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Predicting Well-being Longitudinally for Mothers Rearing Offspring with Intellectual and Developmental Disabilities

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Abstract

Background—Well-being outcomes for parents of children with intellectual and developmental disabilities (IDD) may vary from positive to negative at different times and for different measures of well-being. Predicting and explaining this variability has been a major focus of family research for reasons that have both theoretical and applied implications.

Methods—The current study used data from a 23-year longitudinal investigation of adoptive and birth parents of children with IDD to determine which early child, mother, and family characteristics would predict the variance in maternal outcomes 20 years after their original measurement. Using hierarchical regression analyses, we tested the predictive power of variables measured when children were 7 years old on outcomes of maternal well-being when children were 26 years old. Outcome variables included maternal self-report measures of depression and well-being.

Results—Final models of well-being accounted for 20% to 34% of variance. For most outcomes, Family Accord and/or the personality variable of Neuroticism (emotional stability/instability) were significant predictors, but some variables demonstrated a different pattern.

Conclusions—These findings confirm that 1) Characteristics of the child, mother, and family during childhood can predict outcomes of maternal well-being 20 years later; and 2) Different predictor-outcome relationships can vary substantially, highlighting the importance of using multiple measures to gain a more comprehensive understanding of maternal well-being. These results have implications for refining prognoses for parents and for tailoring service delivery to individual child, parent, and family characteristics.

An almost exclusively pathological focus on the outcomes for families rearing children with intellectual or other developmental disabilities (IDD) characterized research in the mid-20th century. Investigators focused on the poor outcomes associated with stress in the families, primarily at one time period or over short spans of time (Helff & Glidden, 1998). However, more recently there has been an emerging consensus that most families demonstrate resilience and that both short- and long-term outcomes reflect that although problems exist, they are often accompanied, or balanced, by rewards and satisfactions (Crnic, Pedersen y Arbona, Baker, & Blacher, 2009; Floyd, Costigan & Piazza, 2009; Glidden, 2012). Critical

to this consensus has been the large number of studies from a variety of countries that have all arrived at similar conclusions (Glidden & Schoolcraft, 2007; Hastings & Taunt, 2002; Jokinen & Brown, 2005).

Nonetheless, there is substantial variation in the balance of rewards and problems within research samples. Given that psychology's scientific objectives are to understand and explain behavior, it is essential that investigators identify the important antecedents that predict such variation in the outcomes of interest. These antecedents can immediately precede the outcome, such as the antecedent of a child's diagnosis and the outcome of a parent's initial response to it. Alternatively, the antecedents can also occur decades earlier, as in the case of a mother's childhood and young adult experiences with disability predicting her reactions to the transition to adulthood of her own son or daughter with disabilities. If the latter, longitudinal methodologies where the same individuals are followed over time are a powerful tool for understanding how contemporary reactions to offspring life circumstances develop and are maintained.

Models of family functioning often include features that may account for such development over time, and lead to predictions about the type and degree of change. For example, the ABCX and Double ABCX models (Hill, 1949, 1958; McCubbin & Patterson, 1983) have had heuristic value, generating substantial empirical research in families with individuals with disabilities (Paynter, Riley, Beamish, Davies, & Milford, 2013; Thompson, Hiebert-Murphy, & Trute, 2013; Weiss, Robinson, Fung, Tint, Chalmers, & Lunskey, 2013). In its most basic form, the A factor specifies variables that represent demands or stressors on the family; the B factor identifies resources that families possess, and the C factor is defined by appraisal, *viz.*, the family's perception of the stressor or demands. These three factors act together, resulting in adaptation that can range from highly positive to highly negative. The double aspect of the model indicates that the process is iterative, and that stressors can increase or decrease, resources can be used up or multiplied, and perceptions of stressors can change, as the family appraises not only the original demands, but also changes over time, including their own reactions.

In research involving families with children or adults with disabilities, many of the variables investigated can be classified as stressors, resources, perceptions of stressors, and adaptation outcomes that fit this Double ABCX model. For example, antecedent or predictor variables that have been studied as stressor variables have included diagnostic category (Corrice & Glidden, 2009; Hodapp, Ricci, Ly, & Fidler, 2003), child adaptive behavior (Blacher & McIntyre, 2006; Griffith, Hastings, Oliver, Howlin, Moss, Petty, & Tunnicliffe, 2011), and child maladaptive behavior (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Nalavany, Glidden, & Ryan, 2009). Family resources have frequently been defined by parent education (Glidden, Bamberger, Turek, & Hill, 2010; Hodapp, Fidler, & Smith, 1998), family income (Shapiro, Blacher, & Lopez, 1998), marital status ((Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Glidden, 1991), and parental coping strategies (Glidden, Billings, & Jobe, 2006; Seltzer, Greenberg, & Krauss, 1995). Various parental personality traits have been viewed as relevant to the C factor of stressor perception (Glidden & Schoolcraft, 2003; Shapiro et al., 1998). Outcome variables representing family adaptation and adjustment have also been numerous, reflecting both parental negative outcomes, such as stress and

depression (Glidden & Schoolcraft, 2007; Singer, 2006), as well as positive outcomes such as subjective well-being and quality of life (Glidden, 2012; Turnbull, Brown, & Turnbull, 2004).

