Positive and Negative Impacts on Caregivers of Children with Intellectual Disability in India

Adithyan G.S[1]*, Sivakami M[2], John Jacob[3]

1. Research Assistant, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai, India
2. Prof & Chairperson, Centre for Health and Social Sciences, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai, India
3. Senior Consultant, Dept. of Family Medicine, Christian Fellowship Hospital, Tamil Nadu, India.

ABSTRACT

Purpose: *The factor integral to the empowerment of children with intellectual disability is the presence and active involvement of support mechanisms such as their family and their caregivers. This study assesses both positive and negative impacts on parents/caregivers of children with intellectual disability in Oddanchatram block of Dindigul District in Tamil Nadu, India.*

Method: *Mixed method techniques (quantitative and qualitative) were used.*

Results: *Although many disturbing realities in the family situation were revealed, there were also positive impacts which are hopeful signs.*

Conclusion: *Empowering the caregivers of children with intellectual disability is the first step towards inclusion of these special children in society. Various strategies to achieve this goal are discussed in the study.*

Key words: *intellectual disability, children, parents, impact, caregivers, strategies.*

INTRODUCTION

Intellectual disability is not a single, isolated disorder. It often originates before the age of 18, and is characterised by significant limitations both in intellectual functioning and in adaptive behaviour (AAIDD, 2007). In recent years, the American Association of Intellectual and Developmental Disability (AAIDD, 2007), Diagnostic and Statistical Manual for Mental Disorders (DSM- 5, 2013) have adopted the new terminology, 'Intellectual Disability' instead of 'mental retardation'. The World Health Organisation (WHO) in the yet-to-be-published 11th edition of the International Classification of Diseases (ICD-11) has also

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* **Corresponding Author:** Adithyan G.S, Research Assistant, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai, India. Email:adithyangs@gmail.com

agreed to revision of the name to 'Intellectual Disability (Salvador-Carulla et al, 2011). Although the change in terminology is a step in the right direction, there is still a great need to improve the lives of children with intellectual disability and their families through the promotion of rights, choices, independence and social inclusion including access to mainstream services (Ali et al, 2008) as people with intellectual disability and their caregivers/parents (the terms are used interchangeably in this article) are often not given adequate importance in most developing countries, including India.

The life and survival of a child with disability depends on a number of external and internal factors. The internal factors are supported and nourished by various external factors. For persons with intellectual disability the situation is more complex. Internal factors are less supportive to survival because intellectual disability results in partial or full incapacitation of one's intellectual capabilities. Among the external factors, the role of families, particularly of the parents, is crucial (IASSID, 2012). Hence, the role of support mechanisms in the form of family services is the most integral component when it comes to the wellbeing of a child with intellectual disability (McConkey, 2005; Hill and Rose, 2009).

Intellectual disability as a disorder has wider negative impacts on the family and the caregivers than any other form of disability (Baxter et al, 2000). There is overwhelming evidence that caregivers experience multiple types of emotional distress on diagnosis of intellectual disability in their children. Shock, disbelief, anger, grief, guilt, embarrassment, depression, withdrawal, ambivalence and fear of stigma are common manifestations (Blacher, 1984; Marsh, 1992; Marvin and Pianta, 1996). In India, Singh et al (2008) found negative impacts among one-fourth of the parents in their study sample; these included difficulties in meeting extra demands for physical care of the child, health-related problems, making career adjustments, experiencing loss of support from their spouses, etc. Studies also point out that parents may experience the impacts of disability in different ways. For example, mothers of children with disabilities were found to exhibit increased depression (Olsson and Hwang, 2001), increased caregiver burden (Heller et al,1997) and increased stress (Herring et al, 2006), as compared to fathers. Studies also reveal that it is not just the presence or absence of disability which causes the negative impacts on the family, but the child's maladaptive behaviour and various care needs (Neely-Barnes and Dia, 2008).

