

Psycho-social Impact of Disability on Parents having Children with Disabilities: A Case Study

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Abstract

“I cannot let my daughter stay alone. Earlier I used to carry her to my workplace. I had to keep a constant vigil on her as she is a girl and many people use to come to my workplace. There is a constant fear in my mind. What if anyone does some wrong with her.”

Children with disabilities are one of the most vulnerable sections of the society. With them, the parents of these children with disability are often subjected to various forms of discrimination that impact them psychologically. Therefore, to understand the psycho-social issues faced by the children with disability and their families, the researcher have employed case study method. Two cases are selected for the study which will throw light on the lack of awareness about disability, stigma, stereotyping and a lack of social support, and will understand the struggle of the parents along with these children in dealing with the situation. The study also suggests various mechanisms to cope with these situations faced by the parents.

Keywords: Disability, Children, Parents, Psycho-Social, Cachar

Introduction

In almost every society worldwide Persons With Disabilities (PWDs) are often subjected to marginalization and discrimination. Among them, Children with disabilities are the most vulnerable, face oppression, and get treated as non-equal to non-disabled children in our society. They face numerous issues and challenges for their inclusion in the mainstream in terms of struggling to get proper rehabilitation services. It is crucial for them to rehabilitate at an early stage. Early detection and rehabilitation have a profound impact on adjusting and normal functioning of these disabled children. The family members also suffer from stress and anxiety while caring for and nurturing their disabled children due to a lack of proper institutional services at the community level. This research paper highlights the plight of children with disability and their families and how they face psycho-social issues in their daily lives.

In India as per census 2011 The total population of India is 1.21 billion and the latest figures on persons with disability have shown only a marginal increase in the number of PWDs in the country with the figure rising from 21.9 million in 2001 to 26.8 million in 10 years. In percentage terms, it has risen from 2.13% to 2.21%. Where as in Assam There are 4,80,065 persons with disability (Census of India, 2011). Barak valley of Assam comprises Cachar, Karimganj and Hailakandi districts. It has a 56,012 disabled

population Out of which there are 27,457 PWDs (49.02%) in Cachar district. There are 3,531 Children with Special Needs (CWSN) are there in Cachar district as per Inclusive Education Department (2018).

Literature Review

Children with disability face various challenges in their daily lives due to poor rehabilitation facilities, lack of services, poor accessibility to education, health care and poor support from the neighbourhood, sometimes from the family itself, and maltreatment by the community making these children vulnerable. (Jayaseelan & Naomi, 2018)

The study by Nath (2007), found that PWDs consider themselves a burden to the family since they are not able to take part in household chores or extend their support. Further, it is also found that PWDs are not respected by their family members or by others which develops depression among them. The differently-abled are seen as consequences of sin done by the parents in rural India. They often face negative attitudes from a society where they are excluded. Goffman refers to stigma as an attribute that is significantly discrediting. A stigmatic person is not considered to be quite human or normal. Therefore, stigma is “the negative perceptions and behaviours of so-called normal people to all individuals who are different from themselves”. Hence, the concept of stigma can be seen as an important social reality that differently-abled people face. The individual is in a situation where he/she is rejected from full social participation and acceptance. A stigmatic person is seen as having a ‘spoiled identify’ and viewed as a strange and different human being and this induces a negative reaction (Goffman, 1961). Among them, people with mental retardation and other psychiatric disability are more vulnerable subjected to maltreatment and distancing themselves from participation in societal functions, which leads to exclusion from the community (Klasing, 2007). It is also found that societal neglect and denial lead to poor mental health issues among these PWDs restricting their social participation. Poor self-esteem and other behavioural problems are seen in Persons with disabilities (D’Mello, Monteiro, & B.M., 2017). Families with psychiatrically disabled children, isolate themselves from social functions because of their child’s condition which can be sometimes abusive and or socially offensive behaviour leading to social withdrawal.

Families of such psychiatric disabled children experience a variety of stress and anxiety. The care-giving time and commitment lead to the negligence of the other members of the family which leads to disruption in family functioning (Srivastava and Kumar, 2015). Mothers of the differently-abled child are overburdened and under constant stress with managing all the household activities along with looking after their child and mostly curtailing their own needs and restrict themselves from participation in the social functions (Antony Raj & Sivamoorthy, 2021).

Benderix, Nordstrom, & Silverg, (2006) in their study discuss the parental stress of having specially-abled children and the hardship and challenges they face. The dependency of the child on the parents, constant anguish among the parents of not having a healthy and typically developed child, emotional breakdown, and adapting and adjusting to the child’s needs among others are some parameters which elevate the stress and anxiousness of the parents. Having a friendly environment at home, an empathetic attitude from friends, family members or other close associates, and formulation of facilities like daycare centres or home-based services for the specially-abled children between the government and parents of

specially-abled children would help in benefitting those children and easing the social and psychological environment for the children along with their parents.

DeZelar & Lightfoot, (2019) talks about the complexity of parents having a specially-abled child. The necessity of having formal or informal support groups among parents of these children, building new friendships through these support groups which would in understanding and supporting each other condition better and also the fragility of these support groups which needs to be improved are highlighted. To address these issues, positive actions to connect with community social services, and the formation of PCP that is person-centred planning will help in intervening and building a strong support group, thus helping in enhancing the support for parents with specially-abled children.

