

Parents of today's millennium of Intellectually Disabled Children – Findings (with) Family Impact Questionnaire

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Abstract: Any child born as differently abled, makes an impact on family members. But the impact is not the same on all families, as the severity of child makes the difference on 'impact'. The impact can be termed as burden also. This burden is usually divided into objective and subjective burden as given by (Hoening & Hamilton, 1966) objective burden is related to observable and concrete demands, and the author relates subjective burden to emotional costs and the extent to which family members perceive the burden. The various areas in which the family undergoes changes are expressed through Family impact Questionnaire. The purpose as explained by Donenberg & Baker is to find measures, to lower family stress, thereby improving the coping skill, improve quality of life of parents, siblings. Since heightened stress may negatively bias parents' perceptions of their children (Forehand, Wells, & Griest, 1980; Webster-Stratton, 1988), impair the quality of parent-child interactions, & interfere with parent-focused interventions (Baker, Landen, & Kashima, 1991). Many people refer to the year 2000 as the Millennium. The participant parents in this study, all of them have Intellectually Disabled children born after the year 2000. The family impact scale, developed by Donenberg & Baker in the year, 1993 was used in assessment. Though an old likert scale, it was found to be very useful in assessing the impact of intellectually disabled child on family. This study elaborates on finding with families of Cuddalore district of Tamilnadu.

Key Words: *Differently abled, Impact, parents, siblings, Family Impact questionnaire.*

Introduction:

Good parenting is the parental ability to sufficiently meet a child's need for food, clothes, shelter, education and emotional needs such as affection. The failure of good parenting leads to the child's ill health, problems in survival & development. The developmental disability child brings life changing implications, long-lasting effects in the life of other family members. (Simmerman, 2001; Martin & Colbert, 1997). Parents may 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 1989) they report less parental skills and less marital satisfaction (Rodrigue et al 1990). Studies suggest that parents who experience higher levels of stress interact differently with their children, compared to parents who experience lower levels of stress, their response to child's problematic behavior differs (Conger et al 1995). Family burden has been acknowledged to influence the outcomes of child's disability condition (Falloon, 1985; Perlick, Stastny, Mattis, & Teresi, 1992), and a circular relationship between quality of life in both individuals and their families. High parenting stress is a risk variable, associated with parent depression (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992). The most common developmental disability is **intellectual disability**. Cerebral palsy is the second most common developmental disability, followed by autism spectrum disorder. Other developmental disabilities may include: Attention-Deficit/Hyperactivity Disorder.

Review of literature:

In 1988, Breen & Barkley compared parents of school aged normally developing children with parents of behaviour problem children. They reported higher level of stress and difficulties in day today coping. Mothers of ADHD children exhibited evidenced more negative reactions, less efficacy in parenting role, as described by Johnston & Mash (1989). Gross et al (2008) describes how parental depression plays a role, studies by Vander valk et al (2007) describes marital distress, in affecting education of adolescence. Baker BL, Blacher J, Crnic KA, Edelbrock C (2002) reports behaviour problems in children, because of parental stress. Lack of effective parenting skill also contributes to educational setback as described by Coldwell, Pike, Dunn (2006). From ancient times, researchers like Dyson, Edgar, & Crnic (1989), Singhi, Malhi, & Pershad (2002) investigated whether siblings of intellectually disabled children are at risk of developing diminished self-concept, poor adjustment in family and in other environmental setups. Intellectually disabled children moreover exhibit behaviour problems more frequently than typically developing children, as said by Baker, Blacher, Crnic & Edelbrock (2002). The sibling relationship involves competitiveness, teasing, pride, tears & laughter (Senguttuvan, et al 2014). This is not available when there is single sibling for intellectual disabled child. Moreover, older or younger sibling, unaffected child is expected to care intellectually disabled child. Kim & McHale, Osgood, Crouter (2006) found second born (normal child) in family reports higher level of conflict until age 12, compared to first born. The relationship between child behaviour problems & Parenting stress may be bidirectional (Baker et al, Orsmond, Seltzer, Krauss, & Hong (2003)). Gozun