Although there are many studies on the negative impacts and responses of caregivers of children with intellectual disability, only a few studies throw light on the positive impacts on caregivers, especially in the Indian context. However, more recent studies point out how families adapt to situations like intellectual disability and provide supportive care to their children, rather than looking at family dysfunction only (Jacques, 2015). There are many ways in which parents can reframe the disability experience into a positive one (Neely-Barnes and Dia, 2008). Some qualitative studies have reported instances where parents claim their child's disability has been a source of joy and happiness (Turnbull et al, 1988; Stainton and Besser, 1998); has increased the sense of purpose and priorities (Behr et al, 1992; Stainton and Besser, 1998); expanded personal and social networks and community involvement (Behr et al, 1992; Stainton and Besser,1998)) increased spirituality (Stainton and Besser, 1998; Taunt and Hastings, 2002); increased tolerance and sensitivity (Scorgie and Sobsey, 2000; Taunt and Hastings, 2002); and, created a more positive outlook about the future (King et al, 2006).

However, in India, very few studies have been conducted to assess the negative and positive impacts among caregivers of children with intellectual disability, especially in rural settings. The needs of families with such children are also very complex in a developing country. Therefore, an assessment of the impacts among caregivers of children with intellectual disability can help in developing support mechanisms and strategies to empower these families. The present research is aimed to study the impacts, both negative and positive, on the caregivers of children with intellectual disability.

METHOD

Setting

The study was conducted in Oddanchatram block of Dindigul District in Tamil Nadu, Southern India between September and October 2015. Mixed methods (quantitative and qualitative) were used. Quantitative methods were used to gather numerical data under 10 domains of modified National Institute for the Mentally Handicapped Disability Impact Scale (NIMH, 2000), to study the negative impacts among caregivers of children with intellectual disability. Qualitative methods were used to bring about a narrative presentation of the positive impacts, as this domain had not been explored in earlier literature, especially in the Indian context.

Study Design and Sample

A cross-sectional study was done to assess the negative impacts, using a pre-tested interview schedule among 50 caregivers of children with intellectual disability. The sample was purposively selected from the Sarva Shiksha Abhiyaan (SSA) Registry in Oddanchatram, Dindigul. All caregivers of children with intellectual disability who consented to participate in the study were included. As such there were no exclusion criteria.

No monetary incentives were given for participating in the study.

Study Tool

National Institute for the Mentally Handicapped - Disability Impact Scale (NIMH, 2000) was modified post pretest and was administered to the caregivers to study the negative impacts. The modified NIMH-DIS consisted of two sections. The first section included questions to gather the general and socio-demographic information of both the child with intellectual disability and the caregiver. The second section assessed the negative impacts on caregivers under 10 domains.

In the original NIMH-DIS, each domain was introduced by an open-ended question and quantitative scoring of '2', '1' and '0' was adopted for each of the impact areas, to assess the degree of impact. In the present study, most of the questions were framed to get dichotomous responses but all the 10 domains and the impact areas were retained to assess negative impacts. The original tool also had an eleventh domain on positive impacts, but it was excluded in the present study since the researchers felt that it was inadequate and inappropriate. While the original tool required four assessments and a baseline assessment among parents under each option, this was modified to a one-time assessment in the present study.

Procedure

To understand the positive impacts on caregivers of children with intellectual disability, two focus group discussions (FGD) with 8 participants each and 6 in-depth interviews (5 mothers and 1 father) were conducted. The in-depth interviews were conducted among parents who voluntarily agreed to share their positive experiences while they were being interviewed to assess negative impacts. The in-depth interviews took place in the caregivers' homes. This afforded complete privacy and lasted for approximately 30-45 minutes each. The FGDs were conducted when parents of children with intellectual disability had assembled for an annual meet organised by the day care centre under SSA.

Both the FGDs consisted only of mothers who were ready to share their positive experiences, and took place in the day care centre. The FGDs lasted approximately one hour each and were video-taped in order to make specific attributions. An interview guide was prepared from a review of professional literature on the domain of positive impacts on caregivers of children with intellectual disability. The standard opening question all the participants were asked was - "What were the good changes that have happened to you since this child came into your life?"

Information was also elicited on key areas like community involvement, family relationships, etc. All personal information such as name, address and location were kept anonymous and confidential.

Informed consent was taken from all the study participants prior to the interviews All the participants were informed that they were free to interrupt the interview or refuse to answer any question without facing negative consequences.

The video-tapes of the FGDs and the in-depth interviews were transcribed verbatim before translation to English. The first and second authors finalised the codes that emerged from the data. Under the supervision of the second author, the first author grouped different codes into potential themes and collated all the relevant coded data extracts within the identified themes. Some initial codes formed main themes, whereas others formed sub-themes, and a few were discarded.

