Evidence for the protective and compensatory functions of resilience in children with intellectual and developmental disabilities.

Abstract

Children with intellectual and developmental disabilities (IDD) are more likely to engage in behavior problems than children without IDD. In the present study, we explored whether adverse life experiences and events were related to child behavioral and emotional problems. We also examined whether child resilience would act as a protective factor in this putative association between adverse experiences and child behavioral and emotional problems. Mothers of 310 children with IDD aged between four and 15 years old completed a cross-sectional online survey including measures of exposure to adverse life experiences, child resilience, and behavior and emotional problems. In moderated multiple regression models, we found that exposure to adverse life experiences had a positive association with child behavior problems and peer problems and that these associations were moderated by child resilience. Resilience served a protective function – lowering risk of problems for children exposed to adversity. Child resilience also served a compensatory function; being directly associated with fewer conduct and emotional problems, and increased pro-social behavior. Child resilience may be an important factor in understanding the behavior and emotional problems of children with IDD. Further, especially longitudinal, research is needed. Interventions designed to increase children's resilience may be beneficial for children with IDD.

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

Background

Children with intellectual and developmental disabilities (IDD) are more likely to engage in behavior problems than children without IDD, and the presence of behavior problems has a negative association with other child outcomes, such as social ability and academic achievements (Baker et al., 2003; Campbell, 2003; Einfeld & Tonge, 1996). Mitchell and Hauser-Cram (2009) found several environmental predictors of child behavior problems in children with IDD, such as stressful life events and family climate (consisting of cohesiveness, expressiveness, and conflict in the family).

There is a well-established relationship between adverse or stressful life events and psychopathology amongst the general population of children and young people (e.g., Goodyer, Wright, & Altham, 1990). This association has also begun to be explored among children with IDD. For example, in a study of 102 children with IDD and 58 children without IDD, Saylor, Macias, Wohlfeiler, Morgan, and Awkerman (2009) found that the children with IDD experienced more potentially traumatic life events than their typically developing peers. These potentially traumatic life events were likely related to the complex needs of the child (e.g., school problems, hospitalisations) but others, such as vehicle accidents, were still reported as more likely to be experienced by children with IDD. Children who were exposed to more life events were also more likely to have behavioral and emotional problems.

In a population-defined sample in the UK, Emerson and Hatton (2007) compared exposure to social and environmental risks in 641 children with intellectual disability (ID) and 17,774 children without ID all between the ages of 5-16 years. Children with ID were more likely to live in single parent households, live in poverty, have a mother with mental health problems, have a mother with no educational qualifications, be exposed to two or more recent negative life events, live in a household with no paid employment, have a mother with poor physical health, and live in a “poor functioning” family. All putative risks apart from maternal poor physical health were associated with an increased risk of mental health problems in the ID group.

Children with IDD are thus more likely to experience a variety of adverse life experiences, and there is evidence that these experiences are associated with increased behavior and emotional and mental health problems. However, not all children with IDD exposed to these potential risks have psychological problems. Thus, it is important to consider why this might be the case – what factors might influence the emergence of psychological problems in children with IDD exposed to a range of risks? One construct which could be important is child resilience. However, there has been a lack of research on resilience in children with IDD. Some researchers have examined factors thought to represent potential resilience in children. For example, Gilmore, Campbell, Schochet and Roberts (2013) found children with IDD reported lower levels of tolerance and fewer future goals, and higher levels of emotional sensitivity, than their typically developing peers, although other identified resilience factors, such as optimism and self-esteem, were reported at a similar level as their typically developing peers. However, it is important first to consider theoretically what resilience is and how it might function for children with IDD.

