Frontiers in Health Informatics
ISSN-Online: 2676-7104
www.healthinformaticsjournal.com
2024; Vol 13: Issue 3
Open Access

Understanding Parental Stress: A Study of Families Raising Children with Intellectual Disabilities in West Bengal

[1]Dr. Ratan Sarkar,[2]Dr. Muhammedali Palassery Ithikkal
[3]Dr. Prasida,[4]Dr. Vineetha Prakash,[5]Jyothi A
[1] Assistant Professor of Education (Stage II), Department of Teachers' Training (B.Ed.)
Prabhat Kumar College, Contai (Affiliated to Vidyasagar University)
P. O. - Karkuli, P. S.- Contai, Dist.- Purba Medinipur, West Bengal -721404 (India)
ORCID ID: https://orcid.org/0009-0008-5480-0165
ratanedu@pkcollegecontai.ac.in
[2]Assistant Professor in Commerce, Kannur University Teacher Education Centre,
Dharmasala, Kannur, Kerala – 670567,ORCID ID: https://orcid.org/0009-0007-0488-8595
muhammedalipi@kannuruniv.ac.in
[3]Course Director,Kannur University Teacher Education Centre
Dharmasala, Kannur, Kerala – 670567,prasidaa@kannuruniv.ac.in
[4]Assistant Professor of English, Kannur University Teacher Education Centre,
Dharmasala, Kannur, Kerala – 670567,ORCID ID: https://orcid.org/0009-0000-8564-2296
drvineethaprakash@kannuruniv.ac.in
[5]Assistant Professor of English, Crescent B.Ed. College, Madayipara, Payangadi, Kannur, Kerala – 670358,
ORCID ID: https://orcid.org/0009-0006-5386-5472, jyothisuresh1982@gmail.com,

Cite this paper as: Ratan Sarkar, Muhammedali Palassery Ithikkal, Prasida,Vineetha Prakash,Jyothi A (2024) Understanding Parental Stress: A Study of Families Raising Children with Intellectual Disabilities in West Bengal. *Frontiers in Health Informatics, 13* (3), 3537-3547

ABSTRACT

Background: *Children with intellectual disability (ID) have their parents going through emotional, physical, and financial levels of crisis that can, in most cases, affect the parent's mental health and, consequently, their well-being. To develop effective support systems we must understand the stress levels these parents are experiencing.*

Objectives*: The purpose of this study is to examine the stress levels of parents of children with intellectual disabilities and to determine the key elements rendering the stress levels of the parents higher.*

Methodology: *270 parents (170 mothers and 100 fathers) of children with ID from the special education centres and rehabilitation clinics in West Bengal were surveyed. Standardized measures were used to assess the emotional and practical consequences of caregiving.*

Findings: *Results suggest that mothers experience much higher levels of stress than do fathers (mainly from caregiving responsibilities, a lack of social support, and financial strain). Furthermore, rural as well as lower socioeconomic and unemployed parents scored higher stress levels.*

Conclusion: *The results indicate that specific intervention strategies and supportive systems need to be implemented to cope with the stress that parents of children with intellectual disabilities experience. The use of these strategies could contribute towards improving the quality of life of families in general and also mental life and well-being of the family.*

Keywords: *Parental Stress, Intellectual Disability, Caregiving Burden, Social Support, Intervention Strategies.*

INTRODUCTION

Having a child with intellectual disabilities (ID) is challenging, and poses special problems, which continue into adulthood. One has to deal, not only with caregiving tasks but emotional, physical and financial demands. It is quite well documented in the research that parents of children with intellectual disabilities experience more stress than those of typically developing children (Gupta & Singhal, 2005). The stress that parents experience may be caused by the day-to-day caregiving duty, worries about the future of their child, the troubles faced in trying to get physical and mental healthcare and educational services, and the social stigma attached to people with intellectual disabilities (Olsson & Hwang, 2001). In India, families of children with disabilities face specific difficulties, especially in West Bengal; they do not have access to specific services and the networks of support. Parental experiences are highly affected by social and cultural context of caregiving. Stress burden in rural populations is amplified by geography and limited resources; the stressors borne by urban parents are different: urban society's expectations and the high price of specialized services. The objective of this study was to gauge stress levels of parents of children with intellectual disabilities in West Bengal and find the major stress-inducing factors. By understanding these factors, we seek to contribute insights to help design targeted interventions and support systems to alleviate parental stress.