This high number of both antecedent and outcome variables utilized in past research suggests that a complex constellation of qualities and characteristics of both children and their parents or families explain parental outcomes in families of children with IDD. Moreover, although some research has identified antecedent variables that predict multiple outcome variables, it is also likely that the best combination of predictors is quite different for different outcomes, implying an even greater complexity. For example, Floyd et al. (2009) summarized results from a 15-year longitudinal study of families with young adults with either mild or moderate intellectual disability. The level of disability predicted some, but by no means all, the variables of interest: No differences between IDD groups were found for parent contact and involvement or the level of participation in family activities. However, the participants with mild IDD were more likely to have been married and have a child and to be employed.

Seltzer and Krauss (1989) also reported variation in predictor-outcome patterns. In a sample of 203 older mothers caring for adult offspring with IDD, they found that maternal characteristics such as age, education, income, and marital status were better predictors of physical health and life satisfaction, whereas offspring characteristics, such as type and severity of disability, predicted more variance in parenting stress and burden. For both types of outcome variables, antecedent family and child characteristics, some of which had been in place for many years, successfully predicted later measures, yet each outcome variable was better predicted by a somewhat different subset of antecedents.

Not only will different variables predict different outcomes, but the relation between predictors and outcomes may also change over time, adding another layer of complexity to predictor-outcome relationships. In earlier research with a sample overlapping with the one in the current study, Glidden and Jobe (2009) measured depression four times over 19 years in mothers who had knowingly adopted children with IDD and in a comparable sample of mothers and fathers who had similar children by birth. Depression was initially measured when the children were first diagnosed or adopted, and three more times at approximately six-year intervals. They found large and highly significant differences initially, with adoptive mothers reporting low scores, indicating non-depressed functioning, and birth mothers reporting much higher scores, with approximately half the sample meeting criterion for clinical depression. In the three subsequent data collections, the birth mother scores had declined dramatically and were no longer significantly different from those of the adoptive mothers. Thus, adoptive-birth status, an initially powerful predictor of depression, no longer had predictive value for the outcome of depression at later time periods, after the crisis of diagnosis had subsided.

This variation evident in previous research led us to focus on three related aims in the current study: Our primary aim was to determine the degree to which a set of variables measured when children were young would predict well-being and depression outcomes for their mothers over a 20-year period. The predictors were selected based on their prominence

in theories of family functioning and adaptation, all of which generally focus on family, parent, and child characteristics (Blacher, 2001; McCubbin & Patterson, 1983). We also considered the predictive effectiveness of these variables in previous empirical findings.

A second and related aim was to explain the variability in the effectiveness of these predictors, exploring the patterns of variability and assessing to what degree these patterns could lead to the generation of hypotheses for future study. A component of understanding outcome constructs is to know what antecedent variables predict them. Finally, a third aim was to determine the degree to which these predictors were relatively stable for the same outcomes over time. This third aim will be addressed in a comparison of the data reported in the current study with previously published research from earlier times of the same longitudinal sample.

Method

Participants

Prior to the collection of data, all research protocols were approved by the Institutional Review Board of St. Mary's College of Maryland. The sample consisted of 38 adoptive and 47 birth mothers of children with IDD of varying etiologies, a subset of an original sample of 122 adoptive and 126 birth mothers who were participants in a 23-year longitudinal study with 5 times of measurement. Table 1 displays characteristics of these mothers and children from the time of initial recruitment and data collection, between 1988 and 1995 [Time 2 (T2)--Time 1 was retrospective and conducted at T2), and from 2010–2011, at the Time 5 (T5) data collection.]

Of this sample, 47.1% of the target children were diagnosed with Down syndrome, and 9.5% had cerebral palsy. Other diagnoses were varied, including other chromosomal/genetic anomalies, fetal alcohol syndrome, pre- or post-natal brain damage, and IDD of unknown origin. Diagnoses had been recorded at study entry approximately 20 years earlier than measurement at T5, and were occasionally updated as new information was received by families. As young adults, 82% of the sons and daughters still lived at home, and 97% went to some type of day program that was either competitive, supported or sheltered employment, or training, averaging 20 hours per week. Level of functioning was last assessed when the sons and daughters were, on average, 18 years old. At that time, their mean score on the Community Self-Sufficiency factor of the Adaptive Behavior Scale-School (Lambert, Nihira, & Leland, 1993) was at the 50th percentile of the norming sample of persons with intellectual disability, and at the 5th percentile of the norming sample of persons without intellectual disability. Because these participants represented only 34% of the original sample, we performed analyses to assess whether the attrition from T2 to T5 had been selective. We conducted independent sample *t*-tests for T2 demographic characteristics and other input and outcome measures between those initial participants who remained in the study at T5 and those who did not. Additionally, we conducted a median test of significance on family income and a chi-square test for diagnostic category distribution between these two groups. Among demographic variables, only maternal education differed significantly. Mothers who remained in the study reported higher education levels at T2 ($M = 14.18$ years, $SD = 2.5$ years) than those who did not ($M = 13.32$ years, $SD = 2.1$ year, t

(245) = $-2.82, p = .005$). Furthermore, none of the predictor variables measured at T2 nor the one predictor--Neuroticism--- measured at T3, differed between mothers who remained in the sample and those who did not. Because of their similarities, we considered the sample remaining after 23 years to be representative of the original sample.

