The Burden of Care: A Systematic Review of Parental Stress in Families of Children with Intellectual Disabilities

Ms. Madhu Kumari¹, Dr. Santanu Biswas²

¹Assistant Professor, ²HOD & Associate Professor, ^{1,2}Department of Education, RKDF University, Ranchi, Jharkhand, India

ABSTRACT

This article is based on a review that looked at the emotional, financial, and social aspects of parental stress and how they interact with one other and with parents' well-being as a whole. Caregivers and families face several challenges in raising a kid who has an intellectual handicap. Consequently, a study of parental stress in relation to intellectually disabled children is urgently needed. A significant percentage of the population lives with an intellectual disability. It is critical to understand the stress that these children's parents endure since it may significantly affect their and their children's health. The study's findings highlight the major effect that stressed parents have on their families' ability to operate. Consequently, there is a focus on parents' experiences as a whole, but a dearth of knowledge on the particular difficulties encountered by parents whose children have certain medical needs or who fall somewhere on the spectrum of intellectual impairment. Parents experience stress and difficulties in the near term, but the long-term effects on their mental and physical health and quality of life are less extensively studied. So yet, no studies have examined the effects on siblings of children who have intellectual disability. The specific difficulties and stresses experienced by siblings were underreported.

KEYWORDS: Parental stress, Intellectual disability, Caregiver stress, Family well-being, Coping strategies, Support services

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1. INTRODUCTION

As a parent, one experience a wide range of emotions and triumphs along the way. This path is fraught with distinct and substantial stresses that affect the health of parents whose children have intellectual disabilities. Conditions affecting a child's cognitive functioning are collectively known as intellectual impairments, and these children often require supplementary care, assistance, and resources. Parents' physical, mental, and emotional health may take a hit when they're dealing with the emotional, psychological, and practical challenges of caring for children with intellectual disabilities. The study looked at the many aspects of parental stress, including financial, social, and emotional stresses, and how they interact with parents' well-being as a whole. From infancy throughout maturity, parenting is a system that promotes and sustains children's physical, psychological, social, economic, and intellectual development. It has long been believed that parents of handicapped children are more likely

to suffer from mental illness themselves. (Authors Cummis et al., 1966). Parents experience stress due to the additional demands placed on them by their children's chronic physical and emotional disabilities (Tew & Laurence, 1975; Breslau et al., 1982). Parents often experience significant emotional and mental strain as a result of caring for a kid with intellectual disability. A rethinking of priorities, roles, and relationships within the family is usually necessary. Their families have always cared after most people with intellectual disabilities in India. Many negative outcomes have occurred as a result of this homebased care in today's contemporary culture. The stress that parents of intellectually handicapped children endure has several causes, including societal changes (such as the dissolution of joint families) and economic shifts (such as unemployment, inflation, etc.). Parents with intellectually disabled children may feel more or less stress depending on a number of factors. Research by Honig & Winger (1997),

Huang (1997), Majumdar et al. (2005), and Minnes (1988) all indicate that parental stress is significantly correlated with the degree of their child's intellectual handicap. In the context of caring for children with intellectual disabilities, this systematic review delves deeply into the empirical data pertaining to the intricate connection between stress and well-being as parents. Individuals with intellectual impairments need a higher level of care, focus, and funding due to their specific needs. Parents often encounter financial difficulties, exhaustion from caring for their children, and the challenge of navigating healthcare and school systems that may not always be sufficient to meet their children's requirements. The mental, emotional, and physical health of parents adversely affected by these stresses. The fundamental goal of this comprehensive study is to analyze and combine previous studies on the many facets of parental stress and health in this particular setting of caring. Researchers will examine the interplay between parents' emotional, economical, and social stresses and their general health by delving into the many elements of parental stress. A family's stress levels impacted by the responses of others around them; parents of intellectually handicapped children are acutely aware of and sensitive to the feelings of friends, neighbours, and strangers (Boss, 1988). Parental stress and its relationship to sociodemographic factors and family environment were the foci of this research. Factors that contribute to the 2.1. To identify the specific sources of stress perceived stress of caring for an intellectually disabled kid include the parents' age, marital situation, and degree of education. Oh, Rubin, and Mouw (1994) found that parents who are very young or very elderly are more likely to experience stress. Everyday pressures, stresses, and obligations from family life might be either normative or nonnormative. Capabilities within a family include both material and psychological assets, as well as coping mechanisms. Direct or indirect, the stress that parents experience may have a harmful impact on their children's development. It has been significantly impacted by elements related to children's conduct. When parents are under a lot of stress, it may change how they see their child's impairment and how they respond to them, which in turn can impact their child's skill development. For instance, compared to typically developing children, autistic children are more likely to display problematic behaviors, and parents of autistic children report greater levels of stress related to parenting. But studies on the topic have shown mixed results for families. Parents of disabled children report higher levels of stress compared to parents of typically developing children, according to a few of comparative studies (Baker-