Kahraman and Soylu Karadayi (2015) studied 13 siblings of disabled children. They devised ten questions and conducted semi structured interview to know about how their life is affected due to disabled sibling. Children conveyed that they did not have enough knowledge of the disability, they were worried about negative views of other people towards disabled sibling. The relationship between siblings can be marked with rivalry & conflict, but can also be one of the closest & intimate relationship a person has in childhood, adolescence, and adulthood (Buhrmester & Furman, 1990; volling, 2003). Warm, nurturant, close sibling relationship play important role in developing social competence, ability to resolve conflicts (Dunn & Munn, 1985 Howe, 1991, Herrera & Dunn, 1997). Authors Furman & Buhrmester (1985) Hetherington & clingempeel, (1992) stocker & McHale (1992) have identified four dimensions namely 1) warmth /closeness, 2) conflict, 3) rivalry,4) status/power.

Intellectual disability is a term used when a person has certain limitations in cognitive functioning & skills, including communication, social and self-care skills. These limitations can cause the child to develop and learn more slowly or differently than a typically developing child. Intellectual disability can happen any time before a child turns 18 years old, even before birth. Intellectual disability is the most common developmental disability. According to the American Association of Intellectual and Developmental Disabilities, an individual has intellectual disability if he or she meets three criteria:

- IQ is below 70-75
- There are significant limitations in two or more adaptive areas (skills that are needed to live, work, and play in the community, such as communication or self-care)
- The condition manifests itself before the age of 18

Parents were advised to admit their intellectually disabled in institutions by professionals, long back. But the goal envisaged for them nowadays is to stay in family and take part in community living (Farheen, 2008). The national policy on mental handicap (Government of India, 1988) also emphasis the importance of home based care with parents as partners for the ID children. Daily living skills such as grooming, toileting, mobility itself demand much of parents' time in these children. Added with the burden is bringing them for therapy services. Siblings born along with these differently abled also face difficulties in their developmental stages, when parents care less for them. Perception of these daily hassles will be minimal when they can be trained to cope up. It was seen that parents blame themselves, end up with sorrow and sadness, when they face difficulties over a period of time in the environment. (Norman, 2005). General psychological stress theories explain the relationship between, how external agent, causes stress upon an individual. Moreover the stress reactions developed by the individual, (Lazarus, 1993) cognitive appraisal of the event, coping mechanism of the person, are the other three factors which determines the effect of stress. From the family impact questionnaire assessment, it could be understood that, if intellectually disabled children is available in family, parents of this millennium, also, were stressed. The author of this article can find that the parent's education, parent's income and parent's family structure all play only a speculative role (theoretical) in influencing stress. Holding an ID child, at this millennium also influences stress, beyond the treatment advancements. Parent's perception of disabled child's impact on the family could be assessed with FIQ. Parents can complete the form in ten minutes. It's a four point likert scale, assessment, rating is done from (0) not at all to (3) very much. English version is used for the study. The **family impact questionnaire** measures parenting – specific stress as suitable to roles, responsibilities and experience of parenting a differently abled child. It has six subscales, to assess the parent's perception of their child's impact on family members.

Family impact questionnaire-R, devised by Geri Donenberg & Bruce L. Baker

- (a) Assess feelings and attitudes about child. (By comparing with other children of same age), Questions like, 'My child brings out feelings of frustration and anger more', 'I feel like I am working alone in trying to deal with my child's behaviour' are available to explain about this component.
- (b) Impact of child on social life is assessed by Questions like, 'my family avoids social outings more (e.g., restaurants, public events) because of his/her behavior', 'I participate less in community activities because of my child's behavior'.
- (c) Financial impact of child is assessed with Questions like, 'The cost of home alterations and/or fixing and replacing items in the home is more', and 'The cost of educational and psychological services is more'.
- (d) Impact of child on marital relationship of parents was assessed with Questions like, 'My child causes more disagreements between my spouse and me', and 'My spouse is more supportive of the way I deal with my child's behavior'.
- (e) IF SIBLINGS available to the ID child, then Impact on his/her siblings is assessed with Questions like, 'The other children in the family invite friends over to the house less often because of his/her behavior', 'My child prevents his/her siblings from participating in activities more'.
- (f) General Questions like, degree of difficulty living with this ID child, is also made in this FIQ.

Aim & Objectives:

The study aims at finding out the impact of intellectually disabled child, on their families through a standardized, written self-report technique where participants are given, pre-set number of questions to respond.

