



Impact Of Intellectually Disabled Children On Parent's Marital Relationship

Sahiba Chahal

Research Scholar

Department of Sociology

Panjab University, Chandigarh, India

Abstract: The birth of a child is the most anticipated event in a parent's life, but this experience can get tainted upon the discovery of the child suffering from a disability. Parents raising children with intellectual disabilities face unique, lifelong challenges, often more pronounced than other disabilities, impacting various aspects of their lives, especially their marital relationships. This paper explores the challenges encountered by the parents in their married lives. Drawing from existing literature, it highlights the problems faced and coping strategies used by the parents to manage the difficulties associated with caring for an intellectually disabled child. Thus, aiming to help both, the child as well as parents to leading fulfilling lives.

Index Terms – Intellectual disability, families, marital relationship, parents of intellectually disabled, couples, marital adjustment

INTRODUCTION

The birth of a child is the most joyful and gratifying event in a couple's life. Every parent has their own set of hopes and dreams for their child. It is well-known that a child brings with it significant adjustments in the emotional, psychological, physical, economical, interpersonal, as well as social state of the parents. Parents are said to be the child's first role model and parenting is a privileged duty of both; the father and the mother together to prepare the child for the society. According to Floyd and Kenta (1993), while it is the parents that have an effect on socialisation, development as well as the overall well-being of their children, the children consequently exerts similar influence on their parents' well-being (as cited in Shukla,2017). However, factors such as genetics, complications during delivery, brain injury and many others, have the tendency to impact the child's normal development, which may lead to instances of abnormal cognitive behaviour, physical and psychological issues as well as socio-emotional problems. These issues cannot only be debilitating but also have lifelong impact on the child's development.

While the birth of a child is a highly awaited experience, the birth of a special child can come as a huge shock to the parents and have distressing effects on their physical, emotional, interpersonal, familial and social relationships. It also affects their parenting attitude as well as skills, that in return impacts the child's social, psychological, personality and other key areas of development. There is a common saying that when one member of the family falls ill, the well-being of the entire family gets affected. The same is true for parents raising Intellectually Disabled children. Not only does Intellectual disability have a significant impact on the child but it also has a major influence on the parent's lives. Parents raising such children often experience a range of emotions and deal with feelings of guilt, anxiety, depression, hopelessness, failure, trauma, stress, and anger, just to name a few. It is also common for these parents to communicate lack of confidence in their parenting skills as well as possible consequences for their overall marital happiness. Therefore, Akkoh (2000) and Okeke (2001) were of the opinion that parents raising children with disabilities require help from family and community members, healthcare workers, counselors, philanthropists as well as the government in order

to provide the proper required care to their child.

Taanila, Kokkonen and Jarvelin (1996) were of the opinion that the birth of an Intellectual Disabled child requires the family, especially the parents, to adjust to a new routine and lifestyle, which might affect their family life and increase the risk of strain on their marital relationships. These strains may even result in failed marriages. Therefore, the purpose of the article is to highlight the impact of intellectually disabled children on the parent's marital relationship.

I. UNDERSTANDING INTELLECTUAL DISABILITY

Disability is a natural aspect of life that happens to almost everyone at some stage in their life, whether for a short period or permanently. It is an inherent part of being human. According to the World Health Organisation (WHO), an estimated 1.3 billion people (nearly 16% of the population worldwide) - are currently living with significant disability. This includes 720 million adults and 93 million children. It is a global public health issue, affecting 1 in every 6 people across the globe and these numbers only said to increase (WHO,2023).

Intellectual disability, previously known as mental retardation, refers to neuro developmental deficits that are characterised by limitations in intellectual functioning and adaptive behaviour. It usually originates at birth and can manifest during the developmental period or before the age of 22. These disabilities can also be associated with a number of other conditions including neurodevelopmental conditions such as autism & ADHD, neurological conditions such as cerebral palsy, mental health such as anxiety & depression and medical conditions such as meningitis (Lee, Cascella & Marwaha,2023). Often also referred to as developmental or cognitive disabilities, Intellectual disability, impacts various aspects of an individual's life, including self-care, social skills and communication. 'Intellectual functioning' is typically known as intelligence, and includes a broad range of mental activities, including skills such as problem-solving, logical reasoning, ability to learn, verbal skills and so on. While 'adaptive behaviour' includes one's everyday conceptual (understanding, finance, time and language), social (interpersonal skills, following society's rules and laws and practical skills) and practical skills (interaction with others, carrying out daily activities).