Ericzen, Brookman-Frazee, & Stahmer, 2005; Dyson, 1997), lending credence to the idea that disability has negative consequences. Similarly, two studies that compared mothers with normally developing children to those with mentally retarded children indicate that mothers with mentally retarded children are more likely to suffer from depression (Blacher, Shapiro, & Fusco, 1997; Olsson & Hwang, 2001; Center for Epidemiologic Studies Depression Scales). While these studies do find a correlation between parental stress or depression and their children's disabilities, it's worth noting that they didn't account for differences in disability diagnosis or care requirements.

2. The Research Objectives of the Study

Identifying various research agendas related to parental stress of the children with intellectual disability.

- 1. To determine the specific sources of stress experienced by parents of children with intellectual disabilities.
- To examine the detrimental effects on the functioning of families whose children have intellectual disabilities.
- To conduct a review of the unique ways in which parents with intellectual disabilities experience

experienced by parents of children with intellectual disabilities

Intellectually disabled children are an unusual and varied group, with many different kinds of difficulties in cognitive and adaptive functioning. Limitations in intellectual functioning and challenges in areas like communication, self-care, and social integration are hallmarks of intellectual disabilities. Caregivers, parents, and families may face several challenges in raising a kid who has an intellectual handicap. Consequently, a study of parental stress in relation to intellectually disabled children is urgently needed. A significant percentage of the population lives with an intellectual disability. It is critical to understand the stress that these children's parents endure since it significantly affect their and their children's health. It may be particularly difficult for parents of intellectually disabled children to deal with the emotional and behavioral elements of their kid's illness while also figuring out how to provide their child the medical treatment and education they need. Elevated stress levels are a result of these difficulties. A significant percentage of the population lives with an intellectual disability. It is critical to understand the stress that these children's parents endure since it significantly affect their and their children's health. It may be particularly difficult for parents of intellectually disabled children to deal with the emotional and behavioural elements of their kid's illness while also figuring out how to provide their child the medical treatment and education they need. A rise in stress levels may result from these difficulties. Important insights into the kinds of support services and resources required for families with intellectually impaired children gained by understanding the specific stresses experienced by these parents. It allows service providers to customize their solutions to tackle the unique issues that these parents face. After controlling for factors such as child behavior, parental coping style, maternal education, family income, child age, and number of children in the household, Abbeduto et.al. (2004) discovered that there were no longer diagnosisspecific variations in parenting stress. Neither the functioning of children nor their behaviors were shown to be significant predictors of parental depression symptoms or parenting stress when Kersh et al. (2006) controlled for marital quality of children with intellectual disabilities.

2.2. To examine the detrimental effects on the functioning of families whose children have intellectual disabilities

While several studies have looked at how dysfunctional families affect children with disabilities, Lustig (1997) discovered that this is not the case for the majority of these households. According to Lustig's typology research, the majority of families with disabled children showed either a flexible or coherent profile. A mere 7% of families, on the other hand, were vulnerable, meaning they lacked functionality, coherence, resources, and flexibility. Lustig found no evidence that families with disabled children had greater functional challenges than non-disabled households. Therefore, professionals should not automatically assume that a child's handicap is due to a dysfunctional home. While dysfunctional families may increase the likelihood of experiencing stress, the vast majority of families manage to get along just fine. Stress levels in parents were shown to be significantly predicted by spousal depression (Kovshoff, Ward, Di Espinosa, Brown, and Remington, 2005). As a result, professionals should listen carefully to how families describe their time spent caring for a disabled kid, according to the research. Family members' pessimistic views on the handicap could be a threat. The impact of intellectual disability on parents have been the subject of mixed findings in the research. Some studies have shown no negative effects, while others have found strong ones. As an example, 55.38 percent of parents in a study by Indla, Indla, and

Singh (2008) said that their children with ID had a positive influence on the family. The parents reported improved marital connections as well as increased tolerance, empathy, sensitivity, and patience. On the other hand, only 25.26 percent of those who took the survey said that having an ID children is a curse. Having a child with intellectual disability may have several beneficial impacts on a family, according to Mahoney (1958). The child's integrational impact on the family reduced day-to-day stress by channelling the family's positive energy in a constructive direction. Some parents have found a fresh value in the simple things they used to take for granted.