Procedure and Measures

Hierarchical regression analyses were conducted for seven outcome variables with the same seven predictor variables in each model. The predictors and outcomes are described below and descriptive data are presented for them in Table 2. These variables were entered in three steps: Step 1 contained two demographic control variables; Step 2 contained two child-related variables and Step 3 contained three maternal- and family-related variables. All variables were checked for kurtosis and skewness to ensure they met distribution assumptions required by the parametric analyses. Only DEP5, a measure of maternal depression, manifested skewness substantial enough to warrant transformation to $\log_{10}(x + 1)$, as described later. Although all analyses were conducted with standardized scores, the descriptive statistics in Table 2 display untransformed scores for ease of interpretation and comparison with other published data.

Predictor variables—Seven variables were selected as potential predictors from among the hundreds of variables measured at T2. Step 1 contained Adoptive/Birth Status and Family Income, Step 2 contained Diagnosis (Down syndrome or Other) and Cognitive Impairment, and Step 3 contained Maternal Experience with Disability, Neuroticism, and Family Strengths -Accord. The selection was based on the strength of the theoretical and correlational relationships with the outcome variables. The variables included in these final hierarchical models demonstrated significant correlations with at least one, and often more than one, of the outcome variables (see Table 3). In addition, previous research had demonstrated that they were relevant to family functioning models and family adjustment. Each of these variables was measured at T2, with the exception of Neuroticism, which was measured at T3 but, as a personality variable, presumed stable from T2. These predictors of parent, child, and family characteristics are components included in almost all theories and models of family adjustment to children with disabilities (e.g., Blacher, 1984, 2001; Crnic, Friedrich & Greenberg, 1983; McCubbin & Patterson, 1983).

Other variables such as child adaptive and maladaptive behavior, marital status, and other facets of personality, all of which have also been included in models of family functioning were originally considered for these regression models. However, they either were not significantly correlated with outcome variables, or were correlated less strongly than the variables that we included with which they were collinear, e.g., Cognitive Impairment and Adaptive Behavior.

Step 1: Control variables: Step 1 of the hierarchical regression contained two control variables: Adoptive/Birth Status and Family Income at Time 5 (Table 2). Adoptive/Birth Status was viewed as a variable that could influence the perception of the stressor, and Family Income as a resource variable. However, we did not expect either variable to predict

outcomes based on our results at earlier times of measurement, and our review of the bivariate correlations with outcome variables.

Step 2: Child variables: Models of family adaptation are likely to include measures of child functioning such as adaptive and maladaptive behavior (Blacher, 2001; Crnic et al., 2009; Floyd, et al., 2009). In the current study, we had a number of measures of level of ability or impairment at the Time 2 measurement. The Holroyd Questionnaire on Resources and Stress (Holroyd, 1987) factor of Cognitive Impairment demonstrated good psychometric properties in the current sample with Cronbach $\alpha = .79$, and a range of scores from the minimum of 0 indicating little cognitive impairment to the maximum of 6. Moreover, it was significantly correlated with five of the seven outcome variables. A sample item is (*Child's name*) *knows his/her address*.

In addition, past research on the “advantage” of a Down syndrome diagnosis in comparison to other etiologies of intellectual/developmental disabilities contributed to our interest in the impact of diagnosis on outcomes of well-being (Corrice & Glidden, 2009; Glidden, Grein, & Ludwig, in press; Povee, Roberts, Bourke, & Leonard, 2012; Stoneman, 2007). Because 47 percent of the families in the current sample were rearing a child with Down syndrome, we were able to explore the degree to which a Down syndrome diagnosis was or was not a significant predictor for different maternal variables when the offspring were young adults.

Step 3: Parent and family variables: Individual parental characteristics are included in most models of family adaptation (Blacher, 2001; Nihira et al., 1983; Seligman & Darling, 2007). In particular, the trait of mental/emotional stability has been demonstrated to have high predictive power both concurrently and prospectively for depression and measures of well-being (Costa & McCrae, 1992; Glidden & Schoolcraft, 2003; Piedmont, 1993, 1998; Trull, 1992). It is represented in the current study by the NEO Five-Factor Personality Inventory measure of Neuroticism, one of the most widely used measures of personality (Costa & MacCrae). This measure had excellent internal reliability in the current sample (Cronbach $\alpha = .87$) and its bivariate correlations with five of the seven outcome variables were significant.

The maternal characteristic of Experience with Disability was also included as a parent characteristic. It was coded based on transcripts of interviews conducted at T2. Mothers were questioned about their experience and familiarity with disability and were rated on a 3-point scale as having had minimal (0), moderate (1), or extensive (2) familiarity/experiences. We hypothesized that mothers with more experience with disabilities would have an easier initial adaptation that might endure as would be predicted by the Double ABCX model.

Family cohesion figures prominently in multiple models of family adaptation (Nihira, Myers, & Mink, 1983; Seligman & Darling, 2007). It is represented in the current study by Family Strengths-Accord (Olson, Larsen, & McCubbin, 1985). This predictor showed good internal consistency, with a Cronbach alpha of .77 in the current sample. As displayed in Table 3, its bivariate correlations with five of the seven outcome variables were significant.

Outcome variables—The outcome variables utilized in these analyses were all measured at T5, the most recent time of measurement, when the average age of the adult offspring was 26 years.

