Associations between Resilience and the Well-Being of Mothers of Children with Autism

Spectrum Disorder and Other Developmental Disabilities

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Abstract

There is variability in the extent to which mothers are affected by the behavior problems of their children with developmental disabilities (DD). We explore whether maternal resilience functions as a protective or compensatory factor. In Studies 1 and 2, using moderated multiple regression models, we found evidence that maternal resilience functioned as a compensatory factor – having a significant independent main effect relationship with well-being outcomes in mothers of children with DD and autism spectrum disorder. However, there was no longitudinal association between resilience and maternal well-being outcomes. There was little evidence of the role of resilience as a protective factor between child behavior problems and maternal well-being in both studies.

Key words: autism spectrum disorder, developmental disability, mothers, psychological well-being, resilience

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Associations between resilience and the well-being of mothers of children with autism

spectrum disorder and other developmental disabilities

Research showing higher levels of stress and other negative psychological well-being

outcomes (e.g., depression, anxiety) in mothers of children with developmental disabilities

(including autism spectrum disorder and/or intellectual disability) compared to mothers of

typically developing children is well established (Hastings, 2016). In addition, research has

identified that parents of children with autism spectrum disorder (ASD) experience higher

stress levels than parents of children diagnosed with Down's Syndrome, Cerebral Palsy, and

Global Developmental Delay (e.g., Blacher & McIntyre, 2006; Dabrowska & Pisula, 2010;

Hayes, & Watson, 2013). However, there is variability in how mothers respond to the stress

of raising a child with developmental disabilities (DD). In analysis of a population-based

sample, for example, Totsika, Hastings, Emerson, Lancaster and Berridge (2011) found that

40% of mothers of children with DD reported experiencing concerning clinical levels of

emotional problems, and 60% did not.

Within the context of ASD, the behavioral symptoms of ASD and the severity of

symptoms have been explored in association with parental outcomes. It was noted by Smith

et al. (2008) that the literature explores mostly associations between child ASD symptoms,

specifically, and parental outcomes (e.g., Eisenhower, Baker, & Blancher, 2005; Ello &

Donovan, 2005; Lecavalier, Leone, & Wiltz, 2006). However, the question remains if

parental stress is primarily due to the child's ASD symptoms or child behavioral and

emotional problems more generally (e.g., Hastings, Kovshoff, Ward et al. 2005; Herring et

al., 2006).

Previous research has shown behavior problems exhibited by children with DD

explain some of the variation in maternal outcomes. Indeed, child behavior problems are a

risk factor for lower levels of maternal psychological well-being; having been identified in

several longitudinal studies as a significant predictor of an increase in maternal negative

psychological well-being over time (e.g., Baker et al., 2003; Herring et al., 2006; Lecavalier,

Leone, & Wiltz, 2006; Zeedyk & Blacher, 2015). Firth and Dryer (2013) also found that

children with ASD's behavioral and emotional problems affected overall levels of parental

distress, such as stress, tension, anxiety, and depression. The severity of the child's ASD

symptoms are also associated with parental stress and depression, suggesting that the severity

of the child's ASD symptoms is positively related to the level of parental stress (e.g.,

Eisenhower, Baker, & Blacher, 2005; Hastings & Johnson, 2001; Hastings et al., 2005; Hill-

Chapman et al., 2013). Other aspects of ASD symptomology have also been explored, such

as the severity of social impairment, which was found to predict parenting stress (Firth &

Dryer, 2013).

Despite the relationship between child behavioral and emotional problems and

maternal well-being consistently shown in existing research, there is still variability in

mothers' well-being. Not all mothers whose child has significant behavior problems or

elevated ASD symptom severity report increased psychological distress or lower levels of

well-being. For example, positive parental outcomes are also associated with raising a child

with ASD, such as personal growth, improved relationships with others, greater patience, and

more empathy (Hastings & Taunt, 2002; Pakenham, Sofronoff, & Samios, 2005; Scorgie &

Sobsey, 2000). This variability in mothers' well-being suggests that there are additional

factors affecting the relationship between child behavioral problems and maternal well-being.

For example, MacDonald, Hastings, and Fitzsimons (2010) found psychological acceptance

partially mediated the impact of child behavior problems on paternal stress, anxiety, and

depression in a cross-sectional study. In addition, Weiss, Cappadocia, MacMullin, Viecili,

and Lunsky (2012) found supporting evidence, also in a cross-sectional study, that maternal

empowerment is a partial mediator between child behavior problems and greater maternal

distress in mothers of children with ASD. Empowerment is defined as a psychological process in which an individual is active in changing or eliminating potentially stressful events through applying knowledge and skill (Gutiérrez, 1994). Self-efficacy was also found to moderate the effect of child behavior problems on anxiety in fathers of children with ASD (Hastings & Brown, 2002).

One construct which could be important as an explanatory variable for the variability of maternal well-being in families of children with DD, including ASD, is resilience. Resilience is of growing interest in mainstream research. For example, Fletcher and Sarkar (2013) recently reviewed the resilience literature and critiqued the variety of definitions, concepts and theories of psychological resilience. In the disability field, McConnell and Savage (2015) proposed expanding the current research agenda to consider the resilience, and thus adaptation, of families caring for children with DD through greater understanding of the resources needed to meet everyday challenges. In terms of research addressing resilience in parents of children with DD, several potential resilience factors have been explored. These include hope (Lloyd & Hastings, 2009) and self-efficacy (Hastings & Brown, 2002). More recently, a systematic review by Peer and Hillman (2014) suggested that coping style, optimism, and social support may all be factors that influence resilience in parents of children with DD.