2.3. To conduct a review of the unique ways in which parents with intellectual disabilities experience stress

Mothers and dads cope with a child's impairment in different ways and have distinct requirements, according to the research. Researchers have shown that moms of disabled children are more likely to suffer from depression than dads. Compared to the control group (with children who did not have Down syndrome), the women whose children had the disorder reported higher levels of stress, a diminished feeling of coherence, and worse health (Oelofsen and Richardson, 2006). Dunst, Trivette, & Cross (1986), Dyson (1997), and Kermanshahi et al. (2008) are just a few of the studies that found that parents of ID children, particularly mothers, reported reduced stress levels when they received informal social support, knew how to manage their stress, and interacted with all members of their family. One of the most essential ways that spouses or partners may help alleviate the stress that parents with ID children endure is by providing emotional support (Kazak & Marvin, 1984; Upadhyay & Havalappanavar, 2007). Poor intervention outcomes for children with ID are associated with high levels of parental stress, which is an indirect impact of that stress (Hastings & Beck, 2004). Research has shown that families dealing with high levels of stress have a better chance of successfully intervening in children with ID who exhibit challenging behaviors (Rhodes, 2003). This is because families dealing with high levels of stress may also have a lower quality of life overall. According to another research, family systems theory highlights how the family unit is both dynamic and interconnected, with the experiences of one person having the ability to impact the whole system. There are interdependent patterns of behavior and interactions among the many parts of this system, including parents, children, and the system itself. Research including both mothers and dads, or only men, has grown in number in recent years, while the majority of parenting literature has been undertaken with mothers.

3. Materials of the Study

Search terms related to parental stress and intellectually impaired children were used to conduct a systematic literature review in the following online databases: Psyc Info, Research Gate, Academia, and Google Scholar. With respect to the research topics and inclusion criteria, a total of twelve papers were ultimately located. Summarization, classification, and analysis were performed on the data gathered from these publications. To get a more complete picture of the issue, researchers used a mixed-methods strategy to examine the specific stresses experienced by parents of children with intellectual impairments. To gather information about the potential for stress, the Kindler's Personal Stress Assessment Inventory was used. Our stress assessment tool of choice is the "Family Interview for Stress and Coping in Mental Retardation" (FISC - MR) developed by Dr. Satish Girimaji. Based on socio-demographic Researchers used a data sheet and questionnaire to gather information on children's age, gender, education, parents' employment, income, and intellectual impairment level, among other particular sociodemographic and clinical characteristics. Research conducted by Singh, T. K., Indla, V., & Indla, R. R. (2008) provided the necessary data for examining the detrimental effects on parents. The Vineland Social Maturity Scale (VSMS) and the Developmental Screening Test (DST) were used to evaluate the IQ of MR youngsters. The study's participants were chosen from among the parents of children who met the inclusion and exclusion criteria and gave their informed permission. In a study by Aldosari, M. S., and Pufpaff, L. A. (2014), forty parent caregivers participated in focus groups. Four overarching themes were validated across sites after data was coded and evaluated via a deliberate process of data reduction. Researchers Resch et al. (2010) used one-on-one semi-structured interviews to learn about the caregiving experiences and expectations of parents from the second most populous city in Ghana, with a sample size of twenty. The parents' perspectives on their children's education with ID were explored through these interviews. In order to gather information on parents' financial resources, support network, and levels of stress in the parent and child domains, Meppelder, Hodes, Kef, and Schuengel (2015)created and distributed questionnaires. Professionals in the field of education and child care, respectively, reported on issues with student behavior and parental adaptive functioning. From 2014 to 2017, data was gathered from children who attended the service, as well as from clinicians