The spectrum of Intellectual disability can range from mild to profound with varying degrees of impairment. While numerous causes for Intellectual Disability are still unknown, known causes include genetic abnormalities, chromosomal anomalies, single gene mutation, fetal alcohol syndrome, maternal exposure to toxins or infections, complications during delivery, premature births, miscarriages, postnatal, trauma, or other environmental factors. (Kumar & Lal,2024). Report put together in 2011 by the WHO and World Bank estimated that out of the world's total disabled population, approximately 1 to 3% are estimated to have an intellectual disability. Its prevalence in developing countries is evaluated to range from 10 to 15 per 1000 children, of which 85% are said to have mild intellectual disability (Maulik, Mascarenhas, Mathers, Dua & Saxena,2011). However, these figures are challenging to calculate accurately due to under reporting, lack of awareness, stigma, or differences in reporting standards. Whatever the case, Intellectual Disability is a lifelong condition and children suffering from this disability remain under the constant care of the parents well into their adulthood and beyond, given their limited caregiving and adaptive living skills (Glidden, Floyd, Hastings & Mailick 2021). Thus, even as adults these individuals with intellectual disabilities might continue to not only be impacted by the ongoing family dynamics and marital processes at home, as the parents remain important resources and influences in their lives (Conovar,2023). They may also exert considerably equal (if not more) impact on the same family and marital dynamics of their parents as well.

II. MARITAL CHALLENGES FACED BY PARENTS

Fortin, Lachance, Cournoyer, Lamirande-Landry, McKinnon and Richer (2024) in their study pointed out that parenting stress is a widespread issue. The birth of even a normal child brings with it, its own set of challenges and requires adjustment and adaptation, especially by the parents (Saxbe, Rossin-Slater & Goldenberg,2018) and when the child is intellectually disabled these challenges and burdens become even greater (Springer, Turns & Masterson,2018). According to Turnbull and Turnbull (2002) burdens may include stresses regarding expenditure on childcare, psychosocial costs, constant questioning regarding the child's disability, etc. that might have an impact on the parents' relationship (as cited in Seligman & Darling, 2007).

As per Belsky (1984) the quality of a parent's marital relationship has the ability to exert major influence on the child's adjustment levels and overall well-being in the family, considering that their relationship is the heart of family functioning. According to scholars such as Amato (2006) and Parker et al. (2019), while marital discord and distress can significantly chip away effective parenting and consequently, the development of the child; parents having a loving, supportive and positive relationship, that work together efficaciously as co-parents are better able to provide for the demands of their children, disabled or otherwise. As a key part of their children's lives, the marital quality of the spouse's relationships is particularly crucial for children who are especially vulnerable, powerless and needing exceptional parenting, such as children suffering from intellectual disabilities (Kijak,2021).

A meta-analysis conducted by Risdal and Singer (2004) found that parents with disabled children tend to exhibit comparatively more negative marital adjustment as compared to parents, raising normal healthy children, in terms of marital satisfaction and rates of divorce. The stress experienced in the spouse's relationship, due to the child developmental obstacles is often the result of complications, because of strong and contradictory emotions, that might arise within each partner that needs to be faced (Powers,2001), difference in opinions on created situations (Sicile-Kira,2004), as a consequence of parenting a child with special needs. Several researchers in their studies have concluded that marital relationships undergo various stresses as a result of issues brought about by the child's disability (Hauser-Cram, Warfield, Shonkoff & Krauss,2001; Higgins, Bailey & Pearce,2005). Parents frequently undergo higher levels of stress with regards to emotional, physical, financial and marital aspects (Higgins et al.,2005). Marital stress, changes in family functioning as well as economic difficulties or some of the stresses associated with intellectually disabled child problems (Hauser-Cram et al.,2001).