Although some research exists on the resilience of parents of children with DD, there is a lack of conceptual clarity regarding its definition (Peer & Hillman, 2014). Rutter (1987) suggested that "resilience is concerned with individual variations in response to risk. Some people succumb to stress and adversity whereas others overcome life hazards" (p. 317). Resilience is also defined as "the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful" (Walsh, 1998, 2006, p. 263). These two definitions are based around a risk/stress – resilience framework: for resilience to be

displayed, a stressor must be experienced. Therefore, in the current context resilience might be demonstrated when mothers report elevated levels of well-being despite raising a child with DD who has high levels of behavior problems.

Ruiz-Robledillo et al. (2014) found resilience showed associations with overall general physical and psychological health of caregivers of children with ASD. Research suggests that resilience is associated with mental health, such as anxiety, insomnia and depression in caregivers (e.g., Tang et al., 2013). The Resilience Scale for Adults (RSA: Friborg et al., 2006) has been used in a small population of parents of children with DD, as part of a comparison between parents of children with Intellectual Disabilities and parents of children with Sanfilippo syndrome and it was found parents rated *social resources* as their highest protective factor, and *planned future* as their lowest protective factor (Grant et al., 2013), both of which are subscales of the RSA. Resilience research to date in the DD field is generally based on cross-sectional research. However, Bayat (2007) suggested that resilience is a process that can only be shown over time and suggested the need for longitudinal studies. We found only one longitudinal study with parents of children with DD. This study was by Gertstein, Crnic, Blacher and Baker (2009), who conducted a longitudinal study exploring the trajectories of daily parenting stress in parents of young children with DD. The study found factors such as psychological well-being, marital adjustment and positive parent-child relationships affected parenting stress differently in mothers and fathers, and it was concluded that parents affect each other's resilience.

In the broader literature on resilience, there are three main theoretical ways to consider resilience: as a compensatory factor (resilience factors have a direct main effect, reducing negative outcomes directly), as a protective factor (reducing negative outcomes in the context of exposure to risk – a moderated effect), and finally the challenge model, which suggests that when exposed to low levels of risk, resilience builds over time (Brook,

Whiteman, Gordon, & Cohen, 1986; Brook, Whiteman, Gordon, & Cohen 1989; Fergus & Zimmerman, 2005). In terms of the challenge model, Andrews, Page, and Neilson (1993) suggest that childhood adversities may protect against the effects of later life stress, as this produces "steeling effects" (Lyons & Parker, 2007; Oldehinkel & Ormel, 2014; Rutter, 2006; Seery, Holman, & Silver, 2010).

Each of these different conceptualisations of resilience leads to different predictions about maternal outcomes in DD research. To address the limitations in existing research and to ground the examination of maternal resilience in alternative theoretical models, we conducted two separate studies to examine resilience in mothers of children with DD, including ASD, in two different countries: the UK and the USA. In Study 1 we conceptualized child behavioral and emotional problems as a risk factor likely to lead to lower maternal well-being (stress, mental health status, positive perceptions of raising a child with ASD and other DDs, and perceptions of family satisfaction). If maternal resilience acted as a protective factor, we would expect maternal well-being to be less affected when exposed to high levels of child behavioral and emotional problems if they also score high on a measure of resilience, meaning resilience is affecting maternal outcomes at high levels of risk (high levels of child behavioral problems). If maternal resilience acted as a compensatory factor, we would expect resilience to emerge as a significant independent predictor of maternal outcomes – an effect that is not interactive with child behavioral and emotional problems as a risk factor.

Given the paucity of research examining resilience in parents of children with DD, we conducted a second study as a replication and direct extension of Study 1. First, this study sought to examine whether the same cross-sectional associations from Study 1 are found in a sample of mothers of children with ASD residing in the USA. We also explored whether a different measure of resilience, commonly used in research with the general adult population,

will produce similar results as Study 1. Study 2 aimed to determine whether the severity of

the child's ASD symptoms is associated with positive and negative maternal well-being

outcomes when resilience is a moderator, and child ASD symptoms are accounted for.

Second, we examined if resilience functions as a compensatory factor affecting maternal

well-being outcomes. Third, we extend Study 1's cross-sectional design by exploring how

resilience functions longitudinally, thus investigating whether maternal resilience predicts

maternal well-being over time. Study 2 is the first to explore resilience in mothers of children

with ASD longitudinally, as well as with cross-sectional data.

Study 1

This first study examined whether maternal resilience served as a compensatory

(direct, positive impact on maternal well-being) or protective factor (moderated the

association between child behavioral and emotional problems and maternal well-being)

among mothers of children with DD residing in the UK.

Method

Participants. The participants were 312 mothers (300 biological mothers, nine

adoptive mothers, and three foster mothers) of children aged between four and 15 years old

($M = 10.02$, $SD = 3.08$) with DD, 308 of whom reported they were the primary carer of their

child. The mothers' ages ranged from 23 to 67 years ($M = 42.50$, $SD = 7.13$) and 252 were

currently living with a spouse or partner. Maternal and child demographic information are

shown in Tables 1 and 2, respectively.

Procedure. We received approval from an institutional research ethics review board

and an external National Independent Research Ethics Committee and local Research and

Development offices that are part of the National Health Service (NHS) in the UK.

Participants were recruited to complete an online survey through a multi-point recruitment

method, which included emailing online links, distributing flyers and information sheets to

General Practice (GP) surgeries and secondary care services whose focus was to provide a service for children with DD, UK charities relevant to children with DD, and DD parent support groups. Special Educational Needs schools in North Wales and the North West of England were sent flyers and information sheets to distribute to parents. Online recruitment via social media (Twitter and Facebook) and online blogs was also on-going throughout the recruitment period. Several participants requested hard copies of the survey and returned completed surveys by post. As all mothers completed all questions, there were no missing data in this dataset. In total, 355 parents responded to the survey. Of the 326 mothers who completed the survey, nine were excluded as their child was not aged between four and 15, and three were excluded because their children did not live with them full time. The fathers who participated in the survey were excluded from this analysis due to the differences seen in previous DD research between mothers and fathers (e.g., Jones, Totsika, Hastings, & Petalas, 2013). Furthermore, it was unknown if the fathers came from the same family as the mothers. Due to the nature of the recruitment methods, we are unable to determine the overall response rate for this survey.

