



A Theoretical Discourse on Experiences of Parents having Children with Developmental Disability.

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ABSTRACT:

This paper is a review paper. In this paper various studies have been analyzed carried out by various scholars in different parts of the world. As developmental disability is major health issue throughout globe. Keeping in view this review paper has been written in order to understand the problems families face having children with developmental disability. This paper shall highlight various aspects of families pertaining to the parenting stress, depression, anxiety and family burden. Further the paper shall discuss the experiences of parents with respect to child rearing, financial problem, social relations and also the methods parents adopt in order to deal with this problem.

Key words: *Developmental disability, Stress, Parents, economic conditions*

I.INTRODUCTION:

Brown and Patel. (2005) defined developmental disability as a term used to describe lifelong disability attributable to mental or physical or combination of mental and physical impairments. According to Development Disabilities Services and Facilities Construction Act, (1970) people with developmental disabilities have problems with major life activities such as, language, mobility, learning, self-help, independent living etc. Developmental disabilities usually appear clinically before 18 years of age. The limitation of physiological or mental function usually persists through life. Developmental disability is a cognitive, emotional, or physical impairment, especially one related to abnormal sensory or motor development that appears in infancy or childhood and involves a failure or delay in progressing through the normal developmental stages of childhood.

II.FAMILY EXPERIENCE

The burden of caring for children with Down syndrome has been reported to contribute to maternal stress, and the parental function can be affected due to stress and pessimism about the future. While it cannot be disputed that the arrival of a child with a disability results in some distress for most family members, it may be argued that families also have the capacity to make the necessary adjustments and accommodations which are necessary to keep the family functional (**khan, et al, 2018**). Several studies have found that parents of children with chronic disease or disabilities have higher stress scores than parents of normal children. Mash and Johnson,



(1983) studied the parental perceptions of child behavior, parenting self-esteem and mothers reported stress of younger and older hyperactive and normal children. Forty families with hyperactive children and fifty one families with normal children participated in the study. Hyperactivity rating scale, child behavior checklist, parenting sense of competence scale, and parenting stress index were the instruments used for the data collection. Results indicated that parenting self esteem was lower in parents of hyperactive children than in parents of normal children. Mothers of hyperactive children especially younger hyperactive children reported markedly higher level of stress. Inverse relation was found between parental self-esteem and perceptions of child problems, whereas rating of child disturbance and maternal stress were positively correlated. Kazak, (1987) compared mothers and fathers of children with handicapped (n=125) and parents of non disabled children (n=127) from three separate sample on personal stress, marital satisfaction, and social network size and density. Parents of disabled children experienced higher levels of stress in comparison to parents of non disabled children. No difference was found in marital satisfaction. Few group differences were found for social network variables, although mothers of handicapped children had higher density of networks in comparison to mothers of non disabled children.

III.MOTHER'S PERCEPTION

Beckman (1991) compared parental stress of 54 mothers and fathers of children with disabilities with the parental stressors of equal number of mothers and fathers of normal children. Mothers generally reported more stress in parent domain than fathers but both parents experienced high level of stress in child domain. Parents of disabled children reported greater amount of parenting stress than parents of normal children in the child and parent domain of parenting stress inventory. Virtanen, Moilanen, and Inhalainen, (1991) examined causes of stress for mothers of 6-9 years-old-children (n=42) with minimal brain dysfunction (MBD) (hyperkinesia, perceptual or motor deficits, learning disabilities or speech disorder) and among mothers of non-disabled children (n=42) matched for age, sex, social status of the family and marital status. Results indicated that the mothers of children with minimal brain dysfunction experienced more parenting stress than matched controls. The mothers of children with hyperkinesia and perceptual or motor deficits considered their mastery lower and experienced less positive affects than their matched controls. The mothers of children with speech disorder experienced less positive affects than their matched controls. Mothers of children with both few and several symptoms experienced more parenting difficulties in the child domain, and more negative cognitive appraisals of their stakes in parenting than mothers of normal children. Meadow-Orlans, (1995) studied mothers and fathers of 20 deaf or hard-of-hearing and 20 hearing-9-month-old infants. Parents completed the parenting stress inventory and questionnaire tapping the stress of life events (SLE). Results indicated that the overall scores on the PSI were quite similar but sub- scale scores show that mothers were more likely than fathers to perceive their infants were distractible and reported more negative spousal relationships. Mothers whose infants are deaf/ hearing hard reported greater life stress compared to mothers of normal hearing infants, especially in relation to finances and work.



IV. PARENTAL STRESS AND SOCIAL SUPPORT

Dyson, (1997) examined parental stress, family functioning and social support in parents of children with developmental disabilities (n= 30) and parents of children with non disabled children (n= 32). Family scale indicated that father and mothers of children with developmental disabilities did not differ from each other. Parents of children with disability experienced a disproportionately greater level of stress relating to their children than parents of children without disability. Fathers' and mothers' stress was associated with aspects of family functioning as perceived by themselves and their spouses. Lenhart divides developmental disabilities into the following four categories: (a) cognitive impairments (e.g., communication disorders; learning disorders like dyslexia, dyscalcula, and attention-deficit hyperactivity disorder [ADHD]; and mental retardation), (b) sensory (e.g., blindness and deafness) and other physical impairments (e.g., mobility and motor skills), (c) genetic disorders (e.g., Down syndrome, fragile-X syndrome, and Phenylketonuria [PKU]), and (d) neurological disorders (e.g., autism, cerebral palsy, and epilepsy). These categories are not mutually exclusive; for instance, PKU (a genetic disorder characterized by hyperactivity and mental retardation) would be considered both a cognitive impairment and a genetic disorder.

