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## Long-term Impact of Parental Well-Being on Adult Outcomes and Dementia Status in Individuals with Down Syndrome

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### Abstract

Parental characteristics were significant predictors of health, functional abilities, and behavior problems in adults with Down syndrome ( $n = 75$ ) over a 22-year time span, controlling for initial levels and earlier changes in these outcomes. Lower levels of behavior problems were predicted by improvements in maternal depressive symptoms. Higher levels of functional abilities were predicted by prior measures of and improvements in maternal depressive symptoms. Better health was predicted by prior measures of maternal depressive symptoms, paternal positive psychological well-being, relationship quality between fathers and their adult children, and improvements in maternal positive psychological well-being. Dementia status was also predicted by parental characteristics. The study suggests the importance of the family context for healthy aging in adults with Down syndrome.

### Keywords

Down syndrome; aging; family

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A highly significant change in the survival of people with Down syndrome has occurred during the last two generations, with life expectancy estimates increasing from 12 in 1949 to nearly 60 years of age today (Bittles & Glasson, 2004; Penrose, 1949). As adults with Down syndrome age beyond midlife, there is evidence of an elevated rate and earlier onset of the cognitive and behavioral declines associated with dementia (Zigman, Schupf, Urv, Zigman, & Silverman, 2002). There is emerging consensus that, prior to the age of 50, most adults with Down syndrome experience stability in their cognitive and functional abilities (Friedman & Brown, 2001). This pattern of stability prior to the age of 50 is supported by both cross-sectional and longitudinal analyses of the risk of functional and cognitive decline in individuals with Down syndrome (Devenny, Hill, Patxot, Silverman, & Wisniewski, 1992; Devenny, Silverman, Hill, Jenkins, Sersen, & Wisniewski, 1996; Zigman, Schupf, Lubin, & Silverman, 1987; Zigman, Schupf, Sersen, & Silverman, 1995; Zigman et al., 2002). Several cross-sectional studies reported that prior to age 50, adults with Down syndrome tend to have significantly *better* skills than their counterparts with intellectual disability due to other causes, but after age 50 they lose their comparative advantage both functionally and cognitively, experience functional declines at an earlier age and have a

higher risk of Alzheimer's disease (Zigman et al., 1987, 1995, 2002). In longitudinal studies, declines are more pronounced among older adults over age 50, and are more likely among adults with Down syndrome than their counterparts with intellectual disability due to other causes (Devenny et al., 1992, 1996). Other longitudinal studies report similar patterns (Carr, 2000; Carr, 2003; Carr, 2005; Collacott & Cooper, 1997; Hawkins, Eklund, James, & Foose, 2003; Rasmussen & Sobsey, 1994). However, recent findings suggest that early stages of cognitive decline can be identified in some adults at earlier ages than 50 years, and that personality and behavior changes can be associated with these early changes (Adams & Oliver, 2010; Ball, Holland, Hon, Huppert, Treppner & Watson, 2006; Ball, Holland, Treppner, Watson, & Huppert, 2008). These discrepant findings may be due to different methods used. Different measures have been used to assess cognitive deterioration, with more recent work focusing on executive functioning. Longitudinal studies have also used different time intervals between assessments, which may also influence the ability to detect changes.

Adding to the complexity of understanding aging in this population is evidence that aging individuals with Down syndrome are a heterogeneous group. Prasher and colleagues differentiated the trajectories of individuals with Down syndrome who are healthy and those who have health difficulties. In a three-year longitudinal study of 128 adults with Down syndrome (Prasher, Chung, & Haque, 1998), those who had neither dementia nor medical problems at the outset showed a pattern of stability over the study period. However, when the total group was analyzed together (including those who were healthy, those with medical problems, and those with dementia), there was a pattern of decline in functional abilities. The Prasher et al. study clarifies that there are multiple trajectories that characterize individuals with Down syndrome in adulthood, and suggests the need for more finely differentiated analyses during the later years of life.

In particular, mean-level trajectories may mask the considerable individual-level heterogeneity among aging adults with Down syndrome. Recent longitudinal research on adults with Down syndrome revealed a pattern of heterogeneity across different outcome variables (Esbensen, Seltzer, & Krauss, 2008). While measures of health declined over a 9-year period among adults with Down syndrome (ages 17–57, mean age = 32.1), some functional abilities improved and behavior problems became less severe (Esbensen et al., 2008). However, the factors accounting for this heterogeneity have not yet been identified, and the present study was designed to identify one set of prior factors that are predictive of later-life outcomes.

The genetics and biology of Down syndrome define the pattern of aging of individuals with this syndrome, and there is no doubt that dementia and poor health both contribute to declines in cognitive and functional abilities (Evenhuis, 1997; Zigman et al., 2002). Yet the influence of the family may also play a significant role in the course of aging. There are numerous demonstrations in past research of the strength of the family in improving the development of individuals with intellectual disability, including those with Down syndrome. Among young children with Down syndrome, parent-child interactions have been shown to provide a critical context for the child's development (Berger, 1990; Crnic, 1990; Guralnick, 1997; Shepperdson, 1995; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992), which is also fostered by supportive parental social networks (Dunst, Trivette, & Cross, 1986). Among children with Down syndrome, growth in communication, daily living skills and socialization skills is predicted by family cohesion and quality of the mother-child relationship (Hauser-Cram et al., 1999), and more complex play skills are associated with father-child play and the father's level of emotional availability (de Falco, Esposito, Venuti, & Bornstein, 2008). Among adults with Down syndrome, greater independence is associated with lower maternal stress (Carr, 2008). The family environment has also been shown to

explain behavior change in adults with developmental disabilities. High levels of maternal warmth, low levels of maternal criticism, and family adaptability lead to positive changes in symptoms and behavior problems in individuals with developmental disabilities (Baker, Seltzer, & Greenberg, 2011; Greenberg, Seltzer, Hong, & Orsmond, 2006; Hastings & Lloyd, 2007; Smith, Greenberg, Seltzer, & Hong, 2008), although this has not been examined in families of adults with Down syndrome specifically.

