

# Parents having Intellectually Disabled Children: A Systematic review of Quality of Life and Mental wellbeing

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**Abstract** - A parent of children with intellectual disability continues to suffer societal sensibilities. On the one hand, parents with intellectual disability engage within the valued social role of raising children; on the opposite hand attention supported an expectation of their limited capacities to parent. Parents of children with intellectual disability also losing family relationships. The main aim was to identify and intervene in the quality of life of parents, the interventions offered to parents as primary caregivers of children with intellectual disability. To explore parents' perspectives on beneficent for children with intellectual disability in connection with formative years, resources, and to confront the consequences of upraising a child with intellectual disability. The literature primarily addresses the question of whether or not parents with intellectual disability may be adequate parents or reports on methods for improving their parenting styles, this angle focuses on their parenting situation compared thereto of other parents more generally.

**Purpose:** This systematic review is meant to bring out pooled evidence on quality of life (QOL) care givers with children having the intellectual disability which can affect the rehabilitation of the affected child and also focus the mental wellbeing of care givers and parents.

**Method:** Databases such as Research gate, Google scholar, Pub Med/Medline were searched to identify the potential studies.

**Results:** a range of survey methods were utilized by the researchers. Studies also focused on various domains of QOL like financial wellbeing, family support and community interactions, etc. and findings showed a QOL starting from good to excellent. But most of the studies most studies have employed a general measure tool to assess the influence of the intellectual disability on the physical and psychological well-being of parents/caregivers.

**Conclusion:** There is a requirement for more studies associated with this subject. The studies reviewed were from Australia, Kenya, Ireland, and therefore the UK.

Hence, there is scope for further review. The focus of the paper is on the utilization of larger scale datasets to grasp matters care givers with intellectual disability compared with other parents and verify the contextual variables that influence their parenting. There is an evidence gap in the area of QOL and mental wellbeing of parents living with children having intellectual disability.

**Index Terms** - Intellectual disability, Mental wellbeing, parents, quality of life.

## I. INTRODUCTION

People have many dreams for their children. Verbalization of those expectations doesn't occur, but deep down they remain. When they realize their children suffered intellectual disability, their images of their child's potentials diminish. They start imagining that the hopes they once visioned are going to be impossible. Intellectual disability affecting family life is a question an individual wonder! That is a valid point of concern. It is effortful care givers to process the news that their ward has autism, and that they begin to know that their lives are certain to be entirely different than what that they had anticipated it to be and therefore the news is overwhelming. When there is a child on the intellectual disability social activities become a bother. Easy accommodation is not easy for severe disability children. The family will have expectations and check out to meet them as realistic as possible, but it'll not turn as realistic as that they had seemed it to be. Despite situational adjustments memories cannot be made. Though families dream to involve together, they often don't take pleasure in activities because they seem too difficult to manage. Facets of family life that affected by the intellectual disability are family recreation, finances, parents'

physical and psychological wellbeing, family relationships, marital relationships, relationships with friends, neighbors, and relatives. Having a child with intellectual disability presents a number of problems that face have a direct negative effect on parents and family functioning. The impacts on various aspects of family lives are affected including significant stress throughout all family members, physical and mental health of family members, ignorance or neglect of other children's needs, strained sibling relationships. There will be unstable relationships with relatives, friends, and neighbors. The social and communication deficits affect total members of the family as they'll not be a part of any such gatherings. The diagnosis changes occur not only in the life of the child diagnosed but also in that of family members. Families and relationships may be strengthened by coping with the pressures of having an intellectually disabled children through a great support system and a lot of hard work to avoid tragedy. Prevalence of mental illness has a significant impact on the global burden of diseases. Among the urban population of developing countries, 5.3% are suffering from mental illness (Deswal, & Pawar, 2012). Intellectual disability or retardation because it persists throughout lifetime adds on to those rates. It contributes to 1.2% of the mental illness in Kerala (Celine, & Antony, 2014). Intellectual disability is that the most prevalent childhood psychiatric disorder. Among them, majority of the cases (85%) belong to mild mental retardation (Harris, 2009), (Ganguly, 2000). A Meta-analysis on the prevalence of intellectually disabled children shows that 10.37/1000 population are affected (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Parents with children having intellectual disability use various coping strategies, which are ineffective most of the time. Parents with children having intellectual disability experience more stress compared to their counterparts, who have children with no intellectual disability.