There is a lack of conceptual clarity in defining what resilience is in existing research and in particular what it means for children with IDD (Peer & Hillman, 2014). Definitions of resilience include “resilience is concerned with individual variations in response to risk. Some people succumb to stress and adversity whereas others overcome life hazards” (Rutter, 1987, p. 317). Resilience is also defined as “the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful” (Walsh, 1998, p. 263). These two definitions are based around a risk/stress – resilience framework: for resilience to be displayed, a stressor or risk factor must be experienced. Resilience is shown when outcomes are more positive than expected given the child's exposure to risk/stressors. In the current context, resilience might be demonstrated when a child is exposed to adverse life experiences but the child does not then show significantly increased emotional or behavior problems.

In the broader literature on resilience, the preceding perspective on the interactive nature of resilience as a protective factor (reducing negative outcomes in the context of exposure to risk – a moderated effect) is one of three main theoretical ways to think about resilience. The other two perspectives are that resilience may be a compensatory factor (risk factors have a direct main effect, reducing negative outcomes directly), and there is a challenge model, which suggests that when exposed to low levels of risk, resilience builds over time (Fergus & Zimmerman, 2005; Brook et al., 1986; 1989)**.** In terms of the challenge model, Andrews, Page and Neilson (1993) suggested that childhood adversities may protect against the effects of later life stress, as this produces "steeling effects" (Oldehinkel & Ormel, 2015; Rutter, 2006; Seery, Holman, & Silver, 2010).

To the best of our knowledge, no research studies have examined evidence for these differing resilience theoretical perspectives in children with IDD. Therefore, the main purpose of the present study was to compare predictions from protective and compensatory resilience models in a cross-sectional research study. Adverse life experiences potentially affecting the child with IDD were conceptualised as constituting putative risk likely to be associated with higher levels of child behavior and emotional problems. Given that a challenge model requires a longitudinal research design, we were unable to explore predictions from this perspective.

Method

Participants

Mothers provided data about 310 children with IDD aged between four and 15 years old (*M* = 10.02, *SD* = 3.08). Seventy-two per cent of the children were male, 54% were also reported by their mother to have a diagnosis of autism, 15% had Down Syndrome, and the remainder were reported as having a variety of different causes for their IDD and a variety of diagnostic labels (including no specific diagnosis, Global Developmental Delay, and genetic syndromes such as Fragile X Syndrome). The mothers' ages ranged from 23 to 67 years (*M* = 42.50, *SD* = 7.14), and 80% were currently living with a spouse or partner. Most mothers (97.5%) were the primary carer for their child. Fifty-six per cent of mothers were educated to University level or above, and 4% of mothers had no formal educational qualifications. Forty per cent of mothers were not currently in paid employment. Twenty-two per cent of mothers lived in a neighbourhood amongst the 20% most deprived in the UK, and 22% lived in a neighbourhood amongst the 20% least deprived in the UK.

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, and distributing advertisements and information sheets to primary healthcare and secondary healthcare services, UK Non-Governmental Organizations (NGOs), and IDD parent support groups. Special Educational Needs schools in North Wales and the North West of England were sent advertisements 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 surface mail. The Bristol Online Survey (BOS) system (https://www.onlinesurveys.ac.uk/) was used as the online survey system to collect the majority of data.

As all mothers completed all questions, there were no missing data in this dataset. In total, 355 parents responded to the survey. The fathers who participated in the survey were excluded from this analysis due to the differences seen in previous IDD research between mothers and fathers (e.g., Jones, Totsika, Hastings, & Petalas, 2013). Of the 324 mothers who completed the survey, eleven were excluded as their child was not aged between ages four and 17 (the age range for the SDQ), and four were excluded because their children did not live with them. Due to the nature of the recruitment methods, we are unable to determine the overall response rate for this survey.

Measures

Four measures, and a demographic questionnaire were used in this study; all measures were completed by the mother of the child with IDD.

Demographic Questionnaire. Demographic information was gathered using a questionnaire developed by the research team. A Total Disability Severity Index was created from seven of these background questions about the child. Six of these questions (speech, hearing, dressing, washing, feeding, mobility) were rated on 3-point scales (0-2), and the seventh (presence of child physical health problems) was recorded as 0 (*not present*), or 1 (*present*). Scores from these seven items were z transformed and then summed to create the Total Disability Severity Index.