Sadiki (2024) in her study regarding the marital adjustment of parents taking care of children with special needs observed that as a result of fathers working longer hours and mothers constant ongoing involvement with the child, the couple reported having less time for each other, causing issues in spending quality time as a couple. Similar results were confirmed by other studies including that of Hutton and Caron (2005) and Chawarska, Klin, Paul, Macari and Volkmar, (2008). Antwi (2023) during his research noted that women in particular became physically exhausted and fatigued, while continuously caring for their child with disability. Since looking after such children demands a lot of time and energy from the parents, it is usually the mothers that take on this time-consuming, care-giving responsibilities, leaving little to no time for their own self-care. Majority of the interviewed parents professed that their caregiving responsibilities left them with little free time and on numerous occasions prevented them from participating in social activities. Families bringing up children with Intellectual Disabilities frequently reported isolating themselves, thus, unlikely to have an active social life. Studies by Witt, Riley and Coiro (2003) and Kahriman and Bayat (2008) indicated that stress caused due to this lack of socialisation of the families and particularly the parents contributed towards increased marital problems (Balci, Kizil, Savaser, Dur & Mutlu,2019). Additionally, Balci et al. (2019) in their study highlighted that parent's inability to dedicate adequate amount of time and attention to their typically developing children which also added to their marital issues.

Children with Intellectual Disabilities and special needs have the tendency to drain the parents off of time, energy and money. Marital problems and distress are reported to exist to a large degree as a consequence of lack of time among the parents for nurturing their own marriage. Oftentimes it is this stress that affects the couple's marital relationship. Researchers like Ellis and Hirsh (2000) and Pisula (2011) were of the opinion that parents raising children with intellectual and developmental disabilities many a times find it hard to grapple with the child's developmental milestones, resulting in increased stress levels, that consequently, have a negative impact on their level of marital relationship satisfaction as well as the continuation of their marital partnership altogether. Additionally, it was also suggested that dissatisfaction in the relationship may stem from numerous recurring, non-specific, yet significant challenges related to the caregiving responsibilities towards the disabled child (Kijak,2021)

Review of literature highlights the fact that a child with Intellectual Disability can disrupt the marital relationship between the parents because of numerous factors including - lack of leisure time, difficult situations arising due to the child's disability, unequal distribution of caregiving responsibilities, detrimental effects of long-term burden of caring for a disabled child as well as chronic stress about the child's overall well-being (Taanila et al.,1996). Apart from higher levels of stress, parents raising intellectually disabled children have also reported experiencing reduced levels of sexual and marital relationship satisfaction as well

as relationship crisis (Wymbs, Pelham, Molina, Gnagy & Wilson,2008). Analysis of a number of studies also revealed that while the quality of marital relationship between the spouses is dependent on the parents understanding of their intellectually disabled child (Wymbs et al.,2008; Hartley, Seltzer, Barker & Greenberg,2011), their relationship also positively correlates with feelings of sexual satisfaction (Janicka & Niebrzysowski,1994). The presence of an intellectually disabled child has the ability to impact marital partners' sexual satisfaction (Kijak,2019). Sexual satisfaction plays a crucial role in the marital relationship by strengthening the bond between the spouses (Yucel & Gassanov,2010), directly or indirectly, increasing an individuals' overall quality of life (Nomejko & Dolińska- Zygumnt, 2012) (as cited in Kijak,2020).

A study carried out by Rada (2013) titled "*Children with autism and the social aspect (impact on the family)*" stated the children with restricted abilities are on numerous occasions the object of conflicts and quarrels in spouses, especially regarding the care schedules, treatments as well as expenditures. Financial and economic issues are oftentimes the basis of arguments among couples in the family. (Sadiki,2024). According to Goudie, Narcisse, Hall and Zuo (2014) children with disabilities are twice as likely to remain in the care of their parents and caregivers, causing higher levels of financial stress as compared to their typically developing counterparts. In order to care for the disabled child, parents (particularly mothers) often quit their jobs in order to provide the child with full time care. In addition, parents of these children may require additional time off of work. They're also highly likely to decline over time or work lesser hours (Bumbalo, Ustinich, Ramcharran & Schwalberg,2005), which has detrimental effect on their financial situation. Cantwell-Barti (2009) revealed that parents taking care of disabled children tend to suffer from financial hardships as a consequence of either paying more to support the child in comparison to what they may be earning or being unable to find employment again. This is in line with the findings of Ludlow, Skelly and Rohleder (2011) who in his study found that caregivers and parents find it challenging to hold on to a career or even learn new skills in order to move ahead or leave their employment to be with their disabled child full time. Numerous scholars including Tali (2002), Opare and Ayim-Aboagye (2016) and Akudugu, Akudugu, Bakang and Alhassan (2020) were of the opinion that financial burden is one of the most unparalleled challenges faced by parents raising children with Intellectual Disabilities. This may typically be due to - inadequate information, inability to access or a lack of resources or help from other organisations and the government as well as stigmatisation and discrimination (Antwi,2023).