Measures. Six measures plus a demographic questionnaire were used in this study; all measures were completed by the mother of the child with DD.

Demographic Questionnaire. Demographic information was gathered using a questionnaire developed by the research team and included questions about the mother (see Table 1 for details) and their child with DD (see Table 2). Demographic variables were re-coded dichotomously: children's physical and sensory abilities, which originally had three categories, were reduced to two, (e.g., able to walk, able to walk with help, or unable to walk without help was reduced to: able to walk with or without help, or unable to walk), maternal employment was re-coded into two categories (no paid employment vs. employed), ethnicity was coded as white British versus all other categories, and education was coded into degree

level and above versus lower than degree level. All other demographic variables were

dichotomously coded (male vs. female; with child diagnosis in four groups that were dummy

coded: autism present vs. no autism present, Down's Syndrome present vs. no Down's

Syndrome present, Cerebral Palsy present vs. no Cerebral Palsy present, and the remainder of

children as a mixed DD group). Socio-Economic Position (SEP) has been associated with

maternal well-being in several studies (e.g., Totsika et al., 2011), and so we gathered relevant

data and combined several indicators into an index of deprivation. The first indicator was

neighborhood deprivation; each participant's postcode was entered into the relevant and latest

UK country databases (England, Scotland, Wales and Northern Ireland) and a quintile rank

was determined. Maternal educational level was scored 0 (*college education or below*), or 1

(*university education or above*). Employment status was scored 0 (*no employment*) or 1

(*employment, full or part time*). Neighborhood deprivation was scored 0 (*low quintile)* or 1

(not deemed low quintile). The highest score of three indicated living in a low quintile

neighborhood, without a paid job, and with educational qualifications below degree level.

Thus, a low score indicates lower socio economic position.

    Child Behavioral and Emotional Problems. The behavioral and emotional problems

of the child with DD were measured using the Strengths and Difficulties Questionnaire

(SDQ: Goodman et al., 1997, 1998). The SDQ is a well validated instrument and research

with children with DD and their parents suggests good levels of reliability (Beck et al.,

2004a, 2004b; Hastings et al., 2006). Cronbach's alpha coefficient for the total difficulties

score was .86 in this present study.

    Maternal resilience. The Brief Resilience Coping Scale (Sinclair & Wallston, 2004) is

designed to assess an adult's ability to recover from stress. The original measure was

designed to test resilience in a sample of women with rheumatoid arthritis. The four questions

in this scale include: "I actively look for ways to replace losses I encounter in life," "I believe

that I can grow in positive ways by dealing with difficult situations," "I look for creative

ways to alter difficult situations," "Regardless of what happens to me, I believe I can control

my reaction to it." The response scale is a Likert response ranging from 0 (*does not describe*

me at all) to 5 (*describes me very well*). The maximum score is 20, and a higher score

indicates greater resilience. According to Sinclair and Wallston (2004) low resilience

participants are those who obtain scores lower than 13, while those who scored above 17 are

considered highly adaptable. Cronbach's alpha coefficient in the present study was .73 for

mothers.

Maternal Stress. General parenting stress related to having a child with a disability

was measured using a shortened seven-item version of the Parent and Family Problems scale

from the Questionnaire on Resources and Stress- short Form (QRSF7: Griffith et al., 2011).

Parents were asked to circle either "True" or "False" for each item based on whether the item

applied to their family. A total stress score is derived by summing the number of negatively

endorsed items (i.e., positively worded items are reverse scored). In the present study, a

Kuder–Richardson coefficient for the seven-item scale of .90 was obtained.

Family Satisfaction Scale. Family satisfaction was measured by the Family

Satisfaction Scale (FSS: Olson & Wilson, 1982), a 14-item scale designed to measure

satisfaction on the dimensions of family cohesion and family adaptability (flexibility).

Cronbach's alpha coefficient for mothers in this present study, for the total family satisfaction

score, including both the cohesion and adaptability subscales was .94.

Maternal Anxiety and Depression. Maternal anxiety and depression symptoms over

the past seven days were measured by the Hospital Anxiety and Depression Scale (HADS:

Zigmond & Snaith, 1983). The HADS has shown good psychometric properties (Hastings et

al., 2005) and good levels of reliability when used with mothers of children with DD (e.g.,

Hastings & Brown, 2002). In the present sample, Cronbach's alpha coefficients for mothers were .85 for depression and .86 for anxiety.

Maternal Positive Perceptions. The Positive Gain Scale (PGS: MacDonald et al., 2010) assesses the positive aspects of raising a child with a disability. The measure consists of seven items about raising a child with intellectual disability and their putative positive impact on the parent and family. The PGS total score was used in the current study (with lower scores indicating higher levels of positive gain). Cronbach's alpha coefficient for the present sample of mothers was .85.

Results

To assess maternal resilience as a moderator or as a compensatory factor, multiple regression analyses were conducted for each of the five psychological well-being measures (anxiety, depression, family satisfaction, positive perceptions and parenting/family stress; see Table 3). Relevant demographic variables were selected to be included in each of the five analyses from bivariate analyses (correlations or t-tests). Mothers of children with Down's Syndrome reported significantly less stress than other mothers ($t(310) = 6.49$, $p < .001$), as well as significantly less anxiety ($t(310) = 4.45$, $p < .001$), and less depression ($t(310) = 3.89$, $p < .001$), and more family satisfaction ($t(310) = 2.95$, $p = .003$), than mothers in the study whose child did not have Down's Syndrome. Mothers of children who had a diagnosis of ASD also had higher stress levels ($t(310) = - 4.18$, $p < .001$), higher anxiety ($t(310) = -4.52$, $p < .001$), higher levels of depression ($t(310) = -3.72$, $p < .001$), and lower family satisfaction ($t(310)= 3.16$, $p = .002$), than mothers of children who did not have an ASD diagnosis.

