may be particularly vulnerable to the effects of caregiving burden (Namkung et al., 2018). Furthermore, for parents of individuals with mental health problems, a longer duration of the condition was associated with higher levels of parental negative affect. On the other hand, older current age was associated with lower levels of negative affect. This is consistent with the position of the Strengths and Vulnerability Integration model (Charles, 2010), which emphasizes the potential for chronic stress to work against normative age-related improvements in well-being. However, also in line with Socioemotional Selectivity Theory, older parents may be in a better position to combat this impact by utilizing more advanced emotion regulation strategies and other interpersonal resources.

The intricacies of combining age-related increases in well-being with the chronicity of caregiving stress make results difficult to interpret, and may help to explain the relatively lower reliability of these findings. Therefore, replication of these results with larger and more diverse samples will be critical in informing any future prevention or intervention efforts. Regardless, it is noteworthy that condition-related factors are predictive of parental well-being longitudinally, when few parents were still co-residing with the target child (only 19% of target children co-resided at Time 2, compared with 38% at Time 1).

#### 4.1. Strengths and limitations

Perhaps the largest strength of this study is its longitudinal design, which allowed us to examine change in well-being over a span of approximately 10 years. Additionally, given the age of the sample, we were able to examine change in many factors that vary throughout the lifespan but are often captured only at one time point, such as the coresident status of the child and the impact of the condition's duration on parental well-being, in addition to capturing multiple instances and

measures of well-being itself. This revealed important nuances compared to previous cross-sectional work with this and similar samples. Finally, the results are strengthened by the fact that the study utilized a nationally representative sample of parents whose participation was not motivated by or dependent on their child's condition, which is uncommon in other work related to non-normative parenting.

Despite the methodological strengths of this study, the results must be interpreted in light of its limitations. By combining parents into the broad categories of having children with developmental conditions, mental health problems, or neither of these problems, we lose some within-group variation that comes with the qualities of the diagnosis. For instance, Masefield et al. (2020) notes that caring for children with multiple disabilities may pose the greatest risk to caregiver health, while individual disabilities may be differentially associated with specific health outcomes. Certainly, differences in diagnostic categories affects the impact of caregiving stress, as well as how stress manifests in the daily lives of parents (i.e., consistent low-level stress versus more acute stress), as well as the long-term nature of the disability. Although these nuances were beyond the scope of the current study, future work with larger samples and more power to detect such effects should consider within-group change among parents of children with more specific diagnoses. Due to the long nature of the study, unmeasured factors likely play a role in influencing the physical and psychological health of these participants, which should be probed in future studies. Finally, as with any study covering such a lengthy period, we were faced with non-random attrition and mortality issues that limited power to detect more specific effects.

#### 4.2. Future directions

In general, the evidence for lifespan gains in well-being presented in this study provides support for Socioemotional Selectivity Theory (Carstensen et al., 2003) as a useful tool for modeling age-related change in populations as well as at the person level. Additionally, this study provides opportunities to further examine the Strengths and Vulnerabilities hypothesis by suggesting that some age-related gains in psychological well-being are observed even in the face of chronic stressors such as caregiving stress, while others, such as changes in affect, may be undermined by this type of stress. Furthermore, given the important group differences between types of caregivers (e.g., those for children with developmental conditions versus those with mental health problems), this study contributes to a body of research suggesting that specific elements of the caregiving experience may contribute to unique strengths and vulnerabilities in the face of chronic stress (e.g., Ha et al., 2008; Song et al., 2018).

Additionally, the current study aligns with previous work that has identified vulnerabilities within groups of parents caring for children with developmental or mental health problems that may be uniquely exacerbated in times of acute stress, such as the current global COVID-19 pandemic. For instance, parents of children with developmental and mental health problems can be more heavily impacted by downturns in the economy (Song et al., 2018), as well as being at risk for psychological, physiological, and cognitive dysregulations (Ha et al., 2008; Seltzer et al., 2009; Song et al., 2016). Presumably, these adverse effects may be intensified during periods such as this one, when finances are more uncertain, time spent at home has increased, and access to resources may be very limited. Therefore, prevention efforts aimed at improving the quality of life of families during periods of acute stress such as the current pandemic should pay special attention to the vulnerabilities of these groups of parents, including the vulnerabilities identified in the current study.

#### 5. Conclusions

Overall, this study supports that parenting a child with developmental or mental health problems is a challenge that impacts the wellbeing of parents, even into their child's adult years and when fewer children reside in the home. However, these difficulties are nuanced by other within-person factors, such as age and sex, as well as factors related to the duration and time of a condition's diagnosis. Future research should include contextual factors, such as social support, employment stress, and other relevant factors may influence how parents with high caregiving stress can cope. It is critical to identify malleable factors such as these, that could serve as intervention targets within this population. Additionally, research particularly with older samples could consider the potential benefits and rewards of unique caregiving situations. For instance, older parents who are more attuned to positive emotionality and social experiences may also be more likely to experience positivity in their interactions with their adult children with disabilities or mental health conditions. Overall, future work should attempt to probe how parents in these situations manage caregiving stress and daily challenges, as well as what sources of internal and external support are most effective in buffering the effects of caregiving stress.

#### **Author contributions**

Carlie J. Sloan, Conceptualization, Formal analysis, Methodology, Visualization, Writing - original draft; Marsha R. Mailick, Funding acquisition, Investigation, Project administration, Supervision; Jinkuk Hong, Data curation, Validation; Jung-Hwa Ha, Conceptualization, Data curation, Validation; Jan S. Greenberg, Funding acquisition, Investigation, Project administration, Validation; David M. Almeida, Funding acquisition, Investigation, Project administration, Supervision.

#### Declaration of competing interest

The authors have no conflicts of interest to declare.

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