Chapter 5

The Stress and Adjustment in the Family of Intellectually Disabled Children

Babita Prusty
Amity University, India

ABSTRACT

ABSTRACT Intellectual disability is a disorder, in which children exhibit intellectual insufficiency as well as inadequate adaptive skills, in conceptual, social, and practical domains, manifested during developmental period. The wellbeing, coping and overall adjustment of parents, siblings and other family members of children with intellectual disabilities is worth studying not only because of understanding of the children suffering from disability but also because of helping, reducing burden and enhancing a healthy physical and mental life of the family members. Research suggests that parents of children with typical development, but their mental health in general might be complicated as well. Certain therapeutic techniques like Psychodynamic therapy, family therapy and behavioral therapies could be used for helping such families.

INTRODUCTION: A PERSPECTIVE OF FAMILY

A View about Parents

When a member of a family becomes seriously sick, it is said the whole family becomes sick. It is the pivotal point of this chapter to explore the consequences of intellectual disability in the context of family. The role of parents and the role of siblings are of prime importance in such a family as a primary caregiver. Even though the pediatrician, psychologist, nurse, psychiatrist, special educator, and other necessary community agents have a very essential role in the management of intellectual disability, the role of family is of utmost importance irrespective of the nature of disabilities. Research suggest that parents of children with disability not only experience higher levels of stress compared to families of children with typical development, but their mental health in general might be complicated as well. Parents may

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experience depression, anxiety (Beckman 1991; Dyson 1991; Emerson 2003; Bristol & Schopher 1984; Hoppes 1990), higher levels of hopelessness, failure, guilt (Jones 1997; Powers 1989; Tommasone & Tommasone 1989), they report less parental skills and less marital satisfaction (Rodrique et al., 1990).

Parents’ psychological well-being is of prime importance. Research emphasized on intervention programs to reduce in parental stress (Davis, 1985; Schilling & Schinke 1984), because high levels of parental stress may have a negative impact on the functioning of the child with disability. Parents may behave ways that have a negative impact on children (Hastings 2002). Studies suggest that parents who experience higher levels of stress interact differently with their children, compared to parents who experience lower levels of stress, and they respond differently to their child’s problematic behavior (Conger, R., Patterson, G.R., & Ge, X., 1995). According to Floyd & Phillipe (1993) self-reported depression from parents was a strong predictor for their efforts to manage actively and successfully their child’s problematic behaviors. The child with intellectual disabilities is not the only one who affects his family’s life and dynamics. The family also affects positively or negatively the child’s development. Research suggests that higher levels of parental stress predict less positive outcomes from the early intervention programs for children with disabilities (Brinker, R. P., Seifer, R, & Smeroff, A. J. 1994), whereas early interventions for children with disabilities are more successful when family problems, parental stress included, are addressed before the intervention program begins. Thus knowing and dealing with parental stress is important for professionals. At last, not only it seems that parental stress interferes with success of intervention programs for children with developmental disabilities. (Robbin et al 1991; Brinker et al 1994), but parents as well, while experiencing high levels of stress, have less positive outcomes from intervention programs designed to improve parental skills (Rhodes 2003; Baker et al 2002).

A View about Siblings

Although there are many positive outcomes of growing up with a sibling having a psychological or behavioral disorder, typical siblings can potentially experience harmful effects of managing and coping with the special demands and stresses of having a sibling with these kinds of difficulties. In order to better understand families, researchers have shown an increasing interest in investigating sibling relationships. Relationships between siblings can be life’s most influential and longest lasting relationships.

Understanding Intellectual Disabilities

Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains. These domains determine how well an individual copes with everyday task. These domains are mentioned below. (American Psychiatric Association, 2013).

- **Conceptual Domain:** It includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- **Social Domain:** It includes empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- **Practical Domain:** It revolves around self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.