Mothers of male children reported higher stress levels than mothers of female children ($t(310) = 2.49$, $p = .01$). Mothers of white British ethnicity reported more anxiety ($t(310) = 2.46$, $p = .01$), and less family satisfaction ($t(310) = .25$, $p = .01$) than mothers of other ethnicities. Pearson's correlations showed mothers from families with higher SEP reported

higher family satisfaction than those mothers from a lower SEP ($r = .12$, $p = .03$), also

families with lower SEP reported lower stress levels ($r = .14$, $p = .01$), lower anxiety levels ($r = .11$, $p = .045$), and lower depression levels ($r = .21$, $p < .001$), than mothers from families

with higher SEP. Older mothers also reported less anxiety ($r = -.17$, $p = .002$) and less

depression ($r = -.13$, $p = .03$) than younger mothers.

The key predictor variable in each analysis was child behavioral and emotional

problems; resilience was entered as a main effect variable, and as an interaction variable with

child behavioral and emotional problems. The "PROCESS" custom dialogue box (Hayes,

2012) was installed into SPSS predictive analytics software for the moderated multiple

regression analyses. Multicollinearity issues between variables were checked using the

Variance Inflation Factor (VIF) and the variables showed no multicollinearity problems (all

values < 10, average > 1, tolerance > 0.1; Bowerman & O'Connell, 1990; Myers, 1990).

Predictor variables were automatically mean-centered when using the PROCESS dialogue

box (the variable mean is subtracted from every value of the variable).

The moderated multiple regression analysis showed that child behavioral and

emotional problems and maternal resilience each had a significant association with maternal

well-being outcomes in all five models. There were two potentially relevant interaction terms,

one statistically significant (maternal stress) and one close to significance (family

satisfaction, $p = .058$) suggesting that the main effects could be interpreted in relation to an

interaction effect. Following the recommendation by Aiken and West (1991), a simple slope

analysis was conducted to aid interpretation of these two interactions. There was a positive

relationship between child behavioral and emotional problems and maternal stress at all three

levels of maternal resilience (all ps < .001). Thus, the nature of the interaction effect was

unclear. Visual inspection of the slopes showed that higher levels of maternal resilience were

associated with lower maternal stress when child behavioral and emotional problems were at low levels.

Discussion

In Study 1, levels of maternal resilience consistently had a significant independent association with maternal positive and negative well-being outcomes when child behavioral and emotional problems were present. Therefore, we found the strongest support for a compensatory model of resilience. Although there were interaction terms (one significant, and one borderline significant) that potentially support a protective factor/moderation model of resilience, the resulting relationships did not follow the predicted pattern of resilience affecting maternal outcomes at high levels of risk (high child behavioral and emotional problems). Instead, we found higher levels of resilience were associated with better maternal outcomes at low levels of child behavioral and emotional problems.

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Study 2

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The purpose of the second study was to extend Study 1 by testing the protective and compensatory function of resilience in mothers of children with ASD residing in the USA. First, to test for the protective function of resilience we examined whether maternal resilience moderated the association between child ASD symptom severity and maternal well-being. Next, the direct effect of resilience on maternal well-being was examined using cross-sectional data to test for the compensatory function of maternal resilience and using longitudinal data to test the challenge model of resilience.

Method

Participants. The current sample was from a larger study of parents of children with ASD ($n = 136$). The participants were 99 mothers of children with ASD (84 male) aged between two and 13 years ($M = 7.78$, $SD = 2.66$). The mothers' ages ranged from 25 to 55 years ($M = 40.00$, $SD = 6.16$). Detailed demographic information is shown in Table 4.

Measures.

Demographic Questionnaire. Demographic information was gathered using a

questionnaire developed by the research team and included questions about the mother and

their child with ASD. The demographic variables presented in Table 4 were recoded

dichotomously: maternal employment was re-coded into two categories (no paid employment

vs. employed), ethnicity was coded as white Hispanic or Latino versus all other categories,

and education was coded into college level and above versus lower than college level. Other

categories were dichotomously coded such as child gender (male vs. female). Three

individual indicators were again combined into an index of deprivation. Each indicator was

scored dichotomously; educational level was scored 0 (*high school education or below*), or 1

(*vocational education, some college classes, college degree, post college professional*

degree). Employment status was scored 0 (*no employment*) or 1 (*employment, full or part*

time). Household income was scored as 0 (*low income, to $24,999*) or 1 (*income above $24,*

999). This is based on the U.S. Department of Health and Human Services, where the

poverty guideline is less than $24,250 for an average of four persons in the household. Total

SEP was calculated by summing the scores of these three indicators from the dichotomous

coding, a high score indicated high socio economic position.

Current Child ASD Symptoms. The severity of child's current ASD symptoms was

measured using the parent report version of the Social Responsiveness Scale (SRS:

Constantino, Przbeck, Friesen, & Todd, 2000). The SRS is a 65-item scale measuring autistic

traits, including social information processing, social use of language, stereotypic/repetitive

behaviors/preoccupations, social awareness, and the capacity for reciprocal social response.

Responses to the questions are using a four-point Likert scale ranging from 1(*never true*) to 4

(*almost always true*). The responses are summed from the 65-items to produce a total score

(index of ASD symptom severity). A higher score indicates a higher level of severity of the

child's current ASD symptoms. Cronbach's alpha coefficients were .88 for Time 1 and .87 for Time 2.