As reviewed, the impact of family characteristics on the development of children with Down syndrome has been established. One of our aims is to extend this investigation to later life, and determine if family characteristics continue to have an impact on aging outcomes of adults with Down syndrome, as measured by health, functional abilities and behavior problems. A second exploratory aim is to examine whether family characteristics serve as predictive factors in the development of dementia among adults with Down syndrome. Our rationale for this hypothesis is based on research findings in the general population that demonstrated that “healthier” family environments provide greater opportunities for environmental enrichment, and environmental enrichment has been related to a reduced risk for late-onset dementia in older adulthood (Jankowsky, et al., 2005; Potter, Costa, Cracciola, Hughes, & Arendash, 2005). If parental depression reduces opportunities for environmental enrichment during development, then those protective effects would not occur and risk for dementia in later life would be relatively higher. Further, maternal depression has been shown to be predictive of the development of depression in children, and depression is, in and of itself, a risk factor for dementia (Gao et al., 2012). Our exploratory analyses focused on the development of dementia also examined the impact of socio-economic status and family size, as these variables have also been identified as risk factors (as reviewed in Borenstein, Copenhaver, & Mortimer, 2006).

In this study, we focus on characteristics of mothers and fathers as measured between 1989 and 2000, and examine their influence on the functional abilities, behavior problems, health, and dementia status in their adult child with Down syndrome as measured in 2010/2011. We hypothesize that parents’ depressive symptoms, positive psychological well-being, and the quality of the relationship with the son or daughter with Down syndrome, as measured between 1989 and 2000, will be associated with more favorable outcomes in the adults with Down syndrome, expressed as better health and functional abilities, fewer behavior problems and a lower likelihood of developing dementia. Specifically, we hypothesize that, among both mothers and fathers, *initial* low levels of depressive symptoms, high levels of positive psychological well-being, and positive relationship quality with the son or daughter with Down syndrome; and *over time*, declines in depressive symptoms, improvements in positive psychological well-being, and improvements in relationship quality with the son or daughter, will be associated with better health and functional abilities, fewer behavior problems, and a lower likelihood of developing dementia.

## Method

### Participants

The current study is based on a subsample drawn from a larger longitudinal study of families ( $n = 461$ ). Initial recruitment criteria in the larger longitudinal study were that in each family, there was a mother age 55 and older whose adult son or daughter with intellectual or developmental disabilities was living at home (Esbensen, Seltzer, & Krauss, 2011; Krauss & Seltzer, 1999). Of the original sample, 169 had a son or daughter with Down syndrome. From 1988 to 2000, eight waves of data were collected at 18 month intervals. A ninth wave of data collection was conducted a decade later (2010/2011) focusing on 75 of the original 169 sons and daughters with Down syndrome, and these adults form the sample for the present analysis.

From the original sample of 169 individuals with Down syndrome, 57 were deceased in 2010, 4 adults with Down syndrome had no surviving family members to contact in 2010, 18 families declined to participate, and 15 families could not be located. Thus, the present sample constituted 80.6% of the eligible participants (i.e., those who survived to 2010 and who had surviving family members who could be located). The 75 surviving adults with Down syndrome were approximately 5 years younger in 1988 than the 94 adults who were not included in the 2010/2011 wave of data collection,  $t(167) = 4.61$ ,  $p < .01$ , but were comparable in gender and level of functioning. All data presented in this article pertain only to information collected about these 75 adults with Down syndrome and their families.

**Demographic Characteristics of Adults with Down Syndrome and their Families (n = 75)**—At the time of the first interview in 1988, mothers served as the primary respondents for all 75 of these adults with Down syndrome. At that time, mothers ranged in age from 55 to 83 years ( $M = 64.5$ ,  $SD = 6.5$ ), and they were primarily married (81.3%). The median family income was between \$15,000 and \$19,999, which was typical for older household incomes at that time (US Census Bureau, 2005). In 1988, the son or daughter with Down syndrome ranged in age from 15 to 43 years ( $M = 28.5$ ,  $SD = 6.0$ ). Over two-thirds were males (65.3%). Three-fourths had mild or moderate intellectual disability (74.6%) and the remaining adults had severe or profound intellectual disability. Our classification of level of intellectual disability was based on three sources: Stanford-Binet (4<sup>th</sup> edition) IQ scores which were administered by our research staff, independent agency records of cognitive testing obtained for each participant, and parental report. As 56% of the sample scored at floor on the Stanford-Binet or was not able to complete testing, individuals were classified by level of intellectual disability rather than IQ score. All surviving adults with Down syndrome and their parents were Caucasian.