Child Behavioral and Emotional Problems. The behavior and emotional problems of the child with IDD were measured using the Strengths and Difficulties Questionnaire (SDQ: Goodman, Meltzer & Bailey, 1998). This measure is for parents of children aged between four and 17 years. There are 25 items scored using a three-point scale from 0 (*not true)* to 2 (*certainly true)*. The SDQ has five subscales including four problem behavior subscales assessing: Conduct disorder, Emotional Symptoms, Hyperactivity, Peer Problems. The final sub-scale is Pro-social Behavior. A total difficulties score is produced by totalling the four problem behavior subscales, giving a scale with a range of scores from zero to 40. The SDQ is a well validated instrument and research with children with IDD and their parents suggests it retains a good levels of reliability with these populations (Beck, Daley, Hastings & Stevenson, 2004a, 2004b; Hastings Daley, Burns & Beck, 2006; Iizuka et al., 2010). In the present sample, Cronbach's alpha coefficient for the subscales were as follows; Emotional Symptoms (.81) Conduct Problems (.71), Hyperactivity (.69), Peer Problems (.54), Pro-Social Behavior (.81), and the total difficulties score was .86.

Child Resilience. The Wagnild and Young Resilience Scale (1993) was originally designed to identify the degree of resilience an individual possesses. The measure is derived from interviews with "resilient" individuals. The original resilience scale has 14 items and measures personal attributes associated with resilience. It has good psychometric properties, and has been used successfully in studies involving adults and adolescents (Wagnild, 1993; Wagnild, 2009). An adapted five-item version of the measure was used for this study as there was no suitable proxy resilience measure found suitable for parent completion. This five-item version was used in the "Feelings Count" survey, conducted by the New Philanthropy Capital (NPC) charity (Nevill, 2009). The NPC survey was a self- report survey for children. Therefore, we adapted the items for parent completion and the items were: "My child usually manages one way or another," "My child keeps interested in things," "My child feels their life has a sense of purpose," "My child finds life really worth living," "My child believes their life has meaning." All items are scored on a seven-point Likert scale from 1(*disagree*) to 7 (*agree*) and a summed resilience score was derived from all five items. In the current study, Cronbach's alpha coefficient for this summed scale was .84.

Adverse Experiences Index. To assess the child's exposure to adverse life experiences, five variables were included in an 'Adverse Experiences Index'. These items were chosen to reflect the key risks identified in Emerson and Hatton's (2007) earlier analysis of mental health problems in children with ID. Three of the variables were included in the demographic questionnaire, and two (negative life events and maternal depression) were assessed using additional measures (see below). Each of the five potential risk variables was dichotomously coded to reflect low risk vs. high risk: Negative life events (7 questions) (no or one life event (score 0) vs. two or more life events (score 1)); maternal education level (school leaving qualifications or above (score 0) vs. no formal qualifications or few school leaving qualifications(score 1)); single parent household (parent lives with partner or spouse (score 0) vs. does not live with partner or spouse (score 1)); maternal depression (scored HADS – see below - clinical cut off of 10 (score 0) vs. scored above clinical cut off (score 1)); neighbourhood deprivation (does not live in a neighbourhood in the 20% most deprived areas of the UK (score 0) vs. does live in a neighbourhood in the 20% most deprived areas of the UK (score 1)). These five variables produced an overall adverse experiences index ranging from zero (no adverse experiences) to five. To best reflect the distribution of this 0-5 adverse experiences index, scores on the index were dichotomously coded (no adverse experiences (score 0) vs. one or more adverse experiences (score 1).