Subjective well-being (SWB): Three SWB items measured parental well-being on a 7-point Likert scale ranging from 1 ('Delighted') to 7 ('Terrible'), with lower scores indicating higher levels of well-being (Andrews & Withey, 1976; Glidden & Jobe, 2009). Mothers responded to: How do you feel about your life as a whole? (SWB-Global); how do you feel about how things are going right now? (SWB-Current); how do you feel about how things are going with (target child's name)? (SWB-Child). At T5, mothers reported, on average, scores of 2.42 (SD = 0.95) for SWB-Global, 2.69 (SD = 1.09) for SWB-Current, and 2.67 (SD = 1.26) for SWB-Child. These means reflect scores midway between the verbal anchors of 'pleased' and 'mostly satisfied'.

Subjective well-being (SWB) Sum: This measure is the sum of the SWB-Global, SWB-Current, and SWB-Child items, with a maximum possible value of 21. For each individual item, lower scores indicate higher levels of well-being. The scores for this sum measure were, on average, 7.75 (2.62), Cronbach $\alpha = .73$.

T5 DEP5: Derived from the Holroyd QRS, the DEP5 is a 5-item scale of True-False items that assesses participant depression, higher scores indicating greater depression (Glidden & Floyd, 1997; Holroyd, 1987). At T5, the 5-item scale had a Cronbach's $\alpha = .75$, $N = 83$ for mothers. For this scale, mothers responded to such items as "I get upset with the way my life is going." The T5 mean response for mothers on this scale was 1.22 (SD = 1.49). Because of generally low scores, expected in a non-clinical sample, the distribution was skewed positively, deviating moderately from normality. To normalize the distribution, we used a LOG10 transformation of the scores after adding 1 to all scores to eliminate zeroes.

Total well-being: To reflect the overall presence of well-being, as well as the absence of depression, we created a sum of each of the three SWB items and DEP5, creating a measure with a maximum score of 26, high scores indicating low levels of well-being. The mean for this total measure for mothers at T5 was 8.96 (3.72), with Cronbach $\alpha = .81$.

Youth Transition-Social Scale (TDRWQ6): The TDRWQ6, referred to hereafter as Youth Transition-Social, contains 6 items derived from the original 28-item Transition Daily Rewards and Worries Questionnaire (TDRWQ; Glidden & Jobe, 2007; Glidden, Ludwig, & Grein, 2012). These items were selected based on their content validity for measuring parental views of their child's social relationships and intimacy during the transition to adulthood (Glidden et al.). Youth Transition-Social items were measured on a 5-item Likert scale ranging from 1 ("Strongly Disagree") to 5 ("Strongly Agree"), with higher scores indicating more rewards and fewer worries with respect to social aspects of the target child's transition to adulthood. At T5, the Youth Transition-Social scale had a Cronbach $\alpha = .58$, $N = 75$, mean = 3.36 (SD = .73), with mothers reporting, on average, a total score of 20.09 (SD = 3.98). The maximum possible score on the Youth Transition-Social scale is 30.

In order to improve the internal reliability of the scale, we created an additional version, which excluded one item with the lowest fit for the scale. It had a Cronbach $\alpha = .65$, $N = 75$ at T5, mean Likert rating = 3.42 (.89). We conducted analyses utilizing both versions of the Youth Transition-Social scale. However, because the results for the two measures were equivalent, and the 6-item Youth Transition-Social Scale had been analyzed for content validity and previously published, we report here only the regression results for the 6-item version.

Hypotheses

Based on models of family functioning as well as on the results of previous research, we hypothesized that high Neuroticism and low Family Strengths-Accord would result in lower well-being and higher depression. Although the empirical evidence was weaker, we also predicted that a Down syndrome diagnosis and lower levels of Cognitive Impairment would result in higher well-being and lower depression.

Results

Final hierarchical models for all outcomes predicted a significant amount of variance. In Table 4 we summarize the results of the hierarchical regressions, described below for each of the outcome variables. In all regressions, all variables except for DEP5 were transformed to standard scores in order to reduce differences among predictors and outcomes that were the result of differing scales of measurement. With the exception of the Youth Transition-Social scale, analyses were conducted with $N = 75-77$, using listwise exclusion when data were missing. The N for the Youth Transition-Social scale was 70.

Subjective Well-being

SWB-Global—The full hierarchical model for Subjective Well-being-Global predicted 25.1% of item variance ($F(7, 69) = 3.29, p < .05$), with Neuroticism independently significant within the model ($t(76) = 2.22, p < .05$). Higher scores on Neuroticism predicted worse Subjective Well-being-Global outcomes.

SWB-Current—The Subjective Well-being-Current model accounted for a total of 27.1% of item variance ($F(7, 69) = 3.67, p < .05$). Two variables, in two separate, independently significant steps, accounted for a significant amount of variance in current well-being: Cognitive Impairment ($t(76) = 2.36, p < .01$), from Step 2, and Family-Strengths Accord ($t(76) = -3.45, p < .05$), from Step 3. Higher Cognitive Impairment of the child and lower Family Strengths-Accord predicted lower current well-being.

SWB-Child—Although Step 1 of this model did not result in a significant change in R^2 , Adoptive/Birth status was a significant predictor ($t(75) = -2.67, p < .05$). The final model predicted 20.2% of the Subjective Well-being-Child variance ($F(7, 68) = 2.46, p < .05$) with two significant predictors: Adoptive/Birth Status and Maternal Experience with Disabilities ($t(75) = -2.47, p < .05$). Mothers who had more experience with individuals with disabilities and whose children were born to them rather than adopted had better subjective well-being with regard to their adult children at T5.