Maternal Resilience. Resilience was measured using the Ego-Resilience 89 Scale (ER-89: Block & Kremen, 1996). The ER89 is a 14-item scale focusing on flexibility, curiosity, generosity and social skills. Sample items include "I quickly get over and recover from being startled" and "I am more curious than most people." Participants are asked to respond on a five-point response scale ranging from 1 (*does not apply at all)* to 4 (*applies very strongly).* Cronbach's alpha coefficients for the current study were .71 for Time 1 and .77 for Time 2.

Depression. Maternal depressive symptoms were assessed using the Center for Epidemiological Studies Depression Inventory (CES-D: Devins et al., 1988; Radloff, 1977). The CES-D is a 20-item self-report questionnaire designed to assess depressive symptoms in adults. Participants are asked to indicate how frequently they have experienced various symptoms during the previous week, using a four-point scale 0 (*rarely or none of the time*) to 4 (*most or all of the time*). A high score is indicative of higher depression in mothers; to achieve this, positively worded items were reverse coded. Previous studies have reported high internal consistency, adequate test-retest reliability, and good criterion and discriminant validity (Devins et al.,1988; Radloff, 1977). Cronbach's alpha coefficients for the current study were .90 for Time 1 and .91 for Time 2.

Anxiety. Maternal anxiety was assessed using the State-Trait Anxiety Inventory (STAI: Spielberger 1983). The STAI is a 20-item widely used self-report measure of anxiety, which measures state anxiety (e.g., current temporary experience of anxiety in specific situations). In the STAI a total score is provided for state anxiety, the score ranges from 20 to 80, and a high score is indicative of higher levels of current anxiety. This measure has been used previously with parents of children with ASD and has demonstrated good internal

consistency for the STAI (Clifford & Minnes, 2013; Reaven et al., 2015).   In this present study Cronbach's alpha coefficients for the state scale were .92 for Time 1 and Time 2.

Family Cohesion. Family cohesion was assessed using the cohesion subscale of the Family Adaptability and Cohesion Evaluation Scales IV (FACES: Olsen, 2011). The cohesion subscale consists of seven items and an example item includes "Family members consult other family members on personal decisions." All items are answered using a five-point scale 1 (*does not describe our family*) to 5 (*very well describes our family*). Higher scores indicate higher cohesion. The FACES IV scales have demonstrated adequate reliability and validity (Olsen, 2011). Cronbach's alpha coefficients were .82 at T1 and T2.

Benefit Finding. Benefit finding was measured using the Post Traumatic Growth Inventory (PTGI: Tedeschi & Calhoun, 1996). The PGTI is a 21-item measure used for assessing positive outcomes when "traumatic events" have been experienced. Participants responded to each item using a five-point Likert scale ranging from 0 *(I did not experience this change as a result of the incident*) to 5 (*I experienced this change to a very great degree as a result of this incident).* In this study, the "incident" is referring to having a child with ASD. The PGTI has good reliability and validity. Cronbach's alpha coefficients for the full scale in this study were .89 for Time 1 and .89 for Time 2.

Loneliness. Maternal loneliness was measured using the revised version of the UCLA Loneliness Scale (Peplau, & Cutrona, 1980). The 20-item scale asks participants to describe their feelings of loneliness through non-lonely items (e.g., *I feel part of a group of friends* and *I lack companionship*). The scale has been shown to have good reliability (Russell, 1996). A higher score reflects a higher level of loneliness reported by the mother. Cronbach's alpha coefficients for this current study were .93 for Time 1 and Time 2.

Procedure. Participants were recruited through online resources throughout the United States (e.g., blogs, Facebook groups, online autism support groups) and through word

of mouth. Mothers who expressed interest in the study were provided with further details about the study and were emailed a unique link to complete all of the questionnaires online. After clicking the link, participants first read and electronically signed the informed consent and then proceeded to complete questionnaires. Upon completion of the survey, parents were mailed a $10 gift card for a national retailer. Approximately six months later, participants were contacted to complete the second part of the survey. Once again, they were emailed a unique link to the survey and completed the questionnaires online. After completion, parents were mailed another $10 gift card for a national retailer. Due to the nature of the recruitment methods we are unable to ascertain how many parents saw the advertising and did not contact us to participate. Thus, we are unable to determine the overall response rate for this survey.

Results

To assess maternal resilience in cross sectional and longitudinal data, multiple regression analyses were conducted for each of the psychological well-being measures (depression, family cohesion, anxiety, loneliness, benefit finding). Demographic variables that were statistically significant with outcome variables were selected to be included in each of the analyses from bivariate analyses (correlations or t-tests). Mothers who had no additional children with ASD in the house had higher scores on the FACES cohesion scale ($t(89) = 2.15$, $p = .03$). Therefore, having additional children with ASD in the house was included as a control variable when family cohesion served as the outcome variable.

All of the continuous variables were examined for normality using Kolmogorov-Smirnov tests; this showed that all variables were normally distributed and suitable for parametric analysis. Multicollinearity issues between variables were checked using the Variance Inflation Factor (VIF) and the variables showed no multicollinearity problems (all values <10, average >1, tolerance > 0.1) (Bowerman & O'Connell, 1990; Myers, 1990).

Cross-sectional analyses. Cross-sectional analyses were conducted to establish whether maternal resilience functioned as a moderator between the severity of the child's current ASD symptoms and maternal outcomes (see Table 5). Using Time 1 data, moderated multiple regression analyses for each of the maternal well-being outcome variables were conducted. The key predictor entered in each analysis was the severity of the child's current ASD symptoms. Maternal resilience was entered in the analyses both as a main effect and as an interaction variable. Significant demographic variables were entered as control variables, when appropriate. The "PROCESS" custom dialogue box (Hayes, 2012) was installed into SPSS predictive analytics software for the moderated multiple regression analyses. Predictor variables were automatically mean-centered when using the PROCESS dialogue box (the variable mean is subtracted from every value of the variable).