Hsiao (2014) studied social support and family demographics to find out the association between healthy family functioning and social support. Along with this, the study explores the potential mediating effect of social support on the relationship between family functioning and family demands in families of children with Down syndrome. Findings of the study suggested healthier family functioning can be predicted with greater social support which provided to the family.

Boyd (2002) conducted a study to find out an association between lack of social support and stress among mothers having children with autism. Findings suggested that mothers who received more social support related emotionally better to their child and experience less stress than their non-receiving counterparts.

Methodology

Case Study method was employed for which the researcher have selected two cases from Cachar district of Assam, India. The cases were identified and selected for research with the help of Resource Person of Inclusive Education department under Sarba Shiksha Abhijan Assam.

In depth interviews were conducted followed by elaborate explanations in this study to understand the plight of children with disability along with their family members facing psycho-social issues in their daily lives. The cases are divided into themes that are identified by the researcher from the study.

Background of the Respondents

Case Study 1

Sandhya (name changed) is the mother of Subir (name changed), a 16 years old young boy living in Panchayet area of Silchar. He is suffering from Multiple Disability (Cerebral Palsy and Mental Retardation) since his birth. Pradip (name changed) is the father of the child who is an auto rickshaw driver by profession, and Sandhya is a homemaker. They are a nuclear family with two children-one son and a younger daughter. Subir is the elder one and their daughter studies in Class 4. Both his parents enrolled Subir in a special school for children with disability in Silchar which is run by an organization named Ujjevan Spastic Society since 2016.

Case Study 2

The researcher is using another case study from his study area for an in depth understanding. Sobita Dey (name changed) is the mother of Pooja Dey (named changed) aged 14, residence of Putichora of Udharbond who is a special child. She is suffering from Mental Retardation since birth. Sobita lives in a joint family with her husband, in-laws and 4 children-one elder daughter, two younger sons and a younger daughter. Krishna (name changed) is the father who is also a patient of mild mental illness because of which he does not have a fix job and engages himself in menial jobs. Sobita works as a cook in the local police station and the whole family runs upon her income. Her younger sons and daughter studies in a nearby government school. Pooja was also went to the same school and completed her schooling till Class 5 after which she discontinued her study because her condition did not permit her to study further.

Findings and Discussions

Analysing the case studies in a detailed manner the following broad themes are identified highlighting the psycho-social issues faced by the children with disabilities along with their family members.

Social Exclusion and Isolation

Parents of children with disabilities are under immense pressure to cope with social isolation facing by them on a daily basis. It is evident in the present cases where the parent of one child opined, “There was no option of sending him to school because he cannot go to a normal school and there was no special school in our area. We started living in isolation. He had no friends because no kids in our area wants to come and play with him indoor and he cannot walk properly so could not go outside and play with them. We started to distance ourselves from our relatives as because he used to cry or babble or use to shout when we use to visit them which they did not like.”

In a similar case of other child, her mother said, “I am so stressed all the time about her condition. She is growing and with her my stress and anxiety keeps on increasing as to who will take care of her in my absence. I cannot rely on anyone. Even in today’s time, people are very superstitions about mental retardation and have no knowledge about it. No parents allow their child to play with my daughter because of her condition and they always make fun of my child.”

It can be seen from the cases above that the parents of these children are living under constant stress and uncertainty about the future of their child. The prevalence of such mental condition amongst parents of specially-abled children is quite common. These specially-abled children often encounter negligence from relatives, peer groups or other close associates leading them to seclusion. The UN Convention of the Rights of Persons with Disabilities (UNCRPD) clearly states to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. But the seclusion from social groups lowers the self-esteem among the parents making it difficult to adapt themselves which is long and painful. Along with this, the gender biases which are already in existence in our society is further accelerate with disability leading the girls been subjected to more stereotyping. The social exclusion, emotional unavailability along with the grief of never seeing their child living a normal life increases the level of stress and anxiety among the parents of specially-abled children.

Barrier Faced in Accessing Formal and Informal Support

Lack of formal as well as informal support is another very problematic zone that is faced by the parents of specially-abled children. The lack of formal support from the government in terms of establishing special schools with special educators, lack of infrastructural support in inclusive schools, public spaces and lack of day care centres stand as a barrier for these children. In the present cases the respondents face same problem where there is no proper formal or informal support group in the area. One of the parents informed, "I got information about a day care centre in Shillong Patty in Silchar named Ujjevan Spastic Society, a special school for differently-abled children but they do not have trained professionals. Still I admitted him in that school so that his skills get improved and he can spend some time in company of other kids of similar condition. Apart from this school there is no other proper rehabilitation centre in Silchar where I can send my son for proper treatment and care." There is no proper rehabilitation Centre in Silchar where they can send him for proper care and treatment and sending him to some other good rehabilitation centre in Guwahati is not feasible for them because of poor economic condition.

In another case the mother responded, "I used to send my daughter to nearby government school along with my other children. But she could never cope with her studies because of her mental condition. As I have a friendly relation with the teachers and headmistress of that school so she somehow completed her schooling till Class 5 but after that she had to discontinue. We do not have any special school for specially-abled children in the entire area and honestly I am not that financially sound to send her to some other special school which are in distanced place."

Attention can be drawn to Right to