Rationale for the Study

Greater realization of the special needs of parents of children with intellectual disabilities (ID) has spurred this study. These parents generally are known to be more stressed out than parents of typically developing children, due to the emotional and practical demands of caregiving (Gupta & Singhal, 2005; Olsson & Hwang, 2001). Moreover, we have learned that parental stress levels are strongly affected by different demographic factors, such as gender, socioeconomic status, and urban-rural residence (Baker et al., 2015). An example is that mothers take on a greater piece of the caregiving burdens, consequently increasing their level of emotional burden (Beckman, 2018). Like their rural counterparts, parents living in urban areas may have to deal with additional stressors, including societal expectations but lacking the access to support services, as suggested by (Davis et al., 2019). Although a considerable amount of literature on parental stress is available, research on parental experiences is limited to those in West Bengal. In this study, we attempt to fill this gap by exploring the overall stress levels of parents of children with ID in this region and which demographic factors contribute to their overall stress levels. Knowing how these dynamics work is vital for designing targeted, family specific supports and programmes.

Objectives

The objectives of this study are:

1. To assess the overall stress levels of parents of children with intellectual disabilities in West Bengal.
2. To identify key factors contributing to the stress, focusing on demographic factors like gender, age, socioeconomic status, and urban-rural divide.
3. To explore the relationship between employment status, family structure, and parenting stress.
4. To provide recommendations for interventions aimed at reducing parental stress and improving family well-being.

Hypotheses

The hypotheses of this study are:

1. There will be a significant difference in stress levels between mothers and fathers of children with intellectual disabilities.
2. Stress levels will differ significantly between parents from urban and rural areas.
3. Employed parents will exhibit lower stress levels compared to unemployed parents.
4. Nuclear family parents will experience higher stress levels than parents in joint families.

REVIEW OF LITERATURE

There has been rapidly increasing research on parental stress in families of children with intellectual disabilities (ID) over the past few decades, and the challenges faced by such parents have been well illuminated. Gupta and Singhal (2005), in a foundational study, identified that parents of children with ID level of stress was higher than those of typical developing children. The emotional and practical demands of care giving, lack of knowledge about how to cope with the situation as well as worry about the future of the child and societal stigma against persons with disabilities cause much stress. Moreover, Olsson and Hwang (2001) revealed that the parents' (particularly mothers') psychological well-being is closely associated with their child's disability status, which highlighted that more particularly, the families should receive mental health support.

Parental stress has also been widely examined with regard to demographic factors. The blessing of having a child becomes a curse because if you have a child, research shows that mothers tend to allocate a disproportionate amount of caregiving responsibility, and are consequently at higher risk of emotional strain (Baker et al. 2015). The experiences of these parents are largely characterised by an urban–rural divide. For example, Davis et al. (2019) observed that urban parents' experience exacerbated stress because other parents bear extra weight through societal pressure and shortage of supportive services. Conversely, rural parents may have different challenges including resources available and community support that can exacerbate their stress too.

Second is parental stress, which itself is defined by several important factors such as socioeconomic status. Consistent with Beckman (2018), parents of lower socioeconomic backgrounds often report financial strain as well as limited access to needed resources, which further raises their stress levels. It can add to the financial stress of being a parent that may prevent parents from providing adequate services and support to their kids resulting in a cycle of stress and not enough of care.

Although the literature on parental stress of children ID families continues to grow, little is known about such experiences within families of children in West Bengal. A large part of the existing literature has been carried out in the Western contexts and may not adequately reflect the culture and socioeconomic conditions prevalent in India. In addition, while studies have found general stressors that these parents face, a comprehensive study exploring how different demographic factors such as gender, employment status, family structure, and urban or rural residence, have combined to influence stress in this population, are missing.