Negative Life Events. Child and family exposure to negative life events was measured using life event questions from the UK Millennium Cohort Study (Centre for Longitudinal Studies, 2012). A total of eight questions were asked. The life event questions referred to possible negative life events in the past 12 months of the child with IDD and their family life. Questions related directly to the child (illness, moving house, and being absent from school or changing school), and any illness or separation of parents and/or their spouses. Mothers responded to indicate whether the life event had occurred.

Maternal Depression. Maternal depression symptoms over the past seven days were measured using the seven depression items from the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) (e.g., “I feel as if I am slowed down”). The HADS has been used with community samples of parents of children with IDD and maintains good reliability for the depression scale (e.g., Hastings & Brown, 2002; Hastings, et al., 2006; Jones, Hastings, Totsika, Keane, & Rule, 2014). In the present sample, Cronbach’s alpha coefficient for the depression score was .85.

Data Analyses

T-tests were used to explore associations between adverse experiences risk group (none vs. one or more risks – see above) and child behavior and emotional problems (SDQ scores). To examine child resilience as a potential moderator or as a compensatory factor, multiple regression analyses were conducted to predict each of the children’s SDQ scores. The Adverse Life Experiences Index dichotomous score was entered in the regression models as a predictor. Child resilience was also entered as a predictor variable along with an interaction term between adverse life experiences and child resilience. A number of other variables were added to the regression models as control factors – variables that in other studies have been associated with behavior and emotional problems in children with IDD (autism, Down syndrome, child age, child sex, and disability severity (using the severity index described above)).

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). The adverse experiences index and the child resilience variable were automatically mean-centred when using the PROCESS dialogue box (the variable mean is subtracted from every value of the variable).

Results

Those children exposed to at least one adverse life experience were reported to have significantly more problems than the no risk exposure group for the SDQ total problems score ($t(308) = -2.840$, $p = <.05$); and following subscales; Conduct problems ($t(308) = -2.256$, $p = <.05$) and Emotional problems ($t(308) = -2.248$, $p = <.05$); all associated with relatively small effect sizes. Peer problems, pro-social behavior and hyperactivity scores did not differ between the risk groups (see Table 1).

[INSERT TABLE 1 AND 2 NEAR HEAR]

The results of the multiple regression analyses are displayed in Table 2.
After controlling for child age, presence of autism diagnosis, presence of Down syndrome, child gender, and child disability severity, child resilience scores were a significant independent predictor for all six SDQ scores. Child resilience had a positive association with pro-social behavior scores and a negative association with the other SDQ scores. After controlling for all other variables in the models, the adverse experiences grouping variable was not a significant independent predictor of SDQ outcomes. However, in two models (SDQ total and peer problems), the interaction between child resilience and adversity exposure was statistically significant suggesting that the main effects could be interpreted in relation to an

interaction effect. Following the recommendation by Aiken, West and Reno (1991), a simple slope analysis was conducted to aid interpretation of these two interactions. For both interactions, visual inspection of the slopes showed there was a relationship between child resilience and child behavior problems only when adversity exposure was at the higher level. Specifically, children with higher resilience scores had lower levels of behavior problems at high adversity exposure compared to children with average or lower levels of resilience (see Figures 1 and 2).

[INSERT FIGURES 1 AND 2 NEAR HEAR]

Discussion

The results of the present study partially replicate previous research in that exposure to one or more adverse life experience was associated with the behavior and emotional problems of children with IDD (Mitchell & Hauser-Cram, 2009). In univariate analyses only, children exposed to one or more adversity were reported as having more total behavior problems, more conduct problems, and more emotional problems.