RESULTS

Socio-Demographics and General Information

While most of the respondents were parents - mothers (68%) and fathers (26%) - three respondents were grandparents acting on behalf of the child's parent. The mean age of the respondents was 40.5 years. Most of the respondents had children with intellectual disability who were 10 years old or more (68%), and most of whom were male children (68%). According to the respondents, 62% of children were diagnosed with 'multiple disabilities', most often cerebral palsy (30%) along with intellectual disability. The other associated conditions included speech impairment, hearing impairment, Down syndrome, epilepsy, congenital heart diseases and various other conditions. Most of the children (76%) received home-based care, while the rest (24%) attended school / day care under SSA. Among the respondents, 44% of mothers and 40% of fathers were illiterate (refer Table 1 and 2 for more information).

Table 1: Socio-demographics and General Information of Caregivers (N=50)

Respondent's relationship to child with intellectual disability		**Percentage**
	Mother	68
	Father	26
	Others (grandparents)	6
Religion		
	Hindu	92
	Christian	6
	Muslim	2
Caste		
	Scheduled Caste	38
	Backward Caste	36
	Most Backward Caste	24
	Open Category	2
Marriage		
	Consanguineous	50
	Non-Consanguineous	50
Mother's age at marriage		
	<=18 Years	48
	19-22 Years	38
	23-30 Years	14
Mother's age during delivery		
	16-19 Years	24
	20-30 Years	60
	31-35 Years	14
	Adopted	2
Type of delivery		
	Normal	70
	Caesarean	24
	Others	4
	N/A (Adopted)	2
Mother's occupation		
	Housewife	76
	Daily wage	8
	Self-employed/Private job	16

Father's occupation		
	Daily wage	50
	Self-employed/Private job	32
	Agriculture	14
	Government job	4
Family's monthly income		
	<1,000	4
	1,000-5.000	42
	5,001-10,000	44
	10,001-20,000	8
	>20,000	2

Table 2: Socio-demographics and General Information of the Child with Intellectual Disability (N=50)

Age category		**Percentage**
	3-9 Years	32
	>10	68
Gender		
	Male	68
	Female	32
Age of detection of disability		
	<1 Year	60
	1-5 Years	34
	5-10 Years	6
Associated condition		
	Children with multiple disability	62
	No associated disability	38
Schooling		
	Home-based care	76
	School-based / Day care	24

Consanguineous marriages were mentioned by 50% of the parents. Almost 50% of the mothers had got married at the age of 18 years or younger, 38% had married between 19-22 years of age, and 14% had married between 23-30 years of age. 60% of the children with intellectual disability were born when their mothers were between 20-30 years of age, 24% were born when their mothers were between 16-19 years of age, and 14% when their mothers were 31-35 years of age. One child had been adopted as the mother was unable to conceive for a long time. 70% of the children were born by normal delivery, 24% by caesarean section and 4% by suction delivery. Birth details of the adopted child were not known.

Mental stress during pregnancy, mainly due to the lack of support from their husbands, was reported by 18% of the mothers. 6% of the mothers reported that they had taken medication for abortion during the incident pregnancy, which did not however have the desired result. Among them, 2 mothers gave their reason as not being ready to have a child at that point of time. Both mothers had taken medication from illegal doctors (quacks). The third mother's reason for taking medication (camphor) was the suspicion that she had conceived a girl child.

Negative Impact on Caregivers

This was studied under 10 domains of NIMH-DIS, namely, physical care, health, career, support structures, financial, social isolation, embarrassment/ridicule, relationships impact, sibling effect and specific thoughts. These were then categorised under three major headings which are presented below.

Personal and Health Impact

This includes the domains on physical care, health impacts on caregivers, impacts on other children, and extreme thoughts.

Physical care: 60% of respondents reported that their children were unable to attend to their basic needs unless assisted by the caregiver. In most cases (90%), mothers were the primary caregivers. 58% of respondents faced difficulties while toileting the child, followed by difficulties in dressing (50%), lifting / carrying the child (50%), bathing (48%), medicating (44%), feeding (44%) and brushing the child’s teeth (40%).

Health impact on caregivers: While 64% of respondents reported no health issues, 36% (of which 61.1% were mothers) reported some health issues which included sleeplessness, asthma, mental worries, etc. 22% also reported that they were taking medication for these problems.