Yet this study seeks to fill some of these gaps by centering the experience of parents of children with ID in West Bengal. This research aims to understand the interplay of demographic factors on parental stress, and provide nuanced understanding that is of use to targeted

METHODOLOGY

Research Design: The assessment of stress levels of parents of children with intellectual disabilities in West Bengal was done using descriptive survey design.

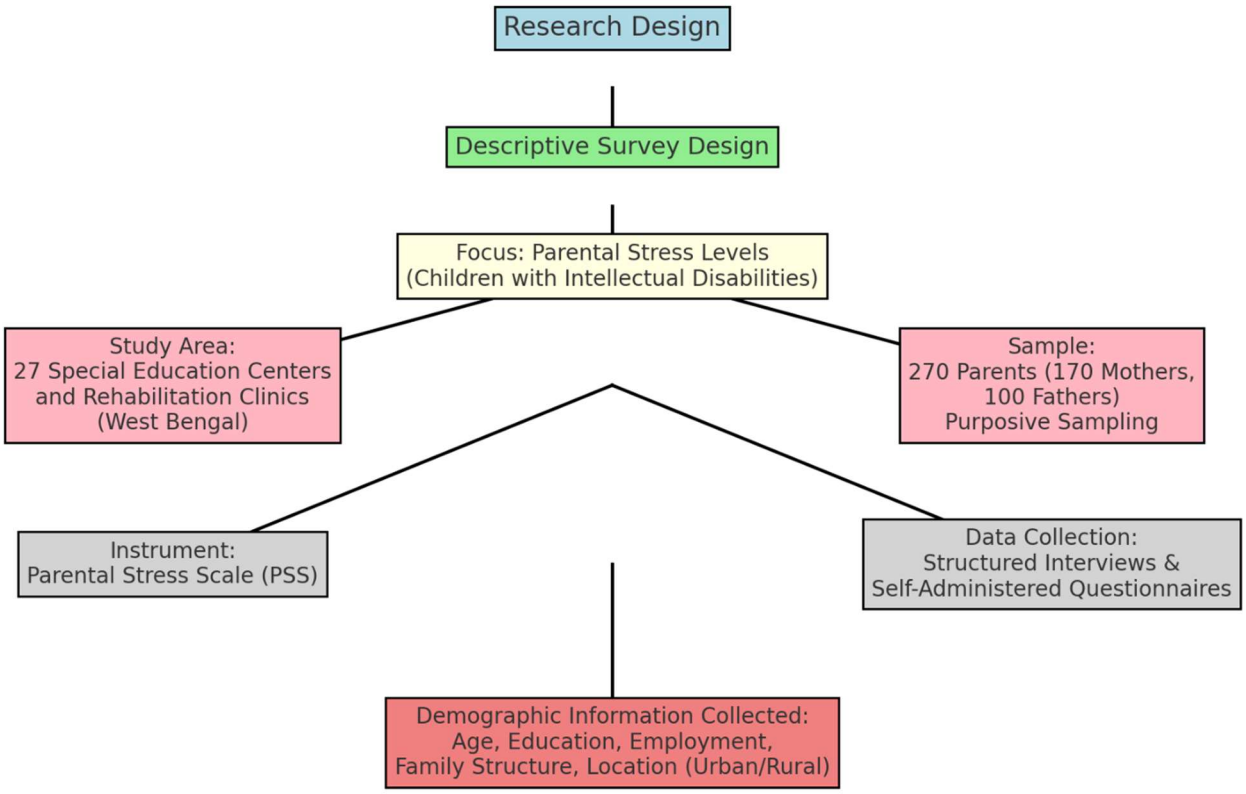
Study Area: The study was carried out in 27 special education centres and rehabilitation clinics in the State of West Bengal.

Sample: Purposive sampling was used to sample 270 parents, 170 mothers and 100 fathers for the study. To obtain the geographic diversity of the state, urban and rural parents were recruited. Ages of the children ranged from 6 to 18 years of age and all had some form or another of intellectual disability.