Data were available from fathers as well as from mothers. Starting at the second wave of data collection in 1989/1990, 50 fathers of the 75 adults with Down syndrome were surveyed. Of the 25 adults with Down syndrome without father data, 20 had deceased or uninvolved fathers and 2 had families that were unable to participate at the second wave of data collection. Only three fathers declined to participate. The 50 fathers ranged in age from 54 to 82 years ( $M = 66.7$ ,  $SD = 6.4$ ). Fathers were included in the study at all subsequent rounds of data collection.

At the initial interview, all adults with Down syndrome were living in the parental home. During the course of the study, some moved out of the parental home. By 2010/2011, only 20% continued to co-reside with their parents, 16% were co-residing with a sibling, and the majority was living in community residences.

The data regarding the 75 adults with Down syndrome were collected from various family member respondents. From 1988 to 2000, the mother served as the primary respondent. However, during this time, 14 mothers either died or became incapacitated, and in such cases a “successor caregiver” (generally the father or a sibling) served as the respondent. At the most recent assessment in 2010/2011, in families where the mother was still alive and able to be interviewed, she was the source of data ( $n = 34$ ). If the mother was not alive or well enough to participate, we turned to fathers as the respondent ( $n = 6$ ). If neither the mother nor the father were alive and able to participate, we interviewed adult siblings ( $n = 35$ ). The demographic characteristics of these respondents at the time of the follow-up, and of the adults with Down syndrome, are summarized in Table 1.

## Measures

**Parental Characteristics**—We focused on three indicators of parental characteristics for this study: depressive symptoms, positive psychological well-being, and quality of the

parent's relationship with the son or daughter. A timeline of the measures that were assessed at each time point is displayed in Table 2. The key *independent* variables in our regression analysis included the initial status of these three variables, for both mothers and fathers, as well as rate of change in these parental characteristics between 1989 and 2000.

Note that in prior exploratory models, we examined whether other measures of the family predicted adult outcome in 2010/2011. These other measures included family size, parental marital status, family income, frequency of contact with family, family cohesion, initial levels of sibling well-being and changes in sibling well-being over the course of the study. However, none of these measures were significant predictors of any of the adult outcomes and were dropped from further consideration.

The Center for Epidemiological Studies-Depression Scale (CES-D) was used to measure depressive symptoms in mothers and fathers (Radloff, 1977). For 20 depressive symptoms, the parent indicated on a 4-point scale how often the symptom was experienced in the last week. A higher score reflects a greater severity of depressive symptoms, and scores greater than 16 represent significant depression (Radloff, 1977). The CES-D has been used extensively with older adults and has demonstrated reliability and validity (Gatz & Hurwicz, 1990; Himmelfarb & Murrell, 1983). Internal consistency for the CES-D was .86 for both mothers and fathers surveyed at the initial assessments. The initial status of depressive symptoms was measured in 1989/1990 for mothers and in 1992/1993 for fathers. Slope scores were calculated based on measures of depressive symptoms between these baselines and 2000 (see Table 2). At the initial interview with parents, 21.1% of mothers and 22% of fathers reported significant depressive symptoms (exceeding 16 points).

The Ryff Scales of Psychological Well-Being were used to measure positive psychological well-being (PPWB) in mothers and fathers (Ryff, 1989). Twenty-five items from the PPWB subscales of autonomy, environmental mastery, personal growth, purpose in life, and self-acceptance were each rated on a six-point scale (1 = strongly disagree to 6 = strongly agree) and summed to create a total score. A higher score reflects greater PPWB. Internal consistency was .88 for mothers at Time 1, and .91 for fathers at Time 2. The initial status of PPWB for both mothers and fathers was measured in 1991/1992. Slope scores were calculated based on measures of PPWB between 1991–2000 for mothers and between 1991–1998 for fathers (see Table 2).

The Positive Affect Index (PAI) was administered to mothers and fathers, and was used to measure perception of the quality of his/her relationship with the son or daughter with Down syndrome (Bengtson & Schrader, 1982). This 10-item scale assesses the parent's feelings towards the son or daughter with Down syndrome and his/her perception of the adult child's feelings towards him/her. Items relate to feelings of intimacy, trust, understanding, fairness and respect, and each item is rated on a 6-point scale. A higher score reflects a perception of a closer relationship. Internal consistency for the PAI was .86 among mothers and .90 among fathers at the initial assessment. The initial status of relationship quality with the son or daughter with Down syndrome for both mothers and fathers was measured in 1989/1990. Slope scores were calculated based on measures of relationship quality between 1989–2000 for mothers and between 1989–1998 for fathers (see Table 2).

**Adult Outcomes**—Four outcomes for adults with Down syndrome were assessed: behavior problems, functional abilities, health, and dementia status. The source of data at each wave of data collection was the mother, unless she was deceased in which case the successor caregiver in the family provided the data. Current measures of these four outcomes, assessed in 2010/2011, served as the *dependent variables* in our analyses and the initial status of three of these outcomes (behavior problems, functional abilities and health)



served as *control variables*. Change in these three measures during the 1988–2000 study period, calculated as slopes, also served as *control variables* in our regression models.