- For the above said aim, the researcher collected, study participants from various areas of Cuddalore district. The questionnaire, selected was Family Impact Questionnaire, and its description is given to parent respondent.
- With the consent of parents, based on the chronological age of ID child, they need to be allotted into separate identities.

- FIQ assessment was described to them. The response, was marked by any one of the parent, in common, at the English version.
- After classifying responses, result needs to be framed.

Methods:

For administering family impact questionnaire, the researcher of this study divided study group parent participants according to the available Intellectual disability child's chronological age. The participants, totally FIFTY in number, basically parents of ID children, were able to understand the English version of the questionnaire. They themselves can mark appropriate responses given against each items, in FIQ.

In this scale, each item was assigned to the factor on which it loaded highest.

- (1) Impact on social life, 11 items
- (2) Negative feelings towards child, 9 items
- (3) Positive feelings toward child, 7 items
- (4) Impact on finances, 7 items
- (5) Impact on the marriage, 7 items
- (6) Impact on siblings, 9 items.

According to DATA available with District Differently Abled Welfare Officer, Cuddalore, about 1500 Intellectually Disabled were registered, through NGO'S at various places, residing at Cuddalore district of Tamilnadu. From these children, Sample (parents) for study was those, who are readily cooperative, who accepted there exists a problem in family.

In the present study, the families of intellectually disabled were divided into separate IDENTITIES. Identity 1 with name GUGAN was having families within age group six months to 5 year ID children. Identity 2 with name SURAM was having ID child of age 6 to 10 year children, Identity 3 with name MUTHU 11 to 15 year's children. Identity 4 was SHWAR with ID children 15 to 20 years. The age of intellectual disabled was fixed as the essential **inclusion** criteria. Number of siblings, gender of siblings and their age, present marital status with education & vocation of siblings were also noted, to distinguish appropriate findings in study. These siblings were living along with intellectual disabled child. At the first assessment, some of the siblings openly accepted that there is a setback in their education due to intellectually disabled child and they need to learn a coping skill for compensating their stress. Being a parent of intellectual disability child is difficult & hence, main focus of the study was parents.

- (1) Overall response of parents in perceiving their difficulty (ID child present) on social life is scored. Among the fifty parents, 31 opted they are very much affected on 11 items related to social life.
- (2) Overall response of parents in negative feelings towards the child was present as highest for female ID children family. (27)
- (3) Overall response in perceiving positive feelings towards child was available with 23 respondents. In this study group, all of them was towards male children.
- (4) Respondents perceived their difficulty (ID child present) on finances & this was given score of 2, 3 (higher, highest score) by all.
- (5) In the marital relationship component, none of them faced SEPERATION, though there were many difficulties in marital relationship.
- (6) The respondent from all families beyond, making a response to sibling related questions, mentioned additionally, their perception of their ID child to PLAY A VITAL ROLE in influencing SIBLING marriage. It is applicable to 14 family participants in this study group. All the respondents in these 14 families described, about their tough situations in getting a partner for the sibling of ID child. They worried, on acceptance of ID child by the new comer of family.

Results:

Family Impact Questionnaire findings show that, in parents of today's millennium also, intellectual disabled child availability makes notable differences in social life, in managing finance. Gender of disabled child also influences the stress. Female ID children induced more stress than male child. That is described elaborately by participants, of Identity 2 with name SURAM (Identity name given in this study by researcher) having females of age 6 to 10 year children and Identity 4, SHWAR group with children 15 to 20 years. Parents having female ID child in this Identity has shown more negative feelings towards the child.

Conclusion:

The present study was done with fifty parents of Intellectually Disabled children. One of the parent was the respondent of the FIQ. To analyze whether parents of present millennium suffer due to presence of Intellectually Disabled child, family impact questionnaire, was administered. Though it was developed during the year 1993, the questionnaire was found to be applicable to the study group, by the researchers. Hence, either at their home or in settings like community hall, assessments were taken. Simple Interviews were conducted along with questionnaire assessments. Parental interview provided information on Parent's perception of ID child and sibling relationship also. Some siblings also participated in the study, along with their parents out of curiosity on "what is happening". After calculation of scores in FIQ, the above findings & results were given. This study has given insight into certain areas of parental sufferings. Correlation of these findings is essential in rehabilitation of the Intellectually Disabled child and family.

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