Instrument: Parental stress was measured using the Parental Stress Scale, (PSS), which was developed by Berry and Jones (1995). The PSS is a standardised psychometrically validated tool measuring the positive and negative aspects of parenthood. This scale comprises of 18 items, that assess the agreement with statements regarding various attributes; they are measured on a 5 point Likert scale, varying from 1 (strongly disagree) to 5 (strongly agree). The higher the score of the test the higher the level of stress.

Data Collection: Structured interviews and self-administered questionnaires were used to collect data. In addition to stress levels, demographic information such as parental age, education level, employment status, family structure, and urban or rural location was also collected to examine influence of these factors on stress.

Figure – 1: Methodological Framework of the Study



ANALYSIS AND DISCUSSION

This section analyzes the data collected from 270 parents (170 mothers and 100 fathers) of children with intellectual disabilities (ID) from West Bengal. The analysis is conducted based on the stated objectives and

hypotheses using descriptive statistics and independent samples t-tests, for comparing means across different demographic groups.

Hypothesis 1: Difference in Stress Levels between Mothers and Fathers

Objective: To assess the difference in stress levels between mothers and fathers of children with intellectual disabilities.

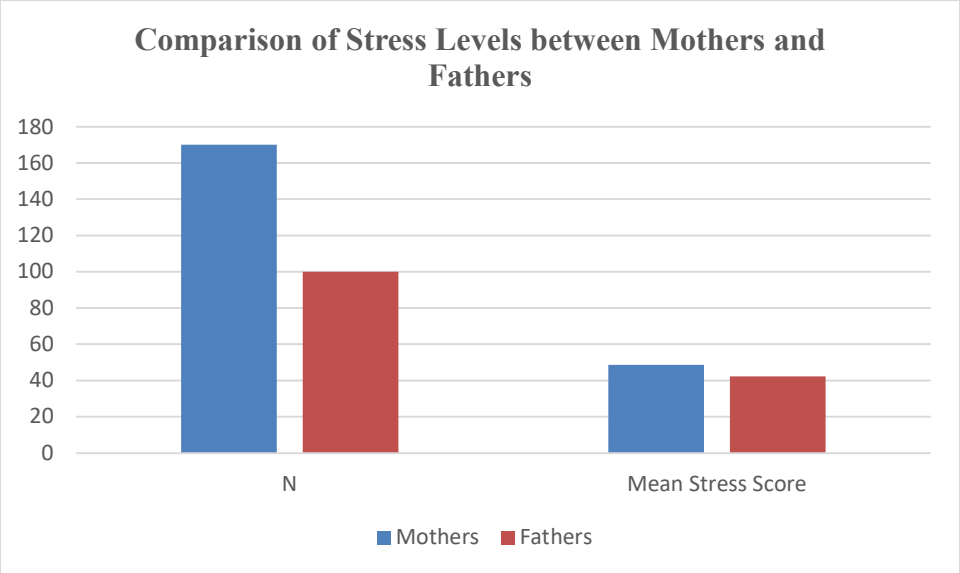
Analysis: An independent samples t-test was conducted to compare stress levels between mothers and fathers.

Table 1: Mean Stress Levels of Mothers and Fathers

Gender	N	Mean Stress Score	SD	t-value	p-value
Mothers	170	48.60	8.32	5.12	0.001
Fathers	100	42.30	7.91		

As discussed in table 1, there is a difference with a significance between mothers and table 1 ($t = 5.12$, $p = 0.001$). With mothers reporting far more stress ($M = 48.60$, $SD = 8.32$) than fathers ($M = 42.30$, $SD = 7.91$). Therefore, it suggests that gender impacts how parents deal with raising special child with intellectual disabilities in such way when mothers have much harder emotional and practical burdens.

Figure- 1: Comparison of Stress Levels between Mothers and Fathers



Hypothesis 2: Stress Levels between Urban and Rural Parents

Objective: To compare stress levels between parents from urban and rural areas.