In the cross-sectional analyses, maternal resilience did not moderate outcomes in any of the models. However, maternal resilience had a significant independent association with maternal depression, anxiety, loneliness, and family cohesion. The severity of the child's current ASD symptoms, as reported by the mother, was a significant independent predictor for the maternal outcomes of depressive symptoms, anxiety, and loneliness.

Longitudinal analyses. Longitudinal analyses were conducted to identify if maternal resilience at Time 1 predicted later maternal well-being at Time 2 (see Table 6). These longitudinal analyses again used regression analyses for each of the maternal well-being outcome variables. Time 2 well-being outcomes were entered as criterion variables in the regression analyses. The key predictor variables entered in each analysis were Time 1 maternal resilience, Time 1 severity of child's current ASD symptoms, the Time 1 score for the criterion variables, and the relevant demographic variable selected from the cross-sectional analyses.

The longitudinal multiple regression analyses showed that maternal resilience did not act as a significant predictor of maternal well-being outcomes at Time 2. The only variable to make an independent contribution to the prediction of later maternal well-being was the severity of the child's current ASD symptoms: mothers reported lower benefit finding scores at Time 2 when their child with ASD had more severe symptoms at Time 1.

Discussion

The cross-sectional analyses in Study 2 led to similar findings to those from Study 1: maternal resilience had a significant independent association with two maternal outcome variables including depression and family cohesion. Therefore, we again found the strongest support for a compensatory model of resilience. The longitudinal analyses found maternal resilience did not act as a significant predictor of maternal well-being outcomes over time.

In the cross-sectional analysis, the severity of the child's current ASD symptoms, as reported by the mother, had a significant independent association with both anxiety and loneliness in mothers of children with ASD. This is consistent with previous research which found that severity of the child's ASD symptoms had a negative effect on maternal outcomes, such as anxiety, (e.g., Firth & Dryer, 2013). The longitudinal analyses also showed high severity of the child's ASD symptoms predicted lower benefit-finding in mothers over time.

General Discussion

The purpose of the present research was to examine whether resilience, the ability to resist the negative impact of adverse situations, promotes psychological well-being in mothers of children with DD, including ASD. Study 1 found support for a compensatory model of resilience whereby maternal resilience was associated with better psychological well-being for mothers of children with DD. Contrary to predictions, we found limited support for the protective model of resilience. Higher levels of resilience only served as a protective factor in the context of low levels of child behavioral and emotional problems and reliably in only one of the regression models tested. Study 2 explored the compensatory and

protective models of resilience in a sample of mothers of children with ASD. Similar to Study 1, support for the compensatory model of resilience was found. Using longitudinal data over six months in Study 2, no support was found for a temporal relationship between resilience and later maternal psychological outcomes.

The compensatory model of resilience posits that resilience has a direct impact on well-being outcomes and we found support for this model in both studies. In Study 1, maternal resilience was associated with all study outcomes in the expected direction. That is, greater levels of resilience were associated with better well-being in mothers of children with DD. In Study 2, using a different measure of resilience, higher levels of resilience was associated with less depressive symptoms, lower anxiety, less loneliness, and better family functioning in mothers of children with ASD. These findings support a growing body of literature showing that positive characteristics (e.g., optimism, hope) of a parent of child with DD are associated with fewer negative outcomes and increased positive outcomes (Ekas, Pruitt, & McKay, 2016; Ekas, Keylon, Pruitt, Ghilain, & Alessandri, 2015; Ekas, Lickenbrock, & Whitman, 2010; Hastings & Taunt, 2002; Lloyd & Hastings, 2009). One aspect that can be explored further is to examine the attributes of "resilient mothers." One possibility is that there may be some overlap between the construct of resilience, as measured in this research, and other constructs commonly associated with maternal well-being. For example, one question on the resilience measure (ER-89) asks "I usually succeed in making a favorable impression," which may be linked to self-esteem. Future studies could measure these types of characteristics and employ person-centered analyses (e.g., latent class analysis, cluster analysis) to determine the combination of characteristics that are common to mothers identified as resilient.

Studies 1 and 2 also examined the protective model of resilience wherein resilience is hypothesized to "buffer" (i.e., moderate) the negative effects of child behavioral and

emotional problems or child ASD symptom severity. In Study 1, although we found a significant interaction between maternal resilience and child behavioral and emotional problems predicting maternal stress, the direction of effects was contrary to our predictions. We found higher levels of resilience were associated with better maternal outcomes at low levels of child behavioral and emotional problems when we expected, based on research in the general population, resilience to be protective at higher levels of child behavioral and emotional problems. In Study 2, we did not find any evidence for the protective model in mothers of children with ASD. The unexpected findings in relation to the regression models in Study 1 may relate to the third theoretical perspective on resilience introduced earlier - the challenge model. Ongoing exposure to children's behavior and emotional problems in mothers of children with DD may have increased their resilience over time and this may be reflected in the data from this cross-sectional study. Over time, mothers of children with DD may rate their children's behavior and emotional problems as being relatively low (i.e., low risk), whereas mothers of typically developing children might rate the same behaviors as being more severe (i.e., "high risk). Therefore, high risk in the current study might constitute "extremely high risk" (having a child with DD and with significant levels of behavior problems) and that may explain why resilience may not be effective at buffering the effects of those severe behaviors on mothers' well-being. We also tested if the compensatory model held over time, addressing the key causality question of temporal precedence. We found no evidence for a compensatory effect over time in Study 2.