## II. OBJECTIVE

Identifying various research agendas related quality of life and mental wellbeing of parents having intellectually disabled children

## III. WHY IS IT IMPORTANT TO HAVE THIS REVIEW?

Intellectual disability is found altogether in the societies. Globally, the prevalence of intellectual disability is estimated to be 30 per thousand. Almost 75% of the population diagnoses as mild intellectual disability, while the remaining 25% have either moderate or severe and profound grade of disability it is the developmental disability that is marked by below normal intelligence and limited daily living skills. Intellectual disability is generally present at birth or develops early in life. When a newborn child is found to be intellectual disability, caregivers are inevitably distressed. Avoidance is common, it affects daily life. Frequently the diagnosis of intellectual disability is not made until after the first year of life, and the parents then have to make great changes in their hopes and expectations for the child. They often experience prolonged depression, anger, guilt and inability to cope with substantial practical and financial problems. A few reject their children, while others become over involved in their care, sacrificing other important aspects of family life. Parents having children with intellectual disabilities always pass through a difficult experience. It inversely affects their life negatively. Government entrusts various supporting schemes for these children care givers, but this doesn't have an effect on stress and QOL of caregivers. They always need sufficient psycho education and therapies for enhancing mental wellbeing. This review will assist in identifying the area of QOL which are affected negatively by their children's disability. By considering the findings of this review, suggestions to change supporting schemes are often suggests. It was found from initial review that no systematic reviews were conducted specific to the present area and this project aims to review the aspect of QOL of mothers with intellectually disabled children.

## IV. METHODS OF STUDY

Parenting an intellectual disability child isn't simple assignment. Along with different problems faced by care givers of cerebral disability, marital adjustment and family environment is extremely taxing matter. Therefore the researcher was concerned to learn the socio-demographic characteristics of the respondents, to discover the economic situation, and the marital adjustment connecting the parents of intellectual disability children A review protocol was established and electronic databases like PubMed, Ind-Med,

Researchgate google scholar, and Proquest were searched for potential studies. Language limitation of studies published in English in the period 2010 to 2020 was included. Case control studies and descriptive studies were included for the review. Studies on parents of children having an intellectual disability and studies related to the QOL of parents with intellectually disabled children were considered. The reviewed papers on studies conducted in residence, school, community, organizations, and rehabilitative setting were included. The primary outcome of the study was quality of life of mothers and secondary outcomes were well beingness and stress

#### V. RELATED WORK BASED ANALYSIS

Initial search resulted in hits with a limited of studies from 2010-2020. Among them, only eight articles were full text available and everyone the article was reviewed. Out of which four studies were conducted in India. a spread of survey methods was utilized by various researchers. Studies specifically that specialize in parents of intellectual disability were limited. The review shows that majority of the participants within the reviewed papers were care givers of intellectually disabled children. Studies specifically done among parents were limited, although the experiences of both care givers and care givers were different. Studies also focused on various areas of QOL like financial wellbeing, family support, and community interactions etc. and findings showed a top quality of Life starting from good to excellent (Caples & Sweeney, 2010). Meta-analysis out of the scope of this review, individuals with intellectual disability aren't subhuman in any respect, but rather, very happy. they're not disposable beings and that they aren't burdens to society. Intellectual disability individuals have the capacity to measure productive, meaningful lives and therefore the ability to affect positively. Many people as they meet the challenges inherent in life.