SWB-Sum—The hierarchical model for the sum score of the three Subjective Well-being items followed a similar pattern to the results of the individual Subjective Well-being measures. The full model accounted for 23.6% of total scale variance ($F(7, 67) = 2.95, p < .05$), with only Family Strengths-Accord independently accounting for a significant amount of variance ($t(74) = -3.01, p < .05$). Neuroticism also approached significance as an independent predictor ($t(74) = 1.74, p = .09$). Again, lower Family Strengths-Accord and higher Neuroticism scores predicted worse Subjective Well-being outcomes.

DEP5

Steps 2 and 3 of the hierarchical model independently predicted a significant amount of variance in DEP5. Cognitive Impairment ($t(76) = 2.36, p < .05$), from Step 2, and Neuroticism ($t(76) = 3.31, p < .05$), from Step 3, each significantly predicted DEP5, with higher scores of both Neuroticism and Cognitive Impairment predicting higher depression. The model as a whole predicted 34.1% of the variance, $F(7, 69) = 5.11, p < .05$.

Youth Transition-Social Scale (TDRWQ6)

The model for the Youth Transition scale followed a different pattern from those of most of the other well-being variables. Together, the three steps predicted 19.6% of scale variance ($F(7, 62) = 2.16, p < .05$), with only Cognitive Impairment independently accounting for a significant amount of variance ($t(69) = -2.36, p < .05$). However, Diagnosis ($t(69) = -1.86, p = .07$) and Maternal Experience with Disability ($t(69) = 1.72, p = .09$) also approached significance. Mothers of a child with less Cognitive Impairment and with Down syndrome, rather than another diagnosis, and who had more prior experience with disabilities reported more positive Youth Transition-Social scores.

Total Well-being

The model for the summed scores of the three SWB items and DEP5 also followed a pattern similar to the models for the individual Subjective Well-being - Global, Subjective Well-being - Current, and DEP5 items. Neuroticism ($t(74) = 3.12, p < .05$) and Family Strengths-Accord ($t(74) = -2.18, p < .05$) each independently accounted for a significant amount of variance. The total model predicted 34.1% of the variance in well-being scores, $F(7, 67) = 4.95, p < .05$. As in the models for the other outcome variables, higher Neuroticism and lower Family Strengths-Accord scores predicted lower well-being.

Discussion

The three aims for this study were: 1) To determine the degree to which we can predict well-being from data about mothers and their families that were collected 20 years earlier; 2) To assess the similarity of predictors for different outcomes; and 3) To compare the stability/change in predictors over time. These aims, then, addressed both the degree of predictability and the extent to which predictors were similarly effective for various maternal outcomes related to the caretaking of a son or daughter with IDD over more than two decades. Furthermore, in regard to the first aim, we hypothesized that low Neuroticism and high Family Accord, a Down syndrome diagnosis and lower levels of Cognitive Impairment would result in higher maternal well-being and lower depression.

With regard to the first two aims, we found some variability in the measures that were the most powerful predictors, as well as in the amount of variance that was predicted for different outcomes. The range of variance accounted for was from 19.6 percent for Youth Transition to 34.1% for DEP5, our measure of depression, as well as for a total well-being outcome that included subjective well-being and depression. However, despite this variability, our hypotheses were at least partially confirmed: Maternal Neuroticism, Family Accord, a Down syndrome diagnosis and child Cognitive Impairment were significant predictors in the hypothesized direction for at least one well-being or depression outcome. Because these predictions were based both on models of family functioning as well as previous empirical findings, they represent consistency within the variability demonstrated.

Of the five non-composite outcome measures, two of them---SWB-Child and Youth Transitions-Social---directly referenced the son or daughter with IDD. In contrast, the other three outcomes---DEP5, SWB-Global and SWB-Current---assessed more general psychological state variables of the respondent. One might expect that the predictors and the amount of variance predicted would be more similar within each of these clusters. In fact, this was not generally the case. Although SWB-Child and the Youth Transition-Social scale both had the least variance predicted, their significant predictors were not the same. For Youth Transitions-Social, only Cognitive Impairment, an indicant of severity of disability/ cognitive impairment during childhood, was significant whereas for SWB-Child, Adoptive/ Birth status and Maternal Experience with Disability were the significant predictors. Moreover, different steps in the models resulted in significant changes in the R^2 for each of these outcome variables, with the maternal and family variables Step 3 significant for SWB-Child, and the child variables entry in Step 2 significant for Youth Transition-Social.

Moreover, despite SWB-Child and the Youth Transition-Social scale both referencing the son/daughter with IDD directly, and correlating $-.473$ with each other, they did not always correlate in the same way with predictor variables. First, SWB-Child significantly correlated only with Maternal Experience with Disability, whereas the Youth Transition-Social scale significantly correlated with both Diagnosis and Cognitive Impairment, as well as Maternal Experience with Disability, such that mothers of adult children with Down syndrome and with more experience with disability at Time 2, and who had children who were less cognitively impaired at Time 2, reported significantly more rewards and fewer worries with regard to the social relationships of their sons and daughters. SWB-Child also correlated similarly, albeit non-significantly, with Diagnosis, but did not with Cognitive Impairment. This finding was not especially surprising, as other studies have also found that severity of disability is not necessarily a predictor of maternal well-being (Glidden & Schoolcraft, 2007; Manuel, Naughton, Balkrishnan, Smith & Koman, 2003).