and parents using rating scales (Sturnton, E., Kehoe, C., & Sharkey, L., 2023). In a study conducted by Vilaseca, Rivero, Ferrer, and Bersabé (2020), the authors examined self-recorded videotapes of parents' behaviors. The behaviors were categorized into four areas: affection, responsiveness, encouragement, and teaching. The researchers used the PICCOLO, a validated Spanish version of the parenting assessment tool, to make their assessments. A sociodemographic survey was given to the parents. The findings showed that parenting styles of moms and dads were quite comparable. Primary data was used to gather information for the study (Shetty, L., & Menezes, S., 2013). The researcher conducted interviews according to prearranged timetables. The investigation made use of local languages, and samples were interviewed for around an hour. The study includes developmental kid evaluations, in-home rates of parenting, and interviews with both parents as well as selfassessments and ratings from each parent (Bristol, Gallagher, & Schopler, 1988).

4. Data Analysis of the Selected Studies

According to the results table that shows the percentages of probable high, medium, and low levels of stress, the majority of caregivers (49%) were at risk of having a medium level of stress based on the analysis of the first objective. Parents' stress levels were unrelated to age, religion, community, educational attainment, profession, monthly income, type, or location when family analyzing sociodemographic variables among those with intellectually impaired children. Find out whether there's a statistical difference in stress levels depending on various factors with the use of student's t-test and analysis of variance - single factor. A confidence level of 95% is used for all tests. There was a non-significant correlation between the parents' stress levels and several socioeconomic variables, according to their sociodemographic characteristics. We used a contextual, descriptive, exploratory, and qualitative research strategy. "What is it like to have an adolescent with intellectual disability?" was the central question. Data was gathered via in-depth interviews, field notes, and observations from eight parents who were selected at random. In order to analyze the data, an independent coder was contacted and theme coding was used.

5. Result of the Study

Emotional stress factors that contribute to parental stress include feelings of melancholy, anxiety, concern, despair, resentment, worthlessness, tension, playing the blame game, having bad wishes, and so on, according to a research on the specific difficulties of parental stress. The average score for emotional

stress is 9.43. When it comes to emotional stress, the standard deviation is 3.41. For parents, the thought of their child's care after death is the worst possible scenario. While 18% of respondents did not express any sadness over children's disabilities, 82% of those who took the survey stated they do. Concern about one's children causes stress for the majority of respondents (74%), but 26% did not recognize the reality. The majority of respondents (54%) said they did not supervise their children when they played with their neighbours, while almost half (46%) said Although 28% of respondents did. acknowledged that others had spotted them playing with their babies, 72% of respondents said they were unaware that anybody was watching. Nearly eightyone percent of parents said they are able to manage their child's behavior, while twenty-two percent said the opposite. Parents exhibited emotional reactions such as sadness, sorrow, anxiety, dread of death and the future, and a sense of neglect towards other family members, according to Ntshingila,

N., Myburgh, C. P., Poggenpoel, M., & Chauke, T. (2021). The couple's relationships improved, and they exhibited more patience, tolerance, empathy, and sensitivity as a result of having this kid (K., Indla, V., & Indla, R. R. 2008). Difficulty meeting additional responsibilities with physical care of the kid, health issues, job changes, loss of support from spouses, etc., accounted for 25.26 percent of the negative impacts in this research. Negative emotions such as "despair," "blaming each other," "comparing child with normal children," "marked disruption in parental job activities," "interpersonal relationships," and so on may occur, according to prior research on related themes. According to this research, "physical care and financial areas" are where parents' negative influences are most noticeable. "Relationship problems among the siblings," "social embarrassment of the family members," "negative impact on the health of caregivers," and other similar issues were identified in households with MR children in the current research. Having an MR kid is already difficult enough, and those issues may make it much worse. The parents of the adolescents in the study by Ntshingila, N., Myburgh, C. P., Poggenpoel, M., & Chauke, T. (2021) reported feeling distressed by the adolescents' violent and destructive behavior as well as their difficult management due to physical deformities. They faced financial limitations and substandard living conditions, which compounded the adolescent's weakness and made it harder to manage. Social stigma, rising prices for all goods and services, rising medical costs, emotional and occupational stress, and other factors all contribute to the perception that the unique kid is a financial and

logistical burden on the family (Shetty, L., & Menezes, S., 2013). When contrasted with a typically developing youngster, they thought that the child's removal significantly impacted their social standing. Because they are self-conscious about their child's condition, many of these parents avoid going to social events or interacting with friends and strangers. In a rural setting, 54.45% of the 6 respondents who took the survey felt uncomfortable going out in public with a disabled kid. In a semi-urban setting, 17 respondents (60.57%) reported difficulty going out for social contact or family leisure with a retarded kid, whereas 5 respondents (45.45%) in an urban setting reported the same thing. When contrasted with a typically developing youngster, they thought that the child's removal significantly impacted their social-standing.