Limitations and Future Research

There are several limitations that warrant discussion. First, upon examining the resilience measures available it was clear there is no resilience measure available that clearly pinpointed the concept of resilience from the definitions and evidence available. However, this is not a direct limitation unique to our study design but comes from a much broader issue

of the difficulty in defining and measuring resilience. The resilience measure selected in

Study 1 was a short, four question measure which may have reduced the internal consistency;

although the internal consistency was still acceptable (.73) within statistical recommendations

(Hayes, 2012). The definitions of resilience in previous literature include the idea of

bouncing back "the ability to withstand hardship and rebound from adversity, becoming more

strengthened and resourceful" (Walsh, 1998, 2006, p. 263). The questions addressed in the

measure of resilience seem to address factors associated with resilient outcomes, such as

handling stress in an adaptive manner. The resilience measure for this study was selected as it

best reflected the core concept of resilience and past definitions, it also scored highly in a

reliability and validity assessment (Windle, 2011). Study 2 was the first to use the ER-89

with mothers of children with ASD, and therefore this ER-89 measure may not be capturing

resilience in these families. However, this measure is widely used in the general adult

population and the Cronbach's alpha coefficients were good in the current study for the ER-

89 (.71 for Time 1 and .77 for Time 2). More research is needed to clarify what these

measures of resilience are capturing. The attributes of "resilience" captured in the ER-89

suggests these do have an association with maternal outcomes. For example, identifying

one's ability to "get over things quickly" suggests successful coping mechanisms. Another

consideration is the theory and discussion in literature of whether resilience can be captured

in a measure, or if it is a process that unfolds over time. Social psychologists generally think

of resilience as a trait-like phenomenon whereas developmental psychologists tend to think of

resilience as something that is demonstrated over time (e.g., see Masten, Powell & Luthar,

2003; Masten & Obradović, 2006).

          Another limitation is that mothers provided all the data in this research which means

there was a lack of source variance. To address this, future research will need to incorporate

independent or multiple informant approaches for key constructs (e.g., child behavioral and

emotional problems). Notably, this study did not include the perspectives of fathers. In general, much of the research involving parents of children with DD focuses on mothers and neglects the unique perspectives of fathers. With respect to this study, it is possible that resilience operates differently for fathers and those differences have important implications for the development of parent-focused interventions. Thus, future research is needed to systematically compare resilience in mothers and fathers of children with DD. The ethnic and SEP diversity was limited in this study. The majority of mothers were White and highly educated. In Study 2, participation was limited only to mothers with internet access, which may contribute to the lack of SEP diversity. This lack of diversity limits the generalizability of the research and poses a problem for informing the development of effective intervention and prevention programs for parents of children with DDs. Future research is needed with parents from diverse ethnic and socioeconomic backgrounds to more fully inform clinical practice.

Finally, Study 1 was limited by its cross-sectional design. This is problematic since temporal precedence has not been established. For example, it may be the case that mothers with higher levels of psychological distress become less resilient. Study 2 attempted to address this concern by including longitudinal data. However, the findings were non-significant. One possible explanation for the non-significant findings in the longitudinal analyses, is the time period between the two data points. The six-month time period between the two data points may not have been enough time for well-being outcomes to change. Previous research with families of children with ASD (e.g., Shattuck et al., 2007) conducted longitudinal analyses for a time period of four and a half years, to reflect the changes seen in child behavioral and emotional problems over adolescence. This study showed that over time as child behavioral and emotional problems decreased, maternal well-being improved. Therefore, future research should consider a longer time frame for follow up, to follow

changes to child behavioral problems, and also to determine whether resilience has built in this time, and if these predict maternal well-being.

Clinical Implications

Despite these limitations, the results of two studies provide initial support for the compensatory model of resilience in mothers of children with DD, including ASD. The finding that maternal resilience is associated with maternal well-being may be used to inform clinical practice in improving well-being in mothers of children with DD, including ASD. In particular, it would be beneficial to directly try to build resilience in mothers to improve their well-being. As one aspect of resilience addresses mothers' positivity, this could potentially be the appropriate target for interventions. A meta-analysis showed that a number of interventions have been successful in the general population in improving positivity, and therefore well-being (Sin & Lyubomirsky, 2009). Several positive psychology interventions were found to be effective in improving well-being, such as a person identifying their strengths and using their signature strengths in new ways (Seligman, Steen, Park, & Peterson, 2005); cognitive strategies for example replaying positive experiences and self-monitoring well-being (Fava, Rafanelli, Cazzaro, Conti, & Grandi, 1998); and practicing emotional skills such as mindfulness and acceptance (Bedard et al., 2003; Grossman, Tiefenthaler-Gilmer, Raysz, & Kesper, 2007). It may be that the previous research into what we suspect to be aspects of resilience, such as positivity, may help form a resilience intervention, which would also help develop a clear concept of resilience. Exploration of these types of interventions which focus on aspects of resilience for families of children with DD is needed in future research. The results of the study also suggest that resilience can be beneficial for all families of children with DD, regardless of diagnosis (ASD vs. non-ASD), the child's behavior and emotional problems, and across cultural context (UK and USA). Thus, the interventions suggested above could be implemented for a variety of families.