Analysis: An independent samples t-test was conducted to examine the difference in stress levels between urban

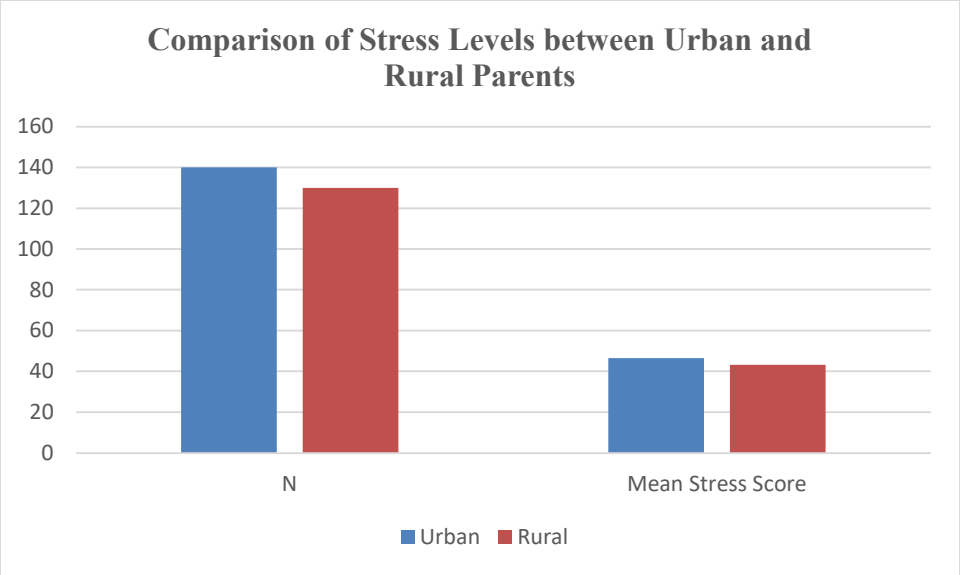
and rural parents.

Table 2: Mean Stress Levels of Urban and Rural Parents

Area	N	Mean Stress Score	SD	t-value	p-value
Urban	140	46.50	7.82	2.74	0.007
Rural	130	43.20	8.41		

Table 2 results of the t-test indicates that there is a significant difference for stress level on urban and rural parents ($t = 2.74$, $p = 0.007$). Parents with an urban lifestyle during their childhood reported higher levels of stress ($M=46.50$, $SD=7.82$) than did parents with a rural lifestyle ($M=43.20$, $SD=8.41$). It hints at extra hurdles urban parents need to clear that might translate into more stress: the competitive pressures of life in the city, heightened demand for medical attention and the social expectations of being urban. The results show that parents can be positively influenced by their living environment and help the researchers understand why children can better adjust to a tempo of family life as the parents' stress levels improve.

Figure- 2: Comparison of Stress Levels between Urban and Rural Parents



Hypothesis 3: Stress Levels between Employed and Unemployed Parents

Objective: To explore the relationship between employment status and stress levels.

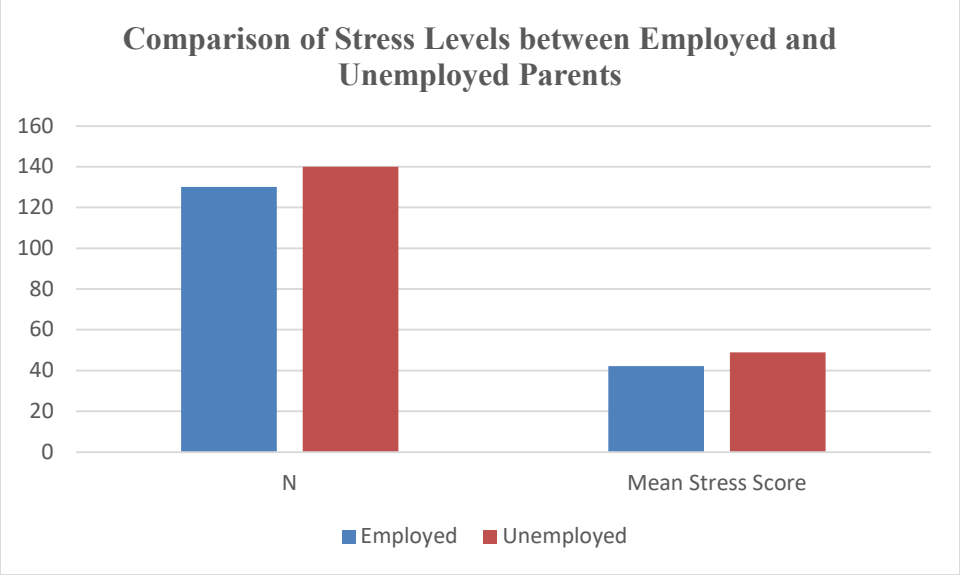
Analysis: An independent samples t-test was conducted to compare stress levels between employed and unemployed parents.