Impact on other children (siblings): 92% of the respondents had either two or more children (Table 3). Among them, 41% said that since they were investing more time on the child with intellectual disability, they were unable to spend time with the other child, and 67 % were of the view that it had impacted the sibling's education.

Table 3: Impact on Siblings

Sibling Effect	Yes		No	
	N	%	N	%
Siblings*	46	92	4	8
Less time for sibling	19	41	27	59
Impact on sibling's education	31	67	15	33
Sibling feels isolated	10	22	36	78
Tension on sibling's future	12	26	34	74
Sibling teased in community	12	26	34	74
Sibling's recreation affected	8	17	38	83
Added responsibility to child	9	20	37	80

Note: *N=50, for rest of the rows, N=46.

Extreme thoughts: 12% of respondents confessed they had thought of killing the child when they came to know that the child had intellectual disability. 16% of caregivers reported suicide attempts. One mother had committed suicide because of the child, as reported by the father. 4% reported that they had thought of abandoning their child.

Impact on Employment and Other Financial Impact

This includes the financial difficulties and negative impacts on employment that the caregivers underwent on account of their child with intellectual disability.

Employment: Of the 48% (n=24) of respondents who were currently employed, 67% reported that they were in poorly paid jobs because of their child's condition. Among the employed participants, 50% reported not being able to go to work on time and 63% reported that they took leave occasionally due to their child's condition. Work was significantly affected for 17% and 25% had to take frequent transfers or had pending work.

Among those who were not employed (n=26), 23% had left a job because of their child and 54% were unable to take up a new job mainly due to condition of their child.

Financial Impact: Most of the respondents stated that they were facing financial difficulties because of their child's condition (Table 4). A majority (76%) of them experienced financial problems because of their child's treatment costs, while a few parents (20%) who had approached witch doctors had added to their financial burden. Most of the respondents (80%) said they were getting government grants/ aid regularly but revealed that it was inadequate to meet their financial needs.

Table 4: Financial Impact

Financial Impacts (N=50)	**Yes (%)**	**No (%)**
Financial difficulty due to Treatment Cost	76	24
Financial difficulty due to Medical Investigations	44	56
Financial difficulty due to Travel to Hospitals	56	44
Financial difficulty in Child's Education	12	88
Financial difficulty in Child Care	54	46
Getting Government Grants	80	20

Social Impact

This includes the domains on support structures, relationships impact, social isolation and social stigma/ embarrassment that the caregivers had faced from the family and society in various walks of life.

Impact on support mechanisms: Majority of the respondents reported that most of the time they did not get any support at all from their friends (82%), relatives (72%), neighbours (64%), in-laws (54%) and parents (50%). In most cases it affected the relationship with their relatives (44%), neighbours (46%), parents (30%), in-laws (36%), and friends (46%).

Social isolation, stigma and embarrassment: It was found that 54% of respondents did not take their child to any social functions for a number of reasons, such as difficulty in managing them, embarrassment and stigma. More than half of them (56%) revealed that they had faced embarrassment / ridicule at least once because of the child. Among them, 56% reported that they had faced embarrassment from their relatives, 34% cited neighbours, 32% blamed community, 26% said family, 12% claimed it was from in-laws, and 4% said friends. 22% reported that they faced social restrictions over attending functions and 32% faced restrictions over recreation.

Positive Impact on Caregivers

It was also necessary to look at how the caregivers of children with intellectual disability define their positive experiences in caring for their child. Hence, the positive impacts were studied qualitatively. The major themes which arose from the in-depth interviews and FGD transcripts included – self-esteem among parents, strengthening of family ties and social responsibility (Figure 1).

Figure 1

Figure 1.a: Theme one & sub-themes

Figure 1.b: Theme two & sub-themes

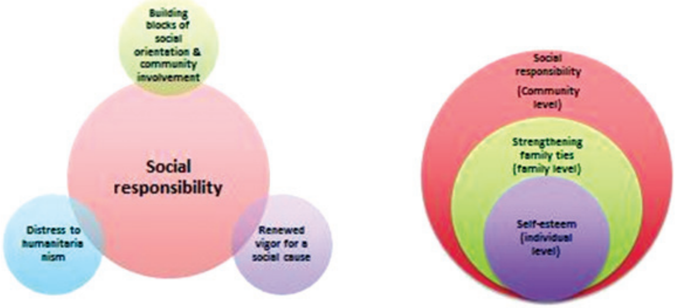

Figure 1.c: Theme three & sub-theme

Figure 1.d: Manifestations of positive impacts at various levels

Self-esteem

Participants spoke about their contentment and pride in various activities of their children. Some caregivers considered their children with intellectual disability to be more responsive than others in the family when there was a need. The mother of a 10-year-old boy with intellectual disability recounted how the child took care of her and the family when she was sick. It shows that during a family crisis, children with intellectual disability will stand as a 'pillar of support', both physically and emotionally, and care for the family like any other child.