In terms of the theoretical test of child resilience as a protective or compensatory factor, our results supported both models. For total behavior problems and peer problems, child resilience moderated the impact of exposure to adversity on behavior problems. These moderation effects followed the pattern predicted from a protection model of resilience: children exposed to adversity had fewer behavior problems when they also had higher scores for resilience. For three other domains (child emotional problems, conduct problems, and pro-social behavior), child resilience did not act as a protective factor but did have an independent main effect relationship with child outcomes. In each case, the relationship was as predicted by a compensatory model (higher resilience scores were associated with lower levels of problems, and increased pro-social behavior). These findings not only require replication, but also need to be extended to longitudinal research designs. The functions of resilience (including a challenge model that could not be tested in a cross-sectional study) all imply causal relationships or the influence of causal relationships. If our results are replicated in longitudinal studies, the pathways via which resilience may influence specific child behavior and emotional problems could be confirmed to vary. That is, we found evidence of a protective function of resilience for some behavior problems and a compensatory function for other behaviors and for emotional problems.

Limitations and Future Research Directions

Given the relatively low internal consistency for the SDQ peer problems scale in the present sample, the findings relating to peer problems should be treated with additional caution. In addition to the lack of longitudinal data, a limitation of this study is that mothers provided data for all variables. Future research could incorporate independent or multiple informant approaches for key constructs, such as for child behavior and emotional problems. Behavior and emotional problems are also not the only child outcomes that may be important to consider in the context of resilience. The development of social networks and friendships, academic attainment, independence skills, and the overall quality of life experienced by children are also important. In addition, exposure to positive life experiences should be explored in future research to extend this area of work beyond an exclusively negative focus.

There is currently no agreed definition of resilience, and arguably resilience is subjective and dependent on many factors. Therefore, resilience may be difficult to measure. The proxy measure used in the current study had associations with study variables consistent with hypotheses about the functions of resilience. In addition, the Cronbach’s alpha coefficient was good for this measure in this study (.84). However, more work is needed to establish the reliability and validity of this measure of resilience for children with IDD. In addition, in future research, it would be important to compare parents’ reports of children’s resilience with that of their child with IDD. Outside of the IDD field, and number of intervention approaches have been developed to target child resilience (Dray et al., 2017). Such interventions could be adapted in future research and tested for effectiveness with children with IDD.

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Table 1.

Adverse Experience Index t test scores associated with SDQ scores.

SDQ Subscale	Group	N	M	SD	*t*	*d*	*p*
Emotional symptoms	0 AE	74	2.78	2.02	-2.248	0.29	.025
	1 or more AE	236	3.44	2.32			
Conduct problems	0 AE	74	3.87	2.92	-2.256	0.30	.025
	1 or more AE	236	4.76	3.04			
Hyperactivity	0 AE	74	7.27	2.32	-1.764	0.23	.079
	1 or more AE	236	7.79	2.13			
Peer problems	0 AE	74	4.76	2.07	-1.728	0.23	.085
	1 or more AE	236	5.25	2.18			
Pro-Social Behavior	0 AE	74	4.79	2.74	1.183	0.16	.238
	1 or more AE	236	4.37	2.76			
Total difficulties score	0 AE	74	18.67	6.87	-2.840	0.38	.005
	1 or more AE	236	21.25	6.84			

Note: Adverse Experiences (AE)