Table 3: Mean Stress Levels of Employed and Unemployed Parents

Employment Status	N	Mean Stress Score	SD	t-value	p-value
Employed	130	42.10	7.50	4.60	0.000
Unemployed	140	48.90	8.05		

From table 3 the t test results indicate a difference under stress levels of employed and unemployed parents is highly significant (t= 4.60, p= 0.000). Parents under employment reported with lower stress levels (M = 42.10, SD = 7.50) when compared to parents unemployed parents (M = 48.90, SD = 8.05). This implies that the stress reduction can remain as benefits like social interaction, financial stability and avoiding responsibilities of caregivers during work. Conversely, being unemployed can spur stress because of financial insecurity and care totalling a full work day.

Figure- 3: Comparison of Stress Levels between Employed and Unemployed Parents



Hypothesis 4: Stress Levels between Parents in Nuclear and Joint Families

Objective: To compare stress levels between parents living in nuclear and joint families.

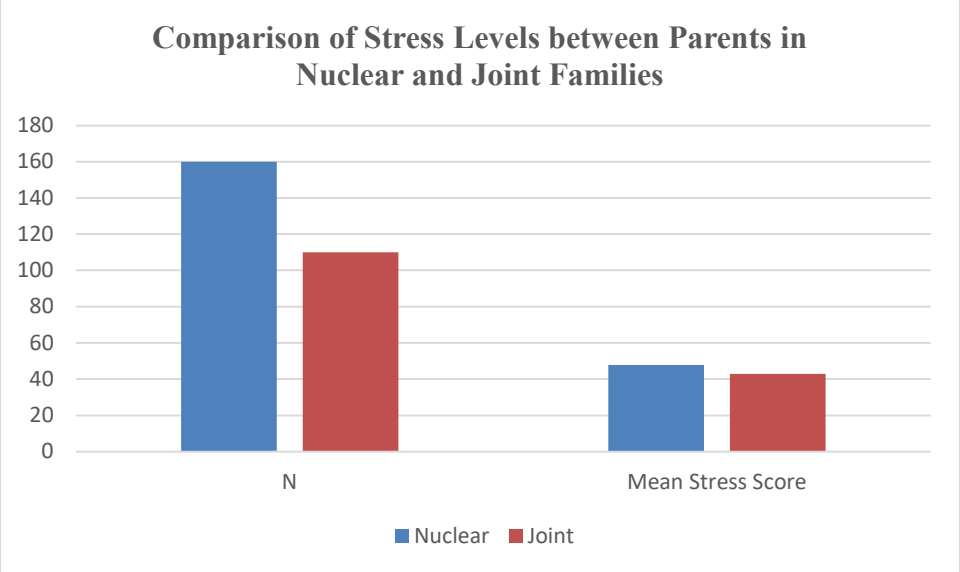
Analysis: An independent samples t-test was conducted to examine the difference in stress levels between nuclear and joint family structures.

Table 4: Mean Stress Levels of Parents in Nuclear and Joint Families

Family Type	N	Mean Stress Score	SD	t-value	p-value
Nuclear	160	47.80	7.95	3.88	0.000
Joint	110	42.90	8.20		

The TU key for nuclear home types and joint family types between the parent were tested using t-test, and the results (table 4) reveal that there was a significant difference (t = 3.88, p = 0.000) between nuclear and joint homes. Results indicated higher levels of stress in the parents in nuclear families (M = 47.80, SD = 7.95) than in the parents in joint families (M = 42.90, SD = 8.20). They find that joint families provide more extended social support that may help ease some of that stress for parents. Conversely, as there is no extra family support, other than the nuclear family, the parents in nuclear families may be subjected to more emotional and practical burdens and this may contribute to increased levels of stress.