Table 1

Study 1: Mothers' Demographic Information

Variable		*n*	*Percent*
Postcode deprivation quintile	1 – Least Deprived	68	22 %
	2	48	15 %
	3	42	14 %
	4	56	18 %
	5- Most Deprived	69	22 %
Education level	No formal educational qualification	11	4 %
	Fewer than 5 GCSE's/ or levels or equivalent	21	7 %
	3 or more a levels (NVQ 3) or equivalent	43	14 %
	University degree	124	40 %
	Masters or doctoral degree	51	16 %
Employment Status	No paid employment	125	40 %
	Part time	125	40 %
	Full time	32	10 %
	Self -employed (full/part time)	30	10 %
Ethnicity	White British	262	84 %
	White Irish	5	2 %
	White Welsh	24	8 %
	Other White background	10	3 %
	Mixed White and Asian	2	1 %
	Other Mixed background	3	1 %
	Black/ Black British- Caribbean	1	<1 %
	White and Black Caribbean	1	<1 %
	Asian/Asian British (Bangladeshi),	1	<1 %
	Asian/Asian British (Indian)	1	<1 %
	Other Asian background	2	1 %

Table 2

Study 1: Children's Demographic Information

Variable	*n*	*Percent*
Male	227	73 %
Autism diagnosis	171	55 %
Various diagnoses and causes of their DD*	93	30 %
Down's Syndrome	48	15 %
Disability from birth rather than acquired	263	84 %
Additional health condition	162	52 %
Secondary diagnosis given	123	39 %
Can feed themselves/ feed themselves with help	295	95 %
Can dress themselves or dress with help	259	83 %
Can walk upstairs without help/ by themselves	256	82 %
Can wash themselves or wash with help	252	81 %
Hearing impairment or deaf	55	18 %
Children did not use speech	39	13 %

*Examples include; no specific diagnosis such as SWAN- Syndrome Without A Name, genetic syndromes such as Fragile X Syndrome, and other diagnoses such as Global Developmental Delay

Table 3

Study 1: Moderated Multiple Regression Analyses Models for the Five Maternal Psychological Well-being Measures

n = 312	Maternal Stress $R^2 = .37$		Family Satisfaction $R^2 = .29$		Maternal Anxiety $R^2 = .25$		Maternal Depression $R^2 = .28$		Positive Perceptions $R^2 = .16$	
Variable	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*	*β*	*p*
Age of mother	.01	.43	-.20	.004	-.07	.06	-.03	.43	.09	**.04**
Autism present	-.31	.21	-.65	.53	.45	.48	.24	.69	.18	.87
Down's Syndrome present	-.82	**.03**	.76	.62	-.68	.35	-.54	.46	.59	.56
Gender of child	-.45	.06	-.01	.99	-.52	.33	.25	.64	.04	.96
SEP	.25	.07	-1.19	**.04**	.37	.25	.95	**.003**	.33	.39
White ethnicity	.37	.26	-2.42	**.03**	1.51	**.03**	.42	.54	.44	.53
Child behavior problems (centered)	.13	**<.001**	-.29	**<.001**	.17	**<.001**	.16	**<.001**	.09	**.02**
Maternal resilience (centered)	-.08	**.004**	.85	**<.001**	-.27	**<.001**	-.39	**<.001**	-.41	**<.001**
Maternal resilience x Child behavioral and emotional problems (interaction)	.01	**.04**	-.04	.06	.01	.62	.00	.77	-.01	.30

Note: Significant (p<.05) associations between variables are in boldface.

Table 4

Study 2: Mothers' Demographic Information

Variable		*n*	*Percent*
Household income	$24,999 or less (low income)	10	10 %
	$25,000 and above (mean or high income)	90	90 %
Education level	High school (grades 10-12)	17	17 %
	Vocational education or some college classes	21	21 %
	College degree	41	41 %
	Post college professional degree (MA, PhD, MD, Law, other)	16	16 %
Employment Status	No paid employment	45	46 %
	Part time	20	20 %
	Full time	34	34 %
Ethnicity	White	86	87 %
	Hispanic or Latino	12	12 %
	Hispanic and/ or Latin American	10	10 %
	Black and/ or African American	2	2 %
	Native American or Aleutian Islander/ Eskimo	1	1 %
	Asian or Pacific Islander	1	1 %
	Other	1	1 %
Marital Status	Single/ separated/ widowed/ divorced	16	17 %
	Married	83	83 %

Table 5

Study 2: Time 1 Cross Sectional Analysis of Maternal Well-being Outcomes

Time 1 Maternal well-being outcomes	Depression $R^2 = .15$ $n = 92$		Anxiety $R^2 = .14$ $n = 92$		Cohesion $R^2 = .18$ $n = 88$		Benefit finding $R^2 = .03$ $n= 91$		Loneliness $R^2 = .15$ $n = 91$	
Variable	β	*p*	β	*P*	β	*p*	β	*p*	β	*p*
Additional child with ASD	--	--	--	--	-2.65	.06	--	--	--	--
Severity of ASD current symptoms	**.11**	**.01**	**.117**	**.01**	.00	.96	.07	.12	**.13**	**.004**
Maternal resilience	**-.45**	**.03**	**-.445**	**.047**	**.34**	**.002**	.15	.54	**-.48**	**.04**
Severity of ASD current symptoms x maternal resilience	.00	.96	.001	.86	.00	.53	-.00	.76	.01	.30

Note. Significant (p < .05) associations between variables are in boldface

Table 6

Study 2: Longitudinal Analysis of Maternal Well-being Outcomes

Time 2 Maternal well-being outcomes	Depression $R^2 = .36$ $n = 70$		Anxiety $R^2 = .23$ $n = 70$		Cohesion $R^2 = .59$ $n = 66$		Benefit finding $R^2 = .42$ $n = 69$		Loneliness $R^2 = .65$ $n = 68$	
Variable	β	p	β	p	β	p	β	p	β	p
Additional child with ASD	--	--	--	--	.94	.43	--	--	--	--
Maternal resilience Time 1	-.27	.20	-.23	.32	.15	.10	.09	.70	-.14	.41
Severity of child ASD current symptoms Time 1	.05	**.18**	.03	**.48**	-.00	.85	**-.09**	**.046**	.04	.21
Outcome Time 1	**.46**	**<.001**	.45	**<.001**	**.73**	**<.001**	**.69**	**<.001**	**.77**	**<.001**

Note. Significant (p < .05) associations between variables are in boldface, longitudinal results are shown after accounting the Time 1 score in each outcome

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