The measure of behavior problems was the ICAP (Inventory for Client and Agency Planning), later known as the SIB-R (Scales of Independent Behavior – Revised) (Bruininks, Hill, Weatherman, & Woodcock, 1986; Bruininks, Woodcock, Weatherman, & Hill, 1996). This measure assessed the frequency and severity of eight types of behavior problems, providing an overall measure of behavior problems. Individual problem behaviors are scored as present or absent. Index scores provide ratings of the seriousness of the problem behavior as sub-clinical (90–110), marginally serious (111–120), moderately serious (121–130), serious (131–140) or very serious (141 or above). Reliability and validity are excellent (Bruininks et al., 1986). A single score, the General Maladaptive Index, reflected the severity of behavior problems at each time point in the study beginning at the second wave of data collection. The initial status of behavior problems was measured in 1989/1990. Slope scores were calculated based on measures of behavior problems between 1989–2000 (see Table 2).

Our measure of functional abilities was a 30-item scale measuring performance of activities of daily living in the areas of housework, personal care, meal related activities, and mobility. This measure of functional skills was based on a revised version of the Barthel Index to measure personal and instrumental activities of daily living appropriate for adults with intellectual or developmental disability (Mahoney & Barthel, 1965; Seltzer, Ivry, & Litchfield, 1987). Each item was rated on a 4-point scale of independence (0 = cannot perform the task at all, 1 = could do but doesn't, 2 = can perform the task with help, 3 = performs the task independently), and averaged for a total score. The internal consistency coefficient for the total score was .80 among the 75 adults at the first wave of data collection. Total functional abilities were assessed at each time point in the study. The initial status of functional abilities was measured in 1988/1989. Slope scores were calculated based on measures of functional abilities between 1988–2000 (see Table 2).

Current health status of the adult with Down syndrome was rated on a 4-point scale (1 = poor, 2 = fair, 3 = good, 4 = excellent). Such global ratings of health have been found to be accurate measures of health status (Idler & Benyamini, 1997). Health of the adult with Down syndrome was assessed at each time point in the study. The initial status of health was measured in 1988/1989. Slope scores were calculated based on measures of health between 1988–2000 (see Table 2).

Dementia status of all adults with Down syndrome was assessed at the ninth wave of data collection in 2010/2011. Dementia status was classified using consensus coding between two licensed clinical psychologists blind to the predictor variables. Consensus coding has been previously used to classify dementia status, and we modeled our coding on the system reported in Silverman, et al. (2004). Assessments utilized in the consensus coding included the following measures administered at the ninth wave of data collection: Dementia Questionnaire for People with Learning Disabilities (Evenhuis, Kengen, & Eurlings, 2006), the Dementia Scale for Down Syndrome (Gedy, 1995), the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (Moss, 2002), reports of current and previous health conditions, current diagnoses, and current medication. All this information was collected from the primary respondent in 2010/11. In addition, respondent information collected in previous waves of data collection and prior longitudinal direct assessments of cognitive ability from the second and third wave of data collection were available to assist in interpreting declines from previous cognitive abilities. Dementia status was categorized as (0) no dementia or (1) possible or definite dementia. Initial coding resulted in 89% agreement among the psychologists. Further discussion resolved any disagreements.

## Data Analysis

Multiple regression was used to test the extent to which prior measures of the mother and father would predict three outcomes in the adults with Down syndrome (behavior problems, functional abilities, health). Regression analyses were run separately for mothers and fathers. *Control variables* were entered in the first block of the regression model. These variables included the *initial level* of the dependent variable and the *slope* of the dependent variable across the initial eight waves of the study period. Person-specific slope scores were created using Empirical Bayes predictions (Rabe-Hesketh & Skrondal, 2005). By controlling for the initial level of the dependent variable, we are examining the impact of parental characteristics on the given outcome in 2010/2011, net of prior level of this outcome in 1988. By further controlling for the slope of the dependent variable between 1988–2000, we are accounting for declines or increases in the dependent variable that may result with aging in the adults with Down syndrome. We include this additional level of statistical control based on the pattern of changes with aging identified in other studies (Esbensen et al., 2008). For example, health in 2010/2011 is being predicted from the level of health in 1988, but since health changes over time, we additionally control for the change in health between 1988–2000. *Demographic covariates* were entered in the second block of the regression model, including current age and level of intellectual functioning of the adult with Down syndrome.

To test the research hypotheses and minimize the number of predictors in any one analysis, separate regression models were run for mothers and fathers, with different measures of parental characteristics being entered in the third block. The third block included the *independent variables* of initial status and slope of one measure of parental characteristics. Person-specific slope scores were created using Empirical Bayes predictions (Rabe-Hesketh & Skrondal, 2005). Separate regression models were run for each adult outcome, with depressive symptoms, positive psychological well-being, and the quality of the relationship being entered as the measure of parental characteristics.

Logistic regression was used to determine the extent to which prior measures of parental characteristics would predict current dementia status in adults with Down syndrome. Demographic covariates, and the initial status and slope of the parent measure were entered in the logistic regression model. Separate regression models were run, one each for the three parental characteristics (depressive symptoms, positive psychological well-being, and relationship quality) for mothers and fathers. Results are presented as odds ratios. Scores significantly higher than 1 indicate a positive relationship. Scores significantly lower than 1 indicate a negative relationship.