Even in households where the mother works outside the home, research by Bristol, Gallagher, and Schopler (1988) found that men who had children with disabilities were less likely to take on the role of primary caregiver than fathers who did not have disabilities. The degree to which a father was involved in his impaired child's care decreased in correlation with the severity of the child's abnormal behaviors; this trend did not hold for the child's siblings. Parents' ability to provide emotional and practical assistance to their children, regardless of their son's disability, was shown to be the strongest indicator of parenting quality. Perceived and observed adaptability were negatively parental significantly predicted by a mismatch between present and "appropriate" spousal support. According to research by Hastings, Kovshoff, Ward, Espinosa, Brown, and Remington (2005), the idea of harmonic responsiveness was put up to clarify how one's support should be adjusted based on their spouse's perceived needs and expectations. Compared to dads, mothers reported higher rates of depression and more positive views of themselves. The results of the regression analysis showed that positive perceptions and paternal stress were both predicted by mother depression. On the other hand, children's behavioural issues (rather than adaptive behavior or autistic symptoms) and the partner's sadness were both predicted by maternal stress.

6. Discussion

The researcher is making an attempt to learn about the stress that parents of intellectually disabled children experience. Reviewing the many articles led to the conclusion that parents have an eternal obligation to care for and assist their children. The financial and emotional tolls of this commitment's duration were substantial. Many parents worry about their children's future, namely their capacity to be self-sufficient, to get the medical treatment they need, and to find stable job. One of the most stressful things is never knowing what the future holds. Daily activities including washing, clothing, eating, and toileting might be more challenging for children with intellectual impairments. Parents may emotionally and physically drained by this added burden of parenting. Therapy, special schooling, adapted equipment, medical care, and other associated costs may add up quickly while caring for a kid with intellectual impairment. To top it all off, many parents may be struggling financially to cover all of their children's extra expenses. Parents often have the difficult task of finding inexpensive and dependable respite care, which leaves them with few options for taking a break from caring. Stress and burnout were exacerbated by this lack of relief. Due to their child's disability, parents of intellectually disabled children may feel lonely and alone. Because no one else can relate to their specific struggles, they have a hard time making friends and joining in on social events. Fighting for a child's rights and the resources they need is a common and often difficult task for parents. It could be difficult and frustrating to figure out how to use the many systems for healthcare, schooling, and social assistance. Isolation and stress are common experiences for some parents of intellectually disabled children because they face criticism and stigma from others. Unfortunately, parents of children with intellectual impairments may already be dealing with a lot of stigma and misunderstanding. It may be emotionally taxing for parents to see their children struggle with things they can't control. They worry for their child's safety and suffer from emotions of sadness and guilt. Taking care of a kid with intellectual disability while also juggling other commitments may be a huge challenge for many parents. Anxiety and fatigue set in as a result of this juggling act. While many studies have looked at parents' experiences in general, very few have examined the particular difficulties encountered by parents whose children have certain medical issues or who fall anywhere on the spectrum of intellectual impairment. Parents experience stress and difficulties in the near term, but the long-term effects on their mental and physical health and quality of life are less extensively studied. So yet, no studies have examined the effects on siblings of children who have intellectual disability. There was a lack of documentation about the stress and specific difficulties experienced by siblings.