The nature of the constructs being measured might explain why they were not all predicted by the same variables, and why even the variables that appeared as significant in multiple models were not similarly important to those models. Subjective Well-being-Child is an umbrella variable, asking respondents to provide overall estimates of how things are going with their sons or daughters. In contrast, Youth Transition-Social is a much narrower construct, measuring rewards and worries related only to social relationships of the young adults with IDD during their transition to adulthood. It is entirely possible that the social

relationship aspect of the offspring's life was perceived by the mother as good (or bad), but other aspects such as physical health and employment status were perceived by the mother somewhat differently, consistent with the importance of appraisal in the ABCX model. Thus, despite their moderate correlation, SWB-Child and the Youth Transition-Social scale did assess somewhat different constructs of maternal well-being.

The other constellation of variables---SWB-Global, Current, and DEP5--- and the summed scores that included these variables, in contrast, were highly correlated with each other and shared several significant predictors. The personality variable of Neuroticism and Family Strengths-Accord, each measured at, or presumed stable from T2, predicted each of these five outcomes, either singly or in combination, with high levels of Neuroticism and low levels of family accord 20 years earlier predicting more depression and less well-being for mothers when offspring were in young adulthood. A substantial amount of variance, an average of 27.5%, was predicted for these five outcomes, suggesting continuity of functioning for the two decades that separated the measurement of the predictors and the outcomes.

Our third question---the stability of predictors over time---does not have a single or simple answer. Stability of some predictors is high, and for other predictors it is low. Neuroticism, for example, has high stability, especially for its prediction of depression and well-being, whereas diagnosis has lower predictive stability. Specifically, Glidden and Schoolcraft (2003) reported that maternal Neuroticism scores predicted more variance in depression than even earlier depression scores predicted. Indeed, Neuroticism was the only significant predictor for depression in a model that also included the four other NEO-PI personality factors (Costa & McCrae, 1992) as well as Family Strengths Pride and Accord (Olson et al., 1985), and three QRS scales (Holroyd, 1987). Together, these predictor variables encompassed a broad array of child, parent, and family characteristics.

In contrast to the consistency of prediction demonstrated by Neuroticism, Adoptive/Birth Status demonstrated the least consistency. Birth mothers reported greater SWB-Child than adoptive mothers at T5, a rather remarkable finding, given that at the time of child diagnosis/placement for birth and adoptive families, respectively, the majority of birth parents were in crisis with high levels of depression, whereas most adoptive parents were eagerly welcoming their new children into their families (Glidden, 1989; Glidden & Jobe, 2009). That birth parents adjusted and reported more well-being with regard to their children than did adoptive parents demonstrates recovery and resilience and is consistent with reports from other investigators (Floyd et al., 2009; Hastings & Taunt, 2002; Scorgie & Sobsey, 2000; Singer, Ethridge, & Aldana, 2007; Skotko, 2011; Stainton & Besser, 1998). Indeed, the current findings of birth mothers actually reporting higher levels of subjective well-being with regard to the child, not only replicates these other findings, but also reinforces the robustness of the recovery.

This recovery is also consistent with positive psychology and its mandate to describe and explain the human characteristics of adaptation, empathy, altruism, bravery, and many other qualities that are generally admired (Seligman & Csikszentmihalyi, 2000; Seligman, Steen, Park & Peterson, 2005). The mother's well-being with regard to the child seemed to be

“protected” from her own emotional instability, in contrast to her well-being overall and currently. Perhaps, one or more of these other positive characteristics such as empathy, attachment, and love moderated the relations between the predictors and outcomes. Of course, this interpretation is highly speculative, as we did not have measures of any of those variables. It would, however, be a potentially worthwhile direction for further research.

What is less speculative, however, is the importance of including stressor perception in models of family adaptation and adjustment. Our interpretation of the seeming inconsistency of the way in which adoptive and birth status predicted child subjective well-being is that over time, birth parents emerged from crisis, accepted the challenge of rearing a child with IDD, and, as they would with other children, accepted and even embraced their role as loving parent and advocate. Thus, the parents’ perceptions of the stressor had changed. At the time of diagnosis/placement, adoptive meant ‘welcoming and committed’, and birth meant ‘in crisis---dazed and depressed.’ Twenty years later the meanings had shifted dramatically for birth parents.

Diagnosis, also, has varied considerably in its prediction of depression and well-being in our longitudinal dataset. Research conducted when the children were, on average, 7 years old, (Cahill & Glidden, 1996; Glidden & Cahill, 1998) found no Down syndrome advantage on measures of depression and well-being when samples were appropriately matched. In contrast, Corrice and Glidden (2009), Glidden et al. (2012) and Glidden, Grein and Ludwig (2014) did find an advantage on some variables, even after controlling for covariates. Specifically, Glidden et al. (2012) reported that the most robust advantage was found for a variable of ease/difficulty of rearing in adulthood, in contrast to no advantage for children with Down syndrome on the same variable when they were, on average, 7 years old. Glidden et al. (2014) reported that comparatively high levels of adaptive behavior for young adults with Down syndrome was a partial explanation for the advantage. Other investigators have also reported changes in the phenotypic trajectories of diagnostic category (Fidler, Most, & Philofsky, 2008; Eisenhower, Baker & Blacher, 2005). Given that different characteristics become more or less important for successful adaptation at different life stages, we should not be surprised at changes that manifest over a 20-year period, especially one which encompasses childhood, adolescence, and young adulthood, periods characterized by rapid and substantial changes in multiple systems of functioning.