#### Quality of life:

All studies were cross-sectional studies published in English. Two publications examine an equivalent sample (Dardas & Ahmad, 2014a, 2014b) and thus metadata for that those studies, for instance when presenting the combined number of people involved altogether studies, were only calculated once. The

literature search is printed in additional detail, having a toddler with an intellectual disability is that the highly demanding situation for the care givers. Because the caregivers are responsible for meeting the requirements of youngsters with a disability, it overburdens them within the aspect of rearing of children. This, in turn, can impair the QOL care givers. Parents of youngsters with intellectual disability showed to possess deteriorated physical health, psychological state, the perception of the environment, and impaired social relationship while comparing to the oldsters of healthy children (Malhotra, Khan, & Bhatia, 2012). Overall QOL of oldsters with intellectually disabled children is significantly impaired than their counterparts. The domain of relation was the main area which was negatively affected in parents of those children (Mothers:  $44.61 \pm 18.12$ , Fathers:  $51.81 \pm 19.71$ ). The difference during this QOL is additionally the results of the mother being initial caregiver and father performing the resource role. Care givers spends her maximum time with the kid in meeting the daily needs. When the socio-economic factor is being considered, parents with lower socioeconomic status shown to possess a poor QOL and need immediate intervention (Kumar, Santhosh, & Joseph, 2013).

Caring an individual with a disability may be a demanding effort regardless of the sort of disability like attention deficit hyperactive disorder, retardation, autism, or learning disorder. Both caregivers of an intellectually disabled child will have a poor QOL but mothers are more suffering from the shortage of non-public support network. Mothers also experience a perception of stress in parenting associated responsibilities of a disabled child (Ravindranadan & Raju, 2008). Need to be cared for an extended time or throughout the life of their offspring create a negative impact on QOL of parents. Thoughts about their child's future – financial and frustrations about health care system, contribute to deteriorated QOL (Yonng, & Koritsas, 2012). Supportive services, accessible health care system, and residential created for caring these children can aid in resolving this issue. The transition from childhood to adulthood may be a crisis not just for a personal but also for the family he/ she belong to. The QOL care givers with intellectually disabled children will got to face a significant challenge during their child's transition from childhood to adulthood. High demand for caring

needs, support services, and low spiritual faith may result in poor QOL care givers. (Bertelli, & Bianco, 2015). Even though much resource is allocated to support care givers of intellectually disabled children, demand is much higher than what is provided. Parents may experience an honest QOL but they always search for supportive services on which they can rely upon. Care of their disabled child is their primary responsibility but the supportive services such as easy access to health care, vocational training, and social care are reported to improve the QOL (Caples, & Sweeney, 2010). Well-being and stress Children with intellectual disability are indicated risk factor for poor parental wellbeing. The relationship between the couple affects their wellbeing as supporting each other in caring the child has an effect on wellbeing. Marital quality and co- parenting have a major role in sense of wellbeing. Parents of children with intellectual disability have a poor individual wellbeing, while compared to mothers of normal children (Norlin & Broberg, 2013). Parents of children with intellectual disability experience a moderate to high stress because of their child's behavior problems. There is a strong positive correlation between the lack of acceptance that the child is having disability and stress. Spiritual supports and use of adaptive coping skills have an indirect correlation with parenting stress. Negative maternal psychological wellbeing compensates the stress in parenting (Norizan, & Shamsuddin, 2010). Dimensions of psychological wellbeing such as anxiety, depression, and stress of mothers are affected by lower levels of hope and more behavioral problems of the child. Higher hope will help in developing a positive effect and enhanced psychological wellbeing. Developing a hope among the mothers will aid improving the psychological wellbeing (Lloyd & Hastings, 2009). A comparison on the subjective wellbeing and stress of the mothers of male and female intellectually disabled children shows that mothers of female children lie in a lower range in wellbeing and higher range in stress. The feeling of hope was found to be significantly good among parents of male intellectually disabled children. Parents of female intellectually disabled were more worried about their child's future, but the study shows that, mothers cared their children in the same way irrespective of their gender (Paliwal & Paliwal, 2015).