The researcher has made an attempt to learn how intellectually disabled children are affected by the detrimental effects of parental stress. Medical bills,

therapy, special education, and adapted equipment may add up quickly while caring for a kid with an intellectual impairment, according to the reviewed publications. There is tension and strife inside the family as a result of this financial hardship. It takes a lot of time to take care of a kid who has an intellectual handicap. Therapy, doctor's visits, and everyday caring take up a lot of time for parents, cutting into their time with their loved ones and the things they like. Caregiving for a kid with intellectual impairment may put a strain on marital relationships due to the additional stress and obligations. Difficulty communicating, spending quality time together, and resolving conflicts are all possible outcomes for couples. To care for an intellectually disabled kid, parents must either take time from work or cut down on their job hours. Because of this, there was a risk of financial instability and professional failures. Parental health suffers because of the physical and mental strains of caring for an intellectually disabled kid. Constant anxiety causes them to put off taking care of their own health, which may lead to neglect or even chronic illness. Everyday life and family interactions were upended by the arrival of a kid with intellectual handicap. The family adjusts to meet the child's specific requirements, and siblings step forward to help out. Because they are unable to provide their disabled kid a "normal" life or fulfil certain expectations, parents can feel anger or guilt, which they direct at their child or themselves. Parents sometimes find it extremely taxing to see their children battle intellectual challenges. Their emotional health takes a hit, and they may develop mood disorders or mental health problems as a result of feelings of sadness, shame, annoyance, and worry. Consequently, not a single research Even while studies on intellectual disabilities tend to center on the kid, little is known about the parents' viewpoints, experiences, needs, and welfare. The effects on grandparents, aunts, uncles, and cousins, as well as their responsibilities in offering support and understanding, may not have been well investigated, in contrast to the usual emphasis on close family members in study.

The study's author has made an attempt to learn how parents of intellectually disabled children experience stress differently. Results from a large number of papers' evaluations showed Social norms, long-established gender roles, and personal experiences all play a part in shaping how mothers and dads with intellectual impairments perceive and cope with stress. In terms of caregiving and parenting duties, society often holds mothers to higher standards. Mothers with intellectual impairments face additional stress from the expectation that they must perform

conventional duties as main caretakers. The stress that fathers feel could vary depending on their specific roles and duties within the family unit. For instance, the kinds of stress they face are impacted by the fact that they are more likely to be financially engaged or seen as secondary caretakers. Women who are mothers and have intellectual impairments face prejudice because of their gender and further stigma because of their parenting skills. Prevalent cultural views on women' responsibilities in child-rearing subject them to increased scrutiny and criticism. Social isolation affect both parents of an intellectually disabled child, however the causes of this isolation might vary. Caregiving obligations and a lack of social chances keep mothers alone, although dads may feel the same way as they don't take part in the same kinds of activities as their children. When it comes to child custody and the engagement of child protective services, parents with intellectual impairments encounter legal obstacles. Yet, fathers feel the effects of gender prejudice in the court system in a different way, which compromise their parenting rights. Parenthood shapes mothers' and dads' sense of self in distinct ways. While moms deal with the stress and expectations of being a "good mother," dads may experience similar things. There were not a plethora of studies specifically addressing this issue, but it is well acknowledged in the literature at large that women are often subjected to greater social expectations in relation to the care and parenting duties they are expected to do. Women who have intellectual impairments often experience additional stress due to these expectations, since they are expected to perform conventional duties as main caretakers. Concerning child custody and the role of child protective services, no research was carried out. The legal system's prejudice against men has diverse effects on dads and compromise their parenting rights.

7. Conclusion

The study on parental stress in children with intellectual disabilities has shown that, on average, parents of children with intellectual disabilities are more stressed out than parents of normally developing children. Several things contribute to this increased stress, such as the difficulties of caring for another person, financial difficulties, and emotional problems. The results show that parents face many different types of stress. External variables, such as social stigma, limited access to support resources, and challenges in navigating complicated healthcare and school systems, in addition to the child's impairment, contribute to these stresses. The study's findings highlight the major effect that stressed parents have on their families' ability to operate. When parents are

under a lot of stress, it may have a negative impact on their relationships with their children, their siblings, and even their marriages. Some of these detrimental consequences may be mitigated, according to the research, by the use of efficient coping mechanisms and robust support networks. Research from a number of studies provide light on helpful therapies and support systems for alleviating stress among parents. Interim care, psychoeducation, peer support groups, and referrals to specialist agencies are all examples of possible approaches. To find the best solutions for various families and cultural settings, further study is required. Finally, the study shows that parents in this group experience a lot of stress and difficulty. It shows that parental stress has a major influence on family dynamics, but it also suggests that there may be ways to help families and parents deal with stress better.

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