It is possible that consistency (or lack of consistency) in the source of data across the nine waves of the study might influence findings. Specifically, it is possible that, for example, a mother who had higher depression scores earlier in the project would be more likely to rate her son or daughter as having unfavorable outcomes. It also is possible that changing informants would introduce variance into the prediction models. To examine the effect of informant (mother or other respondent), we introduced a variable into the analyses where 1 = the mother as the source of data throughout the study and 0 = a father, sibling, or other reporter provided some of the data. Notably, the inclusion of this control variable did not alter the findings and was never significant (data available from first author). Therefore, it is not included in the final models. Missing data on control variables, demographic covariates or independent variables resulted in list-wise deletion of the subject in the regression analyses. The sample size for analyses using maternal predictors ranged from 61 to 71. The sample size for analyses using paternal predictors ranged from 36 to 50. Due to the small sample size in some analyses involving fathers, these analyses should be viewed as exploratory.

## Results

### Descriptive Findings about the Adults with Down Syndrome

In 2010/2011, the adults with Down syndrome ranged in age from 37 to 65 years, with 44% under 49 years of age, 45% between 50 and 59 years of age, and 11% aged 60 or older (mean = 52.1 years). These adults were generally healthy, with 12% in excellent health, 56% in good health, 27% in fair health and only 4% reported to be in poor health. Similarly, only 4% were classified as exhibiting marginally serious behavior problems on the General Maladaptive Index of the SIB-R. About a quarter (28%) of the sample was rated to be mainly independent in performing activities of daily living, nearly half (47%) were rated to be able to perform most activities with help, 19% were rated as able to perform such activities but generally did not, and only 6% were rated as not being able to perform any of the measured activities of daily living.

Twenty-two years earlier, 57% of the adults were in excellent health, 36% were in good health and only 6% were in fair health. A greater number of adults displayed maladaptive behaviors, with 8% being classified as exhibiting marginally serious and 4% moderately serious behavior problems. At the initial interview, the adults with Down syndrome were also reported to be more independent in activities of daily living, with 47% of the sample rated to be mainly independent, 52% rated to be able to perform most activities with help, and 1% rated as able to perform such activities but generally do not. See Table 3 for means and standard deviations of key study variables.

Based on assessments carried out in 2010/2011 and clinical consensus coding, 56 adults with Down syndrome (74.7%) were identified as 'no dementia,' 6 adults (8%) were identified as 'possible dementia,' and 13 adults (17.3%) were identified as meeting criteria for 'definite dementia.' The latter two groups were collapsed to form a group of 19 adults (25%) with possible or definite dementia.

### Predicting Behavior Problems from Parental Characteristics

For our first research question, we hypothesized that parents' higher initial levels of, and improvements in, positive psychological well-being and relationship quality, and lower initial levels of, and declines in, depressive symptoms, would be predictive of lower levels of behavior problems among the adults with Down syndrome in 2010/2011, controlling for initial levels of behavior problems and earlier changes in behavior problems (between 1989–2000). See Panel A, Table 4.

Our hypothesis was partially supported. Reductions in maternal depressive symptoms between 1989–2000 were significantly predictive of lower levels of current behavior problems, even when controlling for age, level of intellectual disability, previous behavior problems and changes in behavior problems that were occurring approximately 10 years ago. However, neither initial levels nor change in depressive symptoms in fathers were predictive of this outcome, nor was the initial levels nor change in the quality of the relationship between the adult with Down syndrome and either the mother or the father.

### Predicting Functional Abilities from Parental Characteristics

For our second research question, we hypothesized that parents' higher initial levels of, and improvements in, positive psychological well-being and relationship quality, and lower initial levels of, and declines in, depressive symptoms, would be predictive of better functional abilities among the adults with Down syndrome in 2010/2011, again controlling for initial levels of functional abilities and earlier changes in functional abilities (between 1988–2000). See Panel B, Table 4.



Again, our hypothesis was partially supported. Specifically, we found that lower initial levels of maternal depressive symptoms in 1988/1989 significantly predicted better functional abilities in 2010/2011 among adults with Down syndrome, as did a reduction in maternal depressive symptoms between 1989–2000, even when controlling for age, level of intellectual disability, previous functional abilities, and changes in functional abilities that were occurring approximately 10 years ago. However, initial levels and change in depressive symptoms in fathers, and initial levels and change in positive psychological well-being and relationship quality in mothers and fathers, did not predict functional abilities in adults with Down syndrome in 2010/2011.

### Predicting Health from Parental Characteristics

For our third research question, we hypothesized that parents' higher initial levels of, and improvements in, positive psychological well-being and relationship quality, and lower initial levels of, and declines in, depressive symptoms, would be predictive of better health among the adults with Down syndrome in 2010/2011, controlling for initial levels of health and earlier changes in health (between 1988–2000). See Panel C, Table 4.

We found support for this hypothesis among both mothers and fathers. First, we found that lower initial levels of *maternal* depressive symptoms in 1988/1989 and reduction in *maternal* depressive symptoms 1989–2000 (trend level) predicted better health in 2010/2011 among adults with Down syndrome, net of the other predictors. Second, we found that higher initial level of *paternal* positive psychological well-being in 1991/1992 and improvements in *maternal* positive psychological well-being between 1991–2000 were significant predictors of better health in 2010/2011 among adults with Down syndrome, even when controlling for age, level of intellectual disability, previous health and previous changes in health. And third, we found that higher initial levels of the father-adult child relationship predicted better health in 2010/2011 among adults with Down syndrome, controlling for the other predictors.