"Whenever I am sick, he will take care of me like my mother used to. He will accompany me to the hospital, make sure that I am taking medicines in time and a lot more. On those days, he will take care of me the same way which I used to take care of him otherwise. It's not just physical support but emotional too. When other family members also become sick, he is very concerned and will be an obedient boy with so much concern. It is like a kind of spontaneous flow of empathy emanating from his soul."

Another mother who had a 12-year-old daughter with intellectual disability narrated that the neighbours appreciated the child for her good conduct in the neighbourhood. The behaviour of a child in society always lifts up parents' spirits. Whenever the child is appreciated by other people, it is a 'moment of pride' for the parents, but the stark reality is that, most often, abilities and good qualities of children with intellectual disability are not acknowledged by society.

"My child doesn't take all that is offered to her by the neighbours but always has a sharing mentality. She is very dear to the neighborhood because of her good conduct. When I hear my neighbours talking highly of her, it always makes me a proud mother."

Often, when society considers these children with intellectual disability as 'bad luck', most of their caregivers view them as a 'sign of fortune and success'. This, in a way, boosts their self-esteem and morale too. A mother simply explained how her boy with intellectual disability has become her 'luck symbol' and attributed her ability to secure a job to her child.

"I took my child continuously to the hospital for physiotherapy to see my child walking. Being a regular visitor, I studied all the techniques in physiotherapy given for special children. When the hospital had a vacancy, they called me for the post of assistant physiotherapy trainer for these children. I got my job because of my son only. I think I can do more justice to the job than anyone else."

Generally, caregivers of children with intellectual disability who accept the condition of their child as a reality become more determined and purposeful in their attitude towards life and strive to fight against the odds. Some succumb to the tragedy, some live with unrealistic expectations, while many live with sheer willpower and a sense of hope. Those who endure are role models of human endeavour and self-confidence. There are many such instances among the parents of children with intellectual disability. Most of the caregivers in the present study echoed a 'sense of hope and optimism' during the course of the FGD and interviews. Both are motivational components that anticipate good things will happen; this also boosts the individual's self-esteem. One mother reassuring herself, said optimistically, that her son with intellectual disability would be able to walk without support in the near future.

"I know that my child won't be able to run around and play like children in the neighbourhood. But I want to see my child walking without support and doing things for himself in the near future. I am sure he will walk one day and support other children like him."

Strengthening family ties

The study also revealed that in most cases the child with intellectual disability nurtures and strengthens the family bonds. The mother of an 8-year-old boy with intellectual disability considered her child as the glue that holds the family together, especially in strengthening the husband-wife relationship.

"The doctor's opinion at the time of his birth was that he (child) would not survive long. But my husband was not ready to accept that and did everything possible for his survival. My son got the best Appa (father). He is now the greatest bond between me and my husband."

Another mother explained how the child with intellectual disability fortifies the bond between siblings.

"Both my daughters look after him like their son. Now all the family is united towards a common endeavour."

Children are always a source of joy and happiness in the family; they lessen any sadness or hardships. Even though the outside world thinks that the families of children with intellectual disability are in distress, the working mother of a 7-year-old boy saw the child as her stress-buster.

"After coming from job, I spend time with him and all my tension vanishes. These are things which money can't buy."

The caregivers of children with intellectual disability have to adjust to variable situations and requirements of the child. Most of the participants in the present study explained how they had adjusted and adapted to these situations and gained patience which added a new meaning to life. The father of a 10-year-old boy narrated how the child became a priority in his life and how he learned to be patient and tolerant. These are important qualities that can help cement family ties.

"Earlier I had lot of anger. I was short-tempered and used to beat my wife. When he (the child) was 3, I beat him for the last time. Now I am very calm and patient to all. If I become angry, my blood pressure will rise and I will die fast. Then who will look after my family? Patience is the nectar that uplifts your soul."