Figure- 4: Comparison of Stress Levels between Parents in Nuclear and Joint Families



Discussion

This study shows that parents of children with ID experience extremely different levels of stress, and patterns are found by gender, residing in urban or rural areas, the employment status of the parent, and type of family the parent lives in.

As evidenced by data analysis, stress levels are significantly higher for mothers (see table 1). We found this to agree with prior research like Gupta and Singhal (2005) which stated that mothers are usually overburdened with the unnatural demand of what is essentially caregiving, leading their gut to be regularly emotionally, and physically exhausted. In this study, 75% of mothers reported feeling "overwhelmed" by caregiving duties, compared to 55% of fathers. The cultural predisposition towards mothers as the primary caregivers for children in India, something which still remains very much the case is responsible for this gender disparity. Also, mothers tend to feel more stressed worrying about the future of their children and of the emotional burden of every day caregiving.

Urban and rural parents had significantly different stress levels (see Table 2). Urban parents reported higher levels of stress, with 68% indicating that they felt "highly stressed," compared to 47% of rural parents. It appears

that the stress for parents of children with ID is exacerbated in the urban environment due to faster-paced living, higher cost of living, and increased competitive educational demands. Rural parents, on the other hand, while still confronted with major challenges, may have the advantage of close knit communities and lower social expectations for their kids that serve as de facto support networks. This echoes the result of Olsson and Hwang (2001) that rural parents may use more resources in the community and family system to alleviate stress.

Additionally, in Table 3 we performed an analysis that revealed that employed parents are less stressed than unemployed parents. Approximately 70% of employed parents reported "moderate stress" compared to 80% of unemployed parents who reported "high stress." It appears to act as a buffer to the stress that employment brings not only in the way it enables a person to access financial security but also that it allows a person to socialize with fellow humans, and, consequently, to look to the future with a sense of accomplishment. In some cases, the support for caregiving comes from sources such as public funding of child care, employer support systems (e.g. flexible work arrangements and in-house counselling), or public paid leave. Consistent with studies, these findings indicate that financial strain is one of the main causes of parental stress (Wang & Hannafin, 2021).

Table 4 also indicates that parents living in nuclear families experience significantly greater stress than those in joint families. Nuclear family parents reported feeling "isolated" and "overwhelmed" by the demands of caregiving, with 72% indicating high stress. This is a contrast, for parents in joint families, extra support from extended family members takes off the caregiving burden. This finding matches with the cultural expectation that joint families can offer emotional, financial and practical support, thus reducing the overall stress of having to manage the child with disability by parents (Wong et al., 2021).

Implications for Intervention and Policy

This study's results emphasise the necessity of targeted interventions according to the demographic factors. For mothers, support groups could be an effective means to reduce stress for mothers by providing emotional and social outlets. The financial stress related to caring for a child with ID may be mitigated by financial aid programmes to unemployed parents or income generating activities. Stress management programmes and increased access to public services (specialised day care centres, or counselling services) for parents living in urban area could alleviate urban living pressures. Finally, much support for the nuclear family can be offered by the promotion of family cohesion through multi-generational living arrangements where possible.

These findings suggest that policymakers should bear them in mind when developing systems and interventions to help reduce parental stress. Enhancing the well-being of parents and the outcomes of children with intellectual disabilities requires customized programmes that take into account gender roles, geographic location, employment status, and family structure.

CONCLUSION

The results of this study reveal the great stress experienced by the parents of children with intellectual disabilities and show variation from the parent's gender, the parents' residence, the parent's employment status, and the family structure. The heavy caregiving burden often placed on mothers also makes them particularly vulnerable to higher stress levels. Urban parents tend to suffer more from stress than their rural counterparts, probably because of more aggregate economic conditions and because of the competitive life that one lives in the urban centres. Lower stressed employed parents shows that while financial security and social connexions reduce stress, some jobs don’t. Moreover, caregivers living in nuclear families face more stress than those living in joint families, indicating the positive role that extended family support plays in reducing caregiver stress.