III. COPING STRATEGIES UTILISED BY PARENTS

As per Erel and Burman (1995), it has been well documented that the quality of relationship between the parents can spill over and impact the quality of relationship between the parent and child. This in turn affects the overall functioning and well-being of the child (as cited in Conovar,2023). The ability of the parent to manage their stress and devise appropriate solutions to control their challenging circumstances is often known as coping mechanisms or strategies. It is common to have concerns and worries regarding the family's and child's future, especially given the child's intellectual disability and its impact. Therefore, healthy coping strategies assist the parents in adjusting to the child's disability and managing the needs and demands of raising such a child (Staats, Goff, Springer & Monk,2015). A number of strategies can be employed by the parents to navigate through their journey of raising their disabled child. Some of them being provided below.

Some parents use a *positive outlook* as a way to handle the challenges they face in their everyday lives while raising the disabled child. It not only helps the parents modify their lives and re-focus their attention so as to be more focused on the requirements of their child, it also helps them maintain their overall wellness. One of the key components of positive perception is the ability of the parents to focus on the child's unique strengths and qualities rather than viewing the disability as a limitation. This slight shift or reframing of their perspective allows the parents to overcome challenges while celebrating small achievements, which in turn bring a sense of joy. Therefore, concentrating on positive facets leads to positive perceptions and positive perceptions enables the parents to develop better coping strategies.

Oftentimes the *existence of siblings* in the family also serves as a coping mechanism for parents, raising children with disabilities as they often play a key role in supporting both - the parents and the disabled child, helping them relieve some of the practical and emotional difficulties that accompany caregiving responsibilities. For parents, the presence of a sibling can be a source of comfort and relief knowing that their intellectually disabled child has a companion in the form of a sibling who can provide understanding,

emotional and practical support, and assistance. The existence of siblings prevents the parents from feeling overwhelmed given their challenging situations, helping them maintain a sense of normalcy within the family and helping parents manage care taking requirements of the disabled child.

Another coping strategy of the parents includes *social support*. Social support is “*support made available to an individual through social relationships to other people, groups, and the greater community*” (Heaney & Israel,2008). Parents often feel stressed and exhausted as a result of the additional care and attention required by their intellectually disabled child, which often results in them putting their own health and welfare at risk for the sake of their child (Cowan & Reed,2002). While parents often depend on their spouses for help (Staats et al.,2015), support and cooperation from others, also results in faster growth and development of the intellectually disabled child. There exists a positive correlation between coping strategy, familial support and mental health (Yang, Gao, Li, Wang, Wang & Wang,2022). Options of counseling and support groups are often resources that families utilise that are helpful at reducing stress and worries of the caregivers (Cowen et al.,2002). Social support also helps lower the caregiver’s anxiety and depression (Gray & Holden,1992). According to Kerr and McIntosh (2000) social support “*may be a good way for people in the society to deal with stress and loneliness*”. They were also of the opinion that interacting with other parents of disabled children can work as an effective strategy to reduce stress for the parents involved.

Spirituality and religion have also been utilised by parents of intellectually disabled children as methods of coping. In a study conducted by Junaidi and Dewantoro (2020) They observed that religion and spirituality were some of the techniques used by parents of disabled children as a means to cope with their stressful situation. Their findings indicated, majority of the participants believed that the child’s disability was God’s will and in light of this, spirituality and putting their faith in their religion might aid t parents who experience stress due to the problems associated with raising the intellectually disabled child. Numerous studies also demonstrated that parents caring for children with intellectual disabilities often described having strong religious beliefs and spiritual values, which provided them psychological strength, positive family relations, the ability to adjust and resolve problems (Khamis,2007; Gallagher, Huth-Bocks & Schmitt,2015)

Awareness regarding the child’s disability can be another powerful coping strategy utilised by parents. A clear understanding of the child’s condition equips the parents to better manage the challenges that come with the intellectual disability and helps them navigate through the complexities of the demands of the child. Apart from the ability to provide proper care to the intellectually disabled child based upon the child’s requirements, it also allows parents to connect to other support systems dedicated to specific disabilities. According to Antwi (2021) parents often lack the necessary knowledge needed to effectively manage the child with disability. Thus, they struggle. All these pointers aim to the fact that awareness allows the parents to proceed from a place of confusion and fear, to a place of acceptance and active participation.