Social responsibility

The parent of a child with intellectual disability can gradually become a crusader for all the causes that other parents face in similar situations. It is actually a journey from distress to humanitarianism. The mother of an 8-year-old girl with intellectual disability, who cannot read, narrated how she argued successfully with officials for the rights of another parent who has a child with intellectual disability.

"I can now talk to any officers without fear. Last week, I went to Collector's office and argued with them for another mother (with a child with disability) who is not getting her (financial) grant properly. I was heard seriously and our demands were accepted."

Parents of these children tend to be more altruistic and can understand the sufferings of children with similar conditions. They act as 'building blocks of social orientation and community involvement'. The mother of a 9-year-old child with intellectual disability explained how she has helped the day care centre for special children when help was needed.

"Whenever the day care is short of biscuits and snacks, we will try to arrange it for the children. The two fans here (day care) are given by my minibus employees. Nobody can close their eyes to the needs of these kids."

Having experienced misery and other struggles, parents of children with intellectual disability tend to become more socially inclined and involved in social activities. The mother of a 14-year-old girl with intellectual disability explained how the day care school for special children recharged her soul and gave her renewed 'vigour to pursue for a social cause'.

"I am happy to come to the day care every day. All these children are now my children. They are all very innocent and more truthful than normal children. The environment uplifts your soul into realms of selflessness and dedication. You are recharged with renewed vigour to pursue your goal."

DISCUSSION

This study examined the negative and positive impacts on caregivers of children with intellectual disability. The study establishes that the most essential support for a child with intellectual disability comes from the family. The parents of children with intellectual disability have a double burden - to protect and take care of their dependent child and to guard their child against the negative attitudes of society. The results of this study showed that most of the parents experienced negative impacts in terms of physical care, financial aspects and at the social level. Despite such negative outcomes, positive outcomes have also been reported in FGDs and in-depth interviews.

The mean age of the respondents was 40.5 years and most of the families belonged to a low socio-economic stratum, with monthly income of less than Rs.10, 000. Since the interviews were generally conducted during the day, it was very difficult to speak to the fathers as most of them were out on work. One of the major findings, based on background information, was that 50% of these parents were blood relations, which points towards the already established fact that consanguineous marriage is a risk factor (Saad et al, 2014) for the child to develop intellectual disability. Marriages within the family are part of tradition among certain castes in Tamil Nadu. Some of these are even obligatory relationships. This needs to be addressed through education and by spreading scientific awareness about the genetic, hereditary and congenital diseases associated with consanguineous marriages. Another important aspect which was revealed was that 24% of the mothers gave birth to their child with intellectual disability when they were younger than 19 years of age, and 14% of mothers gave birth after the age of 31 years. Even though older maternal age is a proven risk factor for development of 'Intellectual disability' among off-spring (Huang et al, 2016), younger maternal age and its relation to the child's intellectual capacity is a less explored area. More research needs to be undertaken to discover the relationship between intellectual disability and young maternal age.

Most caregivers reported that they had experienced difficulties in taking physical care of their child, which in turn led to their own health issues – mainly, psychological problems. Psychological stress including depression was the main health issue of caregivers, especially for mothers in previous studies (Olsson and Hwang, 2001). Parents' stress and strain can be alleviated through interactions and counselling, especially through NGOs working in this region. In the present study, mothers were the primary caregivers for the child with special needs. This also resonates with the findings of the study by Heller et al (1997). Hence, support mechanisms need to be set up for the mother and there should be concentrated efforts to keep her spirits up and boost her morale. Every act of counselling should be at her convenience and, ultimately, aimed at confidence building. Other family members including husbands, siblings and grandparents should also be given proper counselling.

In the area of social impacts, the crux of the matter was found to be society's negative attitude towards children with intellectual disability and their families. When people distance themselves from such disadvantaged sections, it affects the caregivers of children with intellectual disability and they will be reluctant to discuss their problems with others due to the perceived social stigma (Kaur and Arora, 2010). Although it takes time to change the mindset of a larger society, efforts to overcome this stigma should start from the caregivers of the children with intellectual disability. They need to become role models. To this end, the caregivers should be directed towards forming Self Help Groups (SHGs) of similar persons. Group discussions, one-on-one listening, support groups for parents of children with similar disabilities and other potential interventions can provide opportunities to share experiences and encourage peer support and guidance.