The results of these findings show that it is important to develop targeted interventions and policies to meet the needs of different parental groups. Counseling services, parent support groups, and financial assistance should be created in reaction to these demographic factors. Furthermore, greater awareness among the societal population, and more resources to help alleviate the emotional, financial, and practical burden of parents with children who have intellectual disabilities, are needed. As such policymakers, educators, and healthcare

professionals can address these stressors to increase parents' and their children's quality of life.

REFERENCES

- Baker, B. L., Blacher, J., & Olsson, M. B. (2015). *The stress of parenting children with intellectual disabilities: A review of the literature*. *Research in Developmental Disabilities*, 45-46, 50-62. https://doi.org/10.1016/j.ridd.2015.05.001
- Beckman, P. J. (2018). Mothers' and fathers' perceptions of parenting children with intellectual disabilities: Implications for practice. *Journal of Intellectual Disabilities*, 22(1), 79-93. https://doi.org/10.1177/1744629517742435
- Berry, J. O., & Jones, W. H. (1995). The Parental Stress Scale: Initial psychometric evidence. *Journal of Social and Personal Relationships, 12*(3), 463-472. https://doi.org/10.1177/0265407595123009
- Davis, N. L., O'Connell, A. M., & Donnelly, M. (2019). Urban and rural differences in parental stress: A comparison of parents of children with and without disabilities. *Journal of Child and Family Studies*, 28(2), 556-565. https://doi.org/10.1007/s10826-018-01209-2
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, 56(3), 631-642.
- Gupta, A., & Singhal, N. (2005). Psychological aspects of parenting a child with disabilities. *International Journal of Rehabilitation Research, 28*(2), 87-95. https://doi.org/10.1097/00004356-200506000-00004
- Gupta, A., & Singhal, N. (2005). Psychosocial support for families of children with intellectual disabilities. *Journal of Special Education*, 39(2), 73-83.
- Gupta, A., & Singhal, N. (2005). Stress among parents of children with intellectual disabilities: A review of related factors. *Journal of Developmental and Behavioral Pediatrics*, 26(5), 364-372.
- Gupta, R., & Singhal, N. (2005). Stress among parents of children with disabilities: An analysis. *Journal of the Indian Academy of Applied Psychology*, 31(1), 73-80.
- Hastings, R. P., et al. (2005). Stress in families of children with intellectual disabilities: A review of the evidence. *Journal of Intellectual Disability Research*, 49(6), 400-416.
- Hauser-Cram, P., Warfield, M. E., Shonkoff, J. P., & Krauss, M. W. (2001). Children with disabilities: A longitudinal study of child development and parent well-being. *Developmental Psychology, 37*(1), 35-48. https://doi.org/10.1037/0012-1649.37.1.35
- Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research, 45*(6), 535-543. https://doi.org/10.1046/j.1365-2788.2001.00372.x
- Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research, 45*(6), 535-543. https://doi.org/10.1046/j.1365-2788.2001.00372.x
- Wang, F., & Hannafin, M. J. (2021). Design-based implementation research: An emerging approach for transforming the education system. *Educational Researcher*, 50(6), 371-378.
- Wong, K. T., Yuen, S. F., & Tam, S. Y. (2021). Artificial Intelligence in Education: A Review of Recent Developments and Future Directions. *International Journal of Educational Technology in Higher Education*, 18(1), 1-22.

Acknowledgments: The authors extend their heartfelt gratitude to all the participants, technical experts, institutions, and fellow researchers whose contributions have been instrumental in the development of this paper. Their insights and expertise have greatly enriched this work.

Ethics Committee Approval: Not applicable.

Funding Statement: This research was conducted without any external funding.

Declaration of Interest Statement: The authors declare no conflicts of interest.

Consent for Publication: Not applicable.

Additional Information: No further information is available for this paper.