### Dementia Status and Adult Outcomes

For our last research question, our exploratory hypothesis was that positive parental characteristics at the start of the study and improvements in parental well-being between 1989–2000 would predict a lower likelihood of dementia in 2010/2011 among adults with Down syndrome, after controlling for the age and level of functioning of the adult.

As shown in Table 5, we found that higher initial maternal and paternal levels of depressive symptoms, and lower initial levels of paternal relationship quality, were significant predictors of a higher likelihood of a dementia diagnosis in the adult with Down syndrome in 2010/2011. In addition, lower initial levels of maternal positive psychological well-being predicted a higher likelihood of developing dementia in the adult with Down syndrome in 2010/2011, but the effect was only marginally significant.

### Covariates

Age was a significant predictor of adult outcomes, such that older adults were significantly more likely to be classified as having dementia, poorer functional abilities, and poorer health than younger adults, controlling for other factors. The association between age and behavior problems was generally non-significant. Level of intellectual disability was generally not a significant predictor of adult outcome in these analyses, the exception being dementia status. Individuals with severe or profound levels of intellectual disability were more likely to be classified as having dementia.

## Discussion

Parental psychological functioning and the quality of the relationship between the parent and the adult with Down syndrome were significant predictors of adult outcomes approximately 12 years later. These findings indicate that the influence of family environment persists over the life course in a population at high risk of age-related concerns. Specifically, lower levels of behavior problems in the adult with Down syndrome in 2010/11 were predicted by reductions in maternal depressive symptoms between 1989–2000, net of other predictors. A higher level of functional abilities in the adult with Down syndrome in 2010/2011 was predicted by both initial level and reductions in maternal depressive symptoms between 1989–2000, net of the other predictors. Better health of adults with Down syndrome at follow-up was predicted by the mother's initial level of depressive symptoms, by reductions in her depressive symptoms between 1989–2000 (with marginal significance), and by improvements in her positive psychological well-being between 1991–2000, again net of the other predictors. Furthermore, better health was predicted by higher initial levels of positive psychological well-being in fathers and by higher initial levels of relationship quality between the father and the adult with Down syndrome, net of the other predictors.

Dementia status was also predicted by parental characteristics after controlling for age and level of intellectual disability. Adults with Down syndrome were significantly less likely to be classified as having dementia at the 22-year follow-up point if their mother and father had lower initial levels of depressive symptoms, if their mother had higher initial levels of positive psychological well-being (trend), and if the quality of the relationship with their father at the first point of data collection was better. This being the first finding of this type, it should be interpreted with caution pending replication, especially given the uncertainty regarding the mechanisms underlying this association and the lack of an established gold-standard for defining “mild” dementia in this population.

As expected, advancing age contributed significantly to the outcomes, with older adults having poorer health, poorer functional abilities, and a greater likelihood of dementia. However, the earlier characteristics of parents influenced adult status above and beyond aging effects. The largest observed effects were associated with depressive symptoms in mothers.

Outcomes for adults with Down syndrome were predicted by both initial levels and changes in maternal characteristics. In contrast, outcomes were predicted by initial levels but not changes in paternal characteristics. Although direct contrasts were not conducted, these findings suggest a differential pattern of findings among mothers and fathers. The smaller sample size and the fewer data points studied in the analyses involving fathers may have contributed to the different findings and future studies are needed to explore these suggestive findings.

There are significant clinical implications of these findings. The data imply that attending to the mental health of parents, both mothers and fathers, may have long-term positive benefits not only for the parents but also for adults with Down syndrome, although this conclusion warrants evaluation in intervention research. In addition, supporting the quality of the relationship between each parent and the adult with Down syndrome may also contribute to better outcomes. The mechanisms by which better parental psychological functioning and closer parent-child relationships translate over a period of decades into improved health and functional abilities, declines in behavior problems, and a lower likelihood of dementia also warrant future study. Plausible hypotheses include more nurturance, more vigilance about health problems, and greater levels of advocacy by parents on behalf of the adult with Down syndrome, all potentiated by closer family relationships and better psychological

functioning. Improvements in one outcome of aging may also mediate improvements in other outcomes of aging. For example, parental characteristics may improve health outcomes (decrease obesity, improved nutrition), which may in turn serve as a protective factor against the development of dementia (Borenstein et al., 2006; Lahiri & Maloney, 2010). As characteristics of adults with Down syndrome or other intellectual disabilities are also found to impact the well-being of their parents, bi-directional effects between the parent and the adult child may also contribute to our pattern of findings (Esbensen, Seltzer & Greenberg, 2006; Esbensen & Seltzer, 2011; Essex, Seltzer, & Krauss, 1999). These bi-directional effects may serve an iterative process contributing to the heterogeneity of patterns of aging in Down syndrome. As the lifespan continues to increase for adults with Down syndrome, family relationships warrant recognition as important long-term predictors of outcome, as does understanding the influence of bi-directional effects.