A methodological issue that arose in the course of this study concerned the relative advantages of using multiple outcome measures that have some overlap, in contrast to using composite measures that provide a summary of the constructs of interest. Our conclusion from exploring both approaches is that each has its merits. Our well-being total, combining all three SWB measures and depression, provided a composite that reflected the results of two of the three SWB measures and DEP5. However, it did not reflect the different pattern of SWB-Child, nor would it have veridically incorporated the results we found for the Youth Transition-Social scale. Our conclusion, therefore, is that although composite measures are valuable for summary and explanation, they should be used with caution, as they may obscure important differences in the often complex realities that characterize the lives of families.

Despite the value of these results, the approach of this study contained a limitation that should lead to caution in interpretation of the findings. Importantly, two of the predictor and all outcome variables were maternal self-report measures. Moreover, the three subjective well-being items used the same 7-point Likert scale, and the measures of depression and cognitive impairment both only consisted of True-False items. Thus, shared method variance may be responsible for some of the ability of these variables to predict the well-being outcomes. Nonetheless, it should be noted that while the three subjective well-being outcomes were highly similar, each had somewhat different patterns of results, suggesting that although they shared method variance, participants were still responding to them as different constructs, leading us to conclude that shared method variance was not a major limitation.

In sum, being able to predict the patterns of maternal functioning over a two-decade period has important implications for both science and service delivery. Maternal personality, especially emotional stability/instability as reflected in the Neuroticism factor, and Family Accord are strong determinants of resilience and vulnerability throughout the lifespan. Therefore, they should be considered as critical components of models that attempt to explain how individuals respond to life experiences. They also must be taken into account by helping professionals who can recognize that some individuals and families are predisposed to resilience and others to vulnerability. Treatment programs can then be individually tailored to take into account this variability of responses that are indicative of individual differences in resilience and vulnerability. Some mothers and families may be best served by strategies that initially treat their emotional instability and low levels of accord before addressing specific relational or child behavioral problems, whereas others may be able to bypass this aspect of treatment, building directly on their strengths of emotional stability and family accord. As models of family systems have informed us over the years, each member of the unit affects each other member, and both individual and family system characteristics are essential sources for predicting and explaining the trajectory of the family's life.

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Table 1

Family, Parent, and Child Characteristics

Time of Measurement	Parent Age (years)		Child Age (years)		Family Income*		Marital Status		Parent Ethnicity		Child Diagnosis	
	Mean (SD)		Mean (SD)		Median		% Married		% Caucasian		% Down Syndrome	
2	38 (6.3)		7 (2.9)		44000**		82.1		81.2		47.1	
5	58 (6.2)		26 (3.3)		85000		59.5		As above		As above	

Note. N= 85 mothers included in T5 analyses;

* US dollars;

** US\$44,000 in 1990 is equal to approximately US\$76,000 in 2011. See the Bureau of Labor Statistics (http://www.bls.gov/data/inflation_calculator.htm)

Table 2

Family, Parent, and Child Predictor and Outcome Variable Descriptions

Variable	Description	Mean (SD), Median or %
<i>Control and Predictor Variables:</i>		
Adoptive/Birth Status	A dichotomous variable recorded at the time of entry into the study: 1= target child was adopted into the family; 2 = target child was born into the family	55.3% Birth
Family Income	A measure of median Family Income (in US dollars) taken at T2	44,000
Child Diagnosis/Etiology	1 = Down syndrome; 2 = any other etiology	47.1% DS
Cognitive Impairment	Holroyd (1987) QRS short form factor; higher scores = greater impairment	4.17 (1.68)
Maternal Experience with Disability	A 3-point scale derived from interviews conducted with mothers at T2 that assessed mothers' past experiences with disabilities; higher scores indicate greater experience	1.25 (0.71)
Neuroticism	NEO- Five Factor Personality Inventory (Costa & McCrae, 1992), measuring emotional stability at T3; higher scores = higher emotional instability	30.76 (8.82)
Family Strengths Accord	Family Strengths Inventory (Olson et al., 1985); measures family harmony, agreement, conflict resolution; higher scores = more family accord.	16.83 (4.36)
<i>Outcome Variables:</i>		
SWB-Global ¹	Single item 7-point scale assessing overall well-being	2.42 (0.95)
SWB-Current	Single-item 7-point scale assessing current well-being	2.69 (1.09)
SWB-Child	Single-item 7-point scale assessing well-being with regard to the child	2.67 (1.26)
SWB-Combined	The sum of the 3 SWB scores	7.75 (2.62)
DEP5	5-item measure of depression (Glidden & Floyd, 1997). Scores range from 0–5; higher scores = greater depression	1.22 (1.49)
Well-being sum	SWB-Combined + DEP5	8.96 (3.72)
TDRWQ6 (Youth Transition – Social)	Six items from TDRWQ measuring rewards/worries of child's transition to adulthood; 5-point scale: higher scores = greater rewards and fewer worries.	20.09 (3.98)

¹ All SWB items have the same metric: higher scores = lower well-being

Table 3
Summary of Correlations between T2 and T3 Predictor and T5 Well-Being Outcome Variables