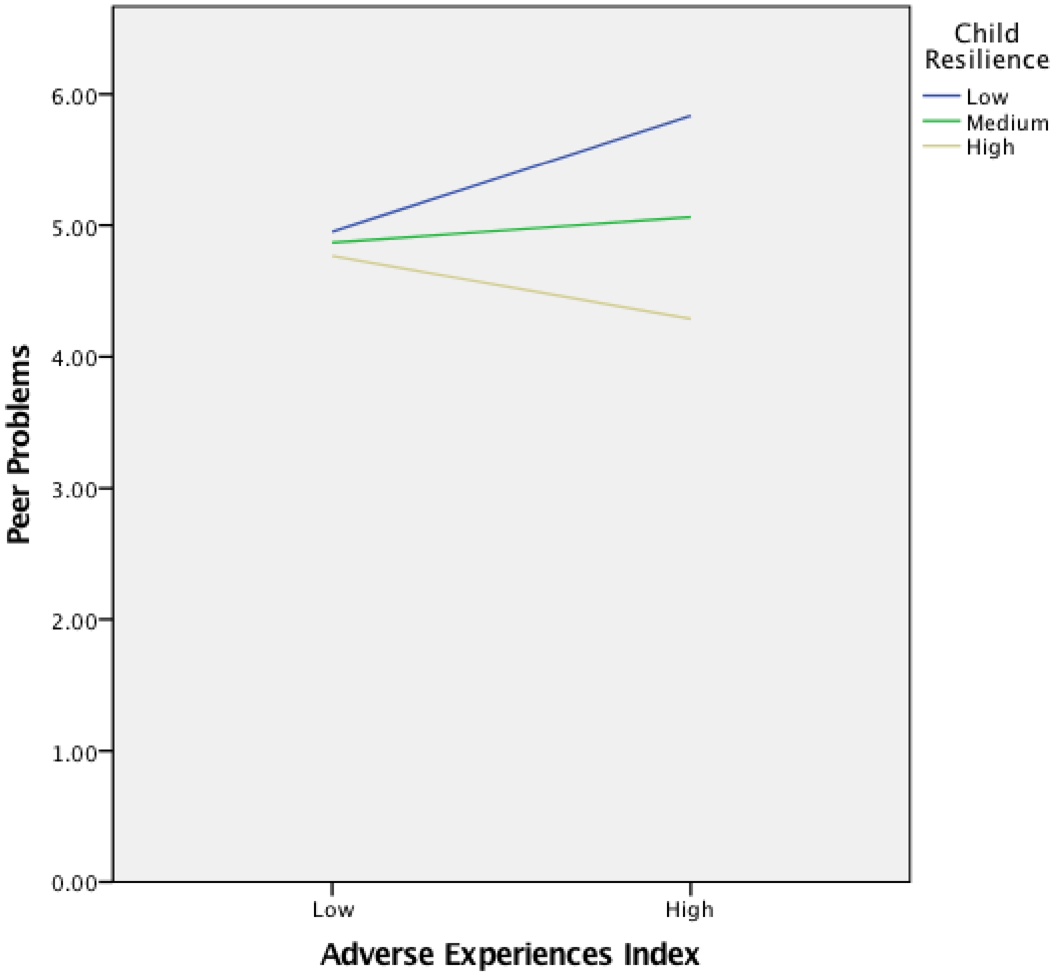

Figure 1. Child Resilience as a moderator between Adverse Experiences and Peer Problems