Whether the disability is mental or physical, the aggravating factor is always financial deprivation. With regard to financial impacts, it was revealed that a majority of the caregivers suffered financial difficulty due to treatment costs for their child. A study conducted by Singh et al (2008) among caregivers of children with intellectual disability also showed that negative impacts were highest in the financial domain. The monetary support which the government offers to these parents was also inadequate and irregular. Poverty compounds disability. Hence, the strategy should be to support the financially weaker sections, where people have to bear the double burden of poverty and of rearing a child with special needs. All healthcare services to the parents as well as the children with intellectual disability should be provided free of cost. Although the parents of these children are entitled to various forms of financial support, there is no effective mechanism to monitor and evaluate whether the money reaches them regularly. The quantum of financial support given by the government should be increased and an effective monitoring mechanism is needed to provide accountability.

Even though the study revealed several disturbing realities in the family situation, the positive impacts provided some hope. There are definite signs of empowerment among children with intellectual disability whose parents have maintained a positive outlook in the face of all the hurdles they encountered. Earlier studies have also documented how positive and negative impacts among families may co-exist and be relatively independent from one another (Blacher and McIntyre, 2006).

An important finding was that caregivers were gaining 'self-esteem'. In many cases, having a child with intellectual disability often spurs the caregiver to fight against all the odds in his/her life. When a person rediscovers his/her capacities in the face of heavy odds, it directly results in improving his/her self-esteem. Self-esteem among parents of children with intellectual disability is so important to the fact that it acts as a positive predictor against perceived stigma (Cantwell et al, 2015), also as a coping mechanism that can mitigate the impact of stress on mental wellbeing (Marcussen et al, 2004).

Another important positive impact was 'strengthening of the family ties'. The finding shows how these children act as the 'unifying agent' in the family and thus fortify the family bonds. The research by Stainton and Besser (2008) also pointed out 'source of family unity and closeness' as a positive impact. Although this cannot be generalised to the fact that all children – whether with intellectual disability or not - strengthen family ties, further studies are needed to support this finding.

'Social responsibility', which emerged as another important finding, has its manifestations more at the level of community and society at large. Stainton and Besser (2008) also revealed how parents of children with intellectual disability improved and expanded their personal and social networks and community involvement. The possibilities for enrichment of the spirit are very real for the primary caregiver of a child with intellectual disability. The challenges may progressively strengthen the parent/caregiver to surmount the odds he/she faces in life. Only a person with deep commitment and compassion for the individual with disability can adjust to the situation. It is a learning process which is built on devotion and practice. Parents of children with intellectual disability broaden their outlook and then become torch-bearers of social change.

The three major themes that emerged from the study can also be seen as elements which interact with each other and manifest at three levels - individual level, family related and society centered (Fig1.d). The relations and interactions between the family members of children with intellectual disability, and even with the wider society, are very important since they help in developing policy frameworks in this regard.

Therefore, the aim should be to focus on strategies for inclusion of parents as a pre-requisite for better assimilation of the child with intellectual disability into society as a whole.

CONCLUSION

The caregivers of children with intellectual disability should be allowed to participate regularly in the social decision-making process, including in the relevant aspects of local self-government. Whenever there are policy changes, special care should be taken to keep within its ambit the needs and concerns of persons with disability. External providers such as the government and NGOs must work closely with families to design and implement interventions that are culturally appropriate and adequate in the given surroundings. Families of children with intellectual disability should also be given knowledge, skills and support to meet and fight for the needs and rights of their child. Parents should be educated about the clinical condition, treatment modalities as well as their rights. The state has made a number of provisions for these children which unfortunately do not reach them. This denial of rights should be dealt with by taking help from various support groups.

The empowerment of parents of children with intellectual disability should be seen as the first step towards inclusion of these special children. Beyond the scope of all strategies, the ultimate factor is to understand that each case is unique and distinct. Hence, the approaches for mainstreaming the children with intellectual disability and their parents should be humanistic, pragmatic, participatory and equitable, so that care is taken not to hurt their sentiments and dignity. The voice of people with intellectual disability is often not present in literature on intellectual disability, so future research should ensure that people with intellectual disabilities are increasingly involved.

Limitation

The findings cannot be correlated or compared since negative impacts were studied quantitatively and positive impacts were studied qualitatively.

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