Measure	1	2	3	4	5	6	7	8	9	10	11	12
1. SWB Global ^d	-											
2. SWB Current	.786***	-										
3. SWB Child	.257*	.391***	-									
4. DEP5 ^b	.645***	.660***	.221*	-								
5. Youth Transition ^c	-.279*	-.337**	-.473***	-.285*	-							
6. Adopt/Birth	.133	.016	-.194 [†]	.078	.022	-						
7. Family Income	-.040	-.041	-.111	-.066	.091	.114	-					
8. Diagnosis ^d	.107	.059	.184 [†]	.017	-.236*	-.127	-.230*	-				
9. Cog. Impair ^e	.260*	.261*	-.117	.315**	-.232 [†]	.238*	.165	-.124	-			
10. Maternal Exp. with Disability ^f	<.001	-.032	-.232*	-.129	.260*	-.156	.186 [†]	-.127	-.004	-		
11. Neuroticism ^g	.426***	.334**	.180	.535***	-.181	.108	-.062	.072	.279*	-.207 [†]	-	
12. FS Accord ^h	-.321**	-.398***	-.136	-.292**	.143	-.276*	.032	-.014	-.061	-.042	-.274*	-

Note: These models use standardized z-scores for all variables except DEP5, which used a log¹⁰ transformation of DEP5+1 to get rid of all 0 values

* $p < .05$

** $p < .01$

*** $p < .001$

[†] $p < .10$

^a Subjective Well-Being (SWB) scales are scored on a 7-point Likert scale- higher scores indicate lower well-being

^b A series of 5 True-False questions derived from the Holroyd QRS- higher scores indicate more depression

^c TDRWQ6 (Youth Transition-Social): 6 items the target child's transition to adulthood; 5-point Likert scale- higher scores = more rewards, fewer worries

^d Child diagnosis; 1 = Down syndrome, 2 = any other diagnosis

^e 6-item subscale measuring the degree of the child's cognitive impairment; higher scores indicate greater impairment

^f A 3-point scale assessing mothers' past experience with disabilities

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^g A factor of the NEO- Five Factor Personality Inventory; higher scores = higher neuroticism

^h A subscale of the Family Strengths Inventory measuring agreement, harmony, and conflict resolution-higher scores indicate more family accord

Table 4
Summary of Hierarchical Regression Models for Subjective Well-Being, Depression, Youth Transition and Total Well-Being Outcomes.

Predictor	Outcomes																					
	SWB Global ^a			SWB Current			SWB Child			SWB Sum ^b			DEP5 ^h			Youth Transition ⁱ			Total Well-being ^j			
	R ²	β		R ²	β		R ²	β		R ²	β		R ²	β		R ²	β		R ²	β		
Step 1	.043			.026			.036			.009			.014			.009			.017			
Adoptive/Birth		-.006			-.197			-.341 [*]			-.239 [†]			-.139			.177			-.208 [†]		
Family Income		-.071			-.054			.188			.047			.031			-.016			.027		
Step 2	.075 [†]			.078 [*]			.019			.038			.129 ^{**}			.135 ^{**}			.076 [†]			
Diagnosis ^c		.091			.028			.100			.088			-.067			-.219 [†]			.023		
Cog. Impairment ^d		.204 [†]			.269 [*]			-.069			.141			.256 [*]			-.301 [*]			.199 [†]		
Step 3	.133 [*]			.167 ^{**}			.148 ^{**}			.188 ^{**}			.198 ^{***}			.052			.248 ^{***}			
Maternal Exp. With Disability ^e		.081			-.033			-.291 [*]			-.124			-.101			.213 [†]			-.127		
Neuroticism ^f		.266 [*]			.113			.149			.211 [†]			.371 ^{**}			.003			.352 ^{**}		
Family Accord ^g		-.223 [†]			-.401 ^{**}			-.243 [†]			-.369 ^{**}			-.206 [†]			.161			-.320 ^{**}		
Total R ²	.251 [*]			.271 ^{**}			.202 ^{**}			.236 ^{**}			.341 ^{***}			.196 ^{**}			.341 ^{***}			
n	77			77			76			75			77			70			75			

Note: These models use standardized z-scores for all variables except DEP5, which used a log¹⁰ transformation of DEP5+1 to eliminate all 0 values

* $p < .05$

** $p < .01$

*** $p < .001$

[†] $p < .10$

^a Subjective Well-Being (SWB) scales are scored on a 7-point Likert scale- higher scores indicate lower well-being

^b Sum of 3 SWB scores

^c Child diagnosis; 1 = Down syndrome, 2 = any other diagnosis

^d 6-item subscale measuring the degree of the child's cognitive impairment; higher scores indicate greater impairment

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- e* A 3-point scale assessing mothers' past experience with disabilities
- f* A factor of the NEO- Five Factor Personality Inventory; higher scores = higher neuroticism
- g* A subscale of the Family Strengths Inventory measuring agreement, harmony, and conflict resolution- higher scores indicate more family accord
- h* A series of 5 True-False questions derived from the Holroyd QRS- higher scores indicate more depression
- i* TDRWQ6 (Youth Transition-Social); 6 items the target child's transition to adulthood; 5-point Likert scale- higher scores = more rewards, fewer worries
- j* Sum SWB Combined + DEP5.