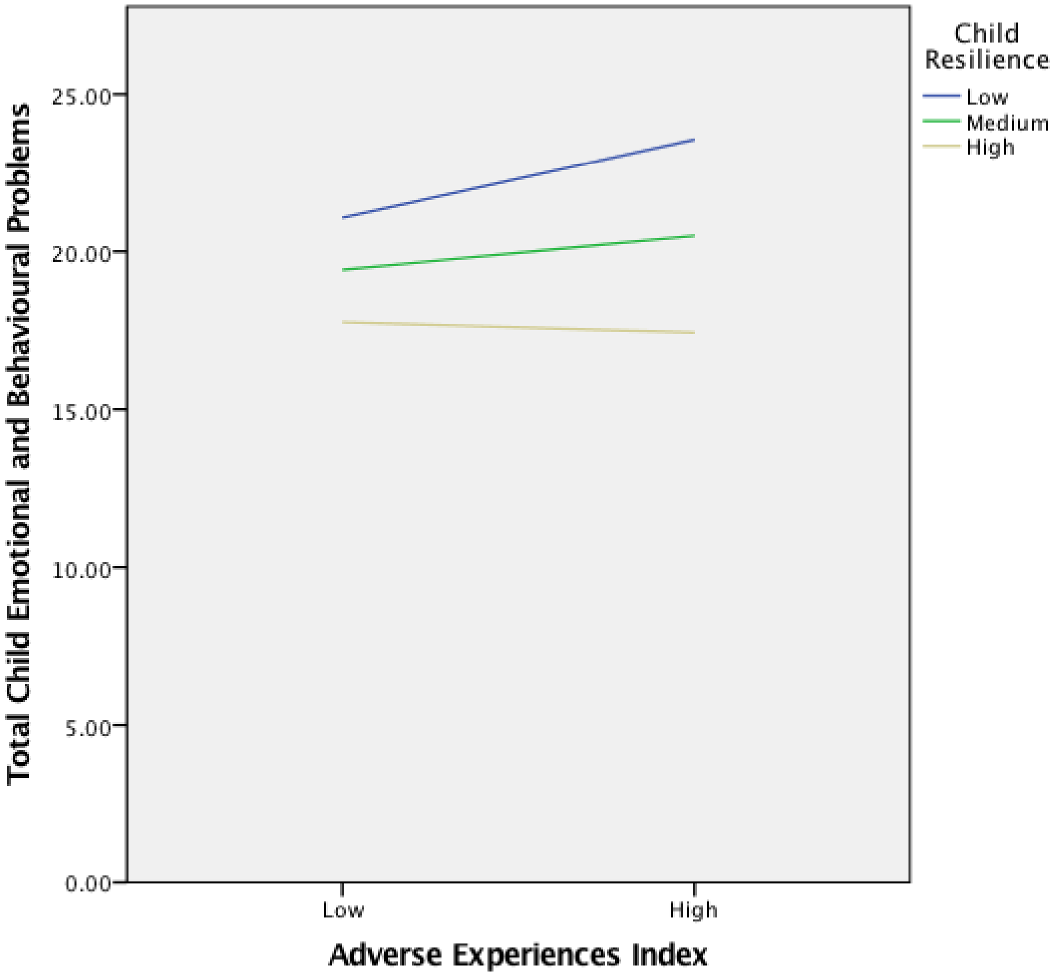

Figure 2. Child Resilience as a moderator between Adverse Experiences and total SDQ difficulties scores.

Table 2.

Moderated Multiple Regression Analyses for child SDQ scores

	Total		Subscales									
n = 310	Total Difficulties Score R = .660 R^2 = .435 F= 28.999		Emotional Symptoms R=.586 R^2 = .343 F= 19.693		Child Conduct Problems R=.476 R^2 = .227 F= 11.019		Hyperactivity R= .390 R^2 = .151 F= 6.737		Peer Problems R= .512 R^2 = .263 F= 13.408		Pro-social Behavior R= .513 R^2 = .262 F= 13.421	
Predictor variable	B	*p*	B	*p*	B	*p*	B	*p*	B	*p*	B	*p*
Age of child	-.110	.264	.053	.258	-.099	**.009**	-.110	**.004**	.046	.190	.083	.065
Autism present	3.713	**<.001**	1.891	**<.001**	.446	.096	.518	.056	.858	**<.001**	.343	.277
Down’s Syndrome present	-3.520	**<.001**	-1.191	**.009**	-.598	.108	-.859	**.023**	-.872	**.012**	1.984	**<.001**
Gender of child	.237	.732	.900	.257	-.253	.341	-.187	.486	-.223	.368	.083	**.003**
Disability Severity Index	-.069	.230	-.035	.231	-.048	**.042**	.008	.749	.006	.784	-.034	.223
Adverse Experiences Index (centred)	1.212	.107	.318	.369	.274	.341	.351	.228	.267	.320	-.026	.938
Child Resilience (centred)	-.682	**<.001**	-.233	**<.001**	-.194	**<.001**	-.104	**<.001**	-.153	**<.001**	.232	**<.001**
Resilience x Adverse Experiences Index (interaction)	-.353	**.049**	-.101	.232	-.002	.976	-.083	.227	-.170	**.008**	.093	.252

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