## V. DISCUSSION

Efforts were made to know the importance of psychological wellbeing and psychological state in day-to-day lifetime of parents of youngsters with intellectual disability to typical mothers or with reference data. during which aspects of QOL and psychological state are the foremost impacted there by the factors that influence parental QOL? The efforts were laid to know the role of psychological state that affects the standard of lifetime of parents of parents/ primary caregivers. The reviews on various literatures couldn't throw much light on the objectives as mentioned above either on the mental wellbeing and physical activities of mothers or its impact thanks to the diagnosis on the standard of life because of the stress on mothers with the active participation of within the family. only a few relevant studies were studied on the QOL of oldsters and care givers as an entire globally. The role of oldsters with intellectually disabled children in a least amount studied and relevant aspects that affect their QOL and social functioning within the Indian context are least understood. Very valuable information throughout the review is that there's no specific creative work and physical and skillful time assessment tool or vocational activities assessment tool relevant to the Indian context. Spare moments or skillful participation or satisfaction scales are generally focused on the disordered child's welfare and or the typically developing children's and or the families. Free time family functioning, family life satisfaction was studied by few researchers. The finding shows that oldsters had an equivalent level of leisure activity as compared with the normally developing population. Free time was related to poor family contact, lower satisfaction with family life.

Free time entertainment was an important indicator of involvement of leisure as studied by Katherine M. Walton, Free time skill enhancement program is that the mediator for both family functioning and family life satisfaction. The encounter with identification, misdiagnosis, insufficient understanding, and parental prior experience endured a negative effect (stress) and dissatisfaction with family life in mothers. Early interventions, health care, financial burden, and stigma had an immediate impact on their social lives, mental well-being, and sacrifices as a results of their children's intellectual disability and its related developmental problems have a detrimental effect on parents' ability to sustain assistance networks and

difficulty in participating in social assignments or family engagements with similar children affected with intellectual disability. On the other hand, the image of refrigerator mother, with another tag of depressive illness, with irresponsible behavior, negligence, and ineffective maternal roles

## VI.CONCLUSION

The implications are clear about areas of focus in working with parents with intellectual disability. Initially is that the necessity to deal with parental social skills, relationships, and networks to reduce social isolation and increase social support. A flow on effect might be anticipated as there's good evidence from social support interventions more broadly that social participation is claimed to raise psychological state within the overall parent population. A specific specialize in the mental state needs of mothers would even be beneficial. This is often particularly so as Mayes and Llewellyn have acknowledged in regard to the presence of child protection within the lives of the various parents with intellectual disability and their grieving following child removal. An additional benefit in getting to maternal mental state is that the feature of upper parental mental state and good social support for the well-being of kids. The advances in computing power brought on to the desk (or notebook) have enabled secondary analysis of larger scale datasets previously beyond the reach of individual researchers. Standard disability questions or a disability module in national population health, social, and labor surveys would further increase the capacity to disaggregate disability data by demographic characteristics like age, sex, race, and socioeconomic status. Critically, disability questions in longitudinal and life course surveys offer the prospect to look at patterns and trends for people with disabilities compared to their non-disabled peers also as information about subgroups of people over time. During an identical vein, having a daily disability that identifies records of individuals with a disability in administrative data collections (such as housing, education, employment, child protection) offers the possibility to appear at demographic characteristics of recipients (service users), varieties of services, and inputs and outputs for people with disabilities compared with their non-disabled counterparts. These initiatives are progressing apace with researchers

within the intellectual disability field capitalizing on the opportunities offered. Datasets like this offer the prospect to explore inequities and disadvantage not only within parent and child generations but also a cross generations over time. This seems particularly pertinent to women with disability who become mothers given their increased likelihood of experiencing well documented risk factors in pregnancy. Research on intellectual disability during a population context is anticipated to still increase in line with expanding international interest within the life circumstances of individuals with disabilities compared to their non-disabled peers. As this happens, identifying appropriate points for intervention and interventions which effectively target inequities and disadvantage can only be within the simplest interests care givers, their children, and society more broadly. Or for poor. A comparison on the subjective wellbeing and stress of the mothers of male and feminine intellectually disabled children shows that mothers of female children dwell a lower point wellbeing and better point stress. The sensation of hope was found to be significantly good among mothers of male intellectually disabled children. Mothers of female intellectually disabled were more worried about their child's future, but the study shows that, mothers cared their children within the same way regardless of their gender.

Review suggests that oldsters of intellectually disabled children experience a poor QOL and social support services are available, they are not sufficient to satisfy the exceeding demands. Services in social care, financial assistance, and easy access to health care services should be the main target of support. Intervention on developing hope, enhancing wellbeing, and stress management are crucial and is that the immediate need for folks with intellectually disabled children. While planning interventions for this population, economic status and future availability need to be considered.

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