IV. POSITIVE ASPECTS OF RAISING AN INTELLECTUALLY DISABLED CHILD

Parenting a special needs child can be hard, detrimental and confusing, but it is also a role accompanied by feelings of satisfaction, happiness as well as triumph (Sadiki,2024). A major portion of the existing literature highlights that marital relationships among parents are adversely impacted following the birth of an intellectually disabled child, however, there are also studies that report the maintenance of good, healthy relationships between the spouses (Sen & Yurtsever,2007). Similar to marital conflict and disagreements, positive marital qualities also have a tendency to spill over into positive adjustment for the child, as a result of parenting practises and other family processes. Just as lower levels of marital quality are correlated to harsh and inconsistent parenting, negative interactions between the parents and disabled child as well as increase levels of behavioural problems in such children (Cui & Conger,2008; Stroud et al.,2015), positive parental practises involving parental warmth, effective behavioural management, and supportive parenting, all results in fewer behavioural issues in the disabled child, positive peer relationships as well as positive marital satisfaction (Cui et al.,2008; Gallagher et al.,2015).

Research into the positive impact of intellectual disability on the primary caregivers is a small but growing field of literature. Although there is no arguing with the fact that having a disabled child acts as a major stressor for family and parents, with marriages being affected as a result of the distress caused by the presence of such children (Grych & Fincham,1990) raising a child with disability doesn’t always have devastating effects on one’s marital relationship (Seligman et al.,2007). Parents bringing up intellectual

disabled children frequently stated that having such a child gave them a sense of value. It developed feelings of empathy, compassion, tolerance, care and love in them. They often credited their child as well as the child's disability for their personal growth and development (Staats et al.,2015). There are reports exhibiting no significant difference in separation rates among families raising a disabled child and those with typically developing children (Begleiter, Burry & Harris,1976; Cooke, Bradshaw, Lawton & Brewer,1986), while certain reports revealed that parents of intellectually disabled children communicated closer to one another and that the family had become one united unit due to the child (Moren,1985; Taanila et al.,1996).

Sadiki (2024) in her study titled "*Marital adjustment of parents of children with special needs*" reported that a majority of the interview parents commonly believed that their unity as a couple and relying on each other, was a way to succeed in coping with the disabled child's issues as well as improving their health. Similar results were also found in some other studies conducted by scholars such as Powers (2001), Fein and Dunn (2007) and Chawarska, Klin and Volkmar (2008). The findings of Junaidi et al. (2020) indicated that majority of the parents believed the child's disability as God's will, which led them to have positive perception of the child's condition and be optimistic about the child's future. Lastly, Tsibidaki (2013) expressed that in an unstable marital relationship, the stress of coping with the child's disability can lead to collapse in the family system. Whereas in relationships that are strong and comparatively non-stressed, the child's disability can result in increased strength and closeness in the parents' marriage.

V. CONCLUSION

Raising a child with intellectual disability is an exceptionally tough and demanding, lifelong journey for parents, oftentimes bringing about significant financial, social and emotional strain. They face numerous challenges, including discrimination, physical and mental exhaustion, loneliness, anxiety, and stress. Marital relationships are also heavily affected due to the impact of the child's intellectual disability. Conflicts arising out of financial strains, lack of resources, contradictory emotions, difference in opinions, lack of quality couple time, sexual dissatisfaction, unequal division of responsibility, exhaustion, lack of privacy, and many more stresses negatively impact parent's relationship. The constant sadness of raising a disabled child along with high caregiving needs, often leaves little time for social interactions further straining their relationships.

Despite these troubles and challenges, parents often make use of coping strategies to help them deal with their circumstances in a better and more positive manner. They tend to find solace by being more aware of the child's disability, having a positive outlook towards the child, making use of social and familial support as well as strengthening their spiritual beliefs and having faith; which in turn helps ease their stress and marital tensions leading to parents' individual growth as well as the growth of their marital relationship collectively, bringing them closer together and uniting them as a family. Furthermore, these unique challenges and added responsibilities that come with taking care of a child with intellectual disability, can contribute negatively or positively towards a parent's marital relationship. However, based on this it can be suggested that it is important for parents to seek support from their family members, their community, support groups and/or professionals in order to better manage these challenges and ensure their own overall well-being. The findings of this paper can serve as a base for future researchers that intend to study this topic further and/or conduct in-depth analysis of the same.

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