Following these widespread reactions, parents usually grieve for their child—the shattering of dreams, possibilities, and potentials (Martin & Colbert, 1997). This painful process of loss often results in an emotional roller coaster where feelings of anger, depression, denial, grief, guilt, physical distress, resentment, and sadness are not uncommon (Gabel et al., 1983; Martin & Colbert, 1997; McCubbin et al., 1982). Although accepting the impairment(s) faced by their children typically becomes easier with time, the emergence of new challenges, incongruities between child achievement and parent expectations, and unmet developmental milestones (e.g., walking, talking, dating, launching, marriage, etc.) often bring renewed feelings of grief and sadness throughout the life cycle (Wikler, 1981). The characteristics of the child with disabilities can drastically increase the stresses associated with caregiving. Challenging child behaviors (e.g., biting, hitting, getting into cupboards and refrigerators, running away, self-stimulation such as poking eyes, head banging, picking nails off), can be a major source of stress to parents and a powerful predictor of out-of-home placement (Kobe et al., 1991). Consequently, children with multiple disabilities are apt to have more special needs, be the source of more parentally-perceived stresses, and are similarly the most likely to be placed. In fact, the vast majority of children with developmental disabilities in out-of-home care are those who have been diagnosed as having severe or profound developmental disabilities (Blacher, 1994).

V. CONCLUSION

After analysis the literature deeply, it has come forth that developmental disability is a serious health issue particularly for those parents who are economically low. This does not mean that rich families having children with developmental disability does not experience any problem. The paper has further revealed that parents face a lot of stress, anxiety and depression due to their child's problem. Health problem of children also affects the social life of parents too, as they have to spend a lot of time with their children. Lifelong health problem makes parents more worried and most of the times due to this problem remain alienated from their relatives and wider society too. Many of the stresses faced by parents of children with developmental disabilities result from their



child's disabilities. Such child-related parental stresses include: (a) initial diagnosis; (b) identities and roles; (c) caregiving; (d) level of disability; (e) availability of, and access to, necessary services; (f) education; (g) financial stresses; (h) decisions about guardianship; and (i) family functioning and relationships.

REFERENCES:

- [1.] Mash, E.J. and Johnston, C. (1983). Parental perception of child behavior problems parenting Self-Esteem and mothers reported stress in younger and older, Hyperactive and normal children. *Journal of Consulting and Clinical Psychology*, 51, 86-99.
- [2.] Kazak. A.E. (1987). Families with disabled children: stress and social networks in three samples. *Journal on Abnormal Child Psychological*, 15, 137-46.
- [3.] Beckman, P.J. (1991). Comparison of mothers and fathers perceptions of the effect of young children with and without disabilities. *American Journal on /MentalRetardation*, 95, 585-95.
- [4.] Virtanen, T.A., Moilanen, J.K. and Ihatainen, M.M. (1991). What causes stress for mothers of children with MBD. *Scand Journal on Soc Medical*, 19, 47-52.
- [5.] Meadow-Orlans, K. P. (1995). Sources of stress for mothers and fathers of deaf and dumb and hard hearing infants. *American Ann Deaf*, 140, 352-7.
- [6.] Dyson, L.L. (1997). Fathers and mothers of school- age children with developmental disabilities: Parental stress, family functioning, and social support. *AmericanJournal on Mental Retardation*, 102, 267-79.
- [7.] Lenhart, S. W. (2000). Protecting workers with developmental disabilities [Electronic version]. *Applied Occupational and Environmental Hygiene*, 12, 171-181
- [8.] Martin, C. A., & Colbert, K. K., (1997). Parenting children with special needs. In *Parenting: A life span perspective* (pp. 257-281). New York: McGraw-Hill.
- [9.] McCubbin, H. I., Cauble, A. E., & Patterson, J. M. (1982). *Family stress, coping, and social support*. Springfield, IL: Charles C. Thomas.
- [10.] Wikler, L. (1981). Chronic stresses of families of mentally retarded children. *Family Relations*, 30, 281-288.
- [11.] Blacher, J. (1984). A dynamic perspective on the impact of a severely handicapped child on the family. In J. Blacher (Ed.), *Severely handicapped young children and their families: Research in review* (pp. 3-50). Orlando, FL: Academic Press.
- [12.] Kobe, F. H., Rojahn, J., & Schroeder, S. R. (1991). Predictors of urgency of out-of-home placement needs. *Mental Retardation*, 29, 323-328.
- [13.] Brown, K.A. and Patel, D.R. (2005). Complementary and alternative medicine in developmental disability. *Indian Journal on Pediatric Nox*, 72,949-52.
- [14.] Developmental Disabilities Services and Facilities Construction Act. (1970). *P.L.91-517*.
- [15.] Khan1. B.A; Zargar. W.A; Najar. S.A. (2018). Negotiating Future Uncertainty: Concerns of Mothers of Children with Down Syndrome in Kashmir, India. *Disability, CBR & Inclusive Development*, Vol. 29, No.1, 2018; doi 10.5463/DCID.v29i1.703