Future research should also continue to examine the effects of socio-economic status and race/ethnicity in these processes, particularly as socioeconomic status has been found to serve as a risk factor for the development of Alzheimer's disease (Moceri et al., 2001). The present sample lacked variability in race/ethnicity and socioeconomic status, and none of the families were living in poverty, which may have accounted for non-significant findings in our analyses of the effect of socioeconomic status on outcomes. Past research has shown that there are substantially shorter lifespans among African-Americans with Down syndrome (Yang, Rasmussen, & Friedman, 2002), but little research has examined the socio-economic gradient of adult outcomes.

These findings, particularly related to fathers, represent a first step toward understanding the complex relationship among earlier family life experiences and their impacts on later adult status. For example, our study was underpowered for detecting interactions or joint effects of multiple family member characteristics in the same model. Because of some small sample sizes, our marginally significant findings should be interpreted with caution. Further, the adults with Down syndrome sampled as a group were in relatively good initial and current health with few behavior problems and semi-independent functional abilities (Esbensen & Seltzer, 2011). Therefore, the patterns reported here regarding the influence of the parents might not be evident with adults who are functioning more poorly and in ill-health.

Nevertheless, there are numerous strengths to the current study. The sample was followed over an extended period of adult development, and by incorporating independent reports from mothers and fathers between 1989 and 2000 on a variety of measures of their own well-being, we decrease the potential effects of reporter bias and method variance on the findings. These potential confounds were also reduced by including reports in 2010/2011 on adults with Down syndrome from a variety of family members. Furthermore, by measuring both initial levels of parental characteristics and changes in parental characteristics, we are able to capture the dynamic features of the family and create a more comprehensive measure of the impact of the family on the aging of adults with Down syndrome. Finally, by controlling for the dependent variables at the start of the study and also for change in the dependent variables over the first 10–12 years of the study period (1988–2000), the predictors of adult outcomes at the 22 year follow-up reflected levels of behavior problems, functional abilities, and health net of their initial status or earlier patterns of change. These were well-controlled statistical models.

This study contributes to our understanding of the aging of adults with Down syndrome, particularly the impact of parental well-being on their aging outcomes. Our findings suggest that both mother and father characteristics have persistent effects on later life outcomes in adults with Down syndrome. Future research is needed to better understand the mechanisms responsible for the associations found in the present study, to develop effective strategies for

informing and supporting families of individuals with Down syndrome regarding the importance of the family as a target for intervention, and to use these insights to improve aging outcomes for adults with Down syndrome.

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**Table 1**

Demographics of respondents at Time 9 (2010/2011).

	N	Age	% Male
Adult with Down syndrome	75	M=51.1, SD=6.0 (range 37–65)	65.3%
Mother	34	M=84.5, SD=5.1 (range 76–97)	0%
Father	6	M=82.3, SD=1.9 (range 80–85)	100%
Sibling	35	M=60.0, SD=7.2 (range 39–74)	28.6%

**Table 2**

Timeline of measures

	Time 1	Time 2	Time 3	Time 4	Time 5	Time 6	Time 7	Time 8	Time 9
<b>Year</b>	1988/ 1989	1989/ 1990	1991/ 1992	1992/ 1993	1994/ 1995	1995/ 1996	1997/ 1998	1998/ 2000	2010/ 2011
<b>Measures of parental characteristics</b>									
Depressive symptoms									
Mothers	X	X	X	X	X	X	X	X	X
Fathers			X	X	X	X	X	X	X
Positive psychological well-being									
Mothers		X	X	X	X	X	X	X	X
Fathers		X		X	X	X	X		
Relationship quality									
Mothers	X	X	X	X	X	X	X	X	X
Fathers	X	X	X	X	X	X	X		
<b>Measures of the adult with Down syndrome</b>									
Behavior problems									
	X	X	X	X	X	X	X	X	X
Functional abilities									
	X	X	X	X	X	X	X	X	X
Health									
	X	X	X	X	X	X	X	X	X
Dementia status									
									X

**Table 3**

Means and standard deviations of measures of parental characteristics and characteristics of adults with Down syndrome.

	<b>Behavior Problems</b>	<b>Functional Abilities</b>	<b>Health</b>
Adult with Down syndrome	104.09 (6.10) <sup>2</sup>	2.37 (0.39) <sup>1</sup>	3.51 (0.62) <sup>1</sup>
	102.36 (3.40) <sup>9</sup>	1.97 (0.77) <sup>9</sup>	2.77 (0.72) <sup>9</sup>
	Depressive Symptoms	Positive Psychological Well-being	Relationship Quality
Mothers	8.63 (7.47) <sup>2</sup>	23.99 (3.33) <sup>3</sup>	51.25 (4.80) <sup>2</sup>
Fathers	9.10 (7.07) <sup>4</sup>	23.28 (3.62) <sup>3</sup>	48.48 (5.74) <sup>2</sup>

<sup>1</sup>Data collected at first wave of data collection;

<sup>2</sup>Data collected at second wave of data collection;

<sup>3</sup>Data collected at third wave of data collection;

<sup>4</sup>Data collected at fourth wave of data collection;

<sup>9</sup>Data collected at ninth wave of data collection.



**Table 4**

Final block of regression models predicting current adult outcomes of behavior problems, functional abilities and health from parents' prior characteristics.

Independent variable entered as 5 <sup>th</sup> and 6 <sup>th</sup> predictor in model						
	CES-D		PPWB		PAI	
	Mother	Father	Mother	Father	Mother	Father
<b>Panel A</b>						
<b>Predicting Current Behavior Problems</b>						
Initial level of BP	-.05	.16	-.00	.10	-.09	.08
Slope of BP	.26 <sup>t</sup>	.29	.22	.36 <sup>t</sup>	.25	.20
Age of adult with DS	.21 <sup>t</sup>	.39 <sup>*</sup>	.25 <sup>t</sup>	.31 <sup>t</sup>	.19	.27
Level of ID	.05	.28	.11	.20	.10	.10
<b>Initial level of IV</b>	<b>.09</b>	<b>-.01</b>	<b>-.11</b>	<b>-.01</b>	<b>-.16</b>	<b>-.05</b>
<b>Slope of IV</b>	<b>.29<sup>*</sup></b>	<b>.22</b>	<b>-.20</b>	<b>-.06</b>	<b>-.03</b>	<b>.09</b>
$\Delta R^2$	.08 <sup>t</sup>	.04	.06	.00	.03	.01
R <sup>2</sup>	.20	.25	.22	.16	.14	.10
<b>Panel B</b>						
<b>Predicting Current Functional Abilities</b>						
Initial level of FA	.34 <sup>**</sup>	.44 <sup>*</sup>	.32 <sup>**</sup>	.33 <sup>*</sup>	.36 <sup>**</sup>	.38 <sup>*</sup>
Slope of FA	.14	.13	.16	.08	.16	.19
Age of adult with DS	-.43 <sup>**</sup>	-.34 <sup>**</sup>	-.38 <sup>**</sup>	-.46 <sup>**</sup>	-.44 <sup>**</sup>	-.48 <sup>*</sup>
Level of ID	.26 <sup>*</sup>	.24	.20 <sup>t</sup>	.26	.18	.12
<b>Initial level of IV</b>	<b>-.21<sup>*</sup></b>	<b>-.11</b>	<b>.09</b>	<b>.13</b>	<b>-.02</b>	<b>.04</b>
<b>Slope of IV</b>	<b>-.18<sup>*</sup></b>	<b>.06</b>	<b>.15</b>	<b>-.01</b>	<b>-.00</b>	<b>-.06</b>
$\Delta R^2$	.06 <sup>*</sup>	.01	.05 <sup>*</sup>	.02	.00	.01
R <sup>2</sup>	.53	.61	.50	.58	.45	.53
<b>Panel C</b>						

	Independent variable entered as 5 <sup>th</sup> and 6 <sup>th</sup> predictor in model					
	CES-D		PPWB		PAI	
	Mother	Father	Mother	Father	Mother	Father
<b>Predicting Current Health</b>						
Initial level of health	.24*	.42**	.25*	.33*	.26*	.42*
Slope of health	.12	.15	.22*	.11	.13	.13
Age of adult with DS	-.36**	-.30*	-.30**	-.39**	-.35**	-.35**
Level of ID	.07	-.08	.02	-.07	-.01	-.14
<b>Initial level of IV</b>	<b>-.28*</b>	<b>-.24</b>	<b>.20</b>	<b>.29*</b>	<b>.13</b>	<b>.24*</b>
<b>Slope of IV</b>	<b>-.20<sup>†</sup></b>	<b>-.01</b>	<b>.24*</b>	<b>.13</b>	<b>.01</b>	<b>.01</b>
$\Delta R^2$	.10*	.05	.13**	.09 <sup>†</sup>	.01	.05
R <sup>2</sup>	.36	.46	.40	.48	.27	.45

BP = Behavior problems; FA = Functional abilities; DS = Down syndrome; ID = Intellectual disability; IV = Independent variable (CES-D, PPWB, or PAI); CES-D = Center for Epidemiological Studies – Depression Scale; PPWB = Positive psychological well-being; PAI = Positive Affect Index.

$\Delta R^2$  reflects the amount of variance accounted for by adding the Initial level of the IV and the Slope of the IV to the regression model.

R<sup>2</sup> reflects the total amount of variance accounted in the regression model.

\*\* = p < .01,

\* = p < .05,

<sup>†</sup> = p < .05, one-tailed.

**Table 5**

Logistic regression models predicting current adult dementia status from prior measures of the parents.

	Exp( $\beta$ )					
	CES-D		PPWB		PAI	
	Mother	Father	Mother	Father	Mother	Father
Age of adult with DS	1.30 <sup>***</sup>	1.34 <sup>*</sup>	1.28 <sup>***</sup>	1.32 <sup>***</sup>	1.27 <sup>***</sup>	1.47 <sup>***</sup>
Level of ID	0.18	0.10 <sup>t</sup>	0.14 <sup>*</sup>	0.18	0.28 <sup>t</sup>	0.17
Initial level of IV	1.14 <sup>*</sup>	1.29 <sup>*</sup>	0.80 <sup>t</sup>	0.83	0.94	0.79 <sup>*</sup>
Slope of IV	19.08	0.45	0.00	0.11	3.52	10.63

DS = Down syndrome; ID = Intellectual disability; IV = Independent variable (CES-D, PPWB, or PAI); CES-D = Center for Epidemiological Studies – Depression Scale; PPWB = Positive psychological well-being; PAI = Positive Affect Index.

<sup>\*\*\*</sup> =  $p < .01$ ,

<sup>\*</sup> =  $p < .05$ ,

<sup>t</sup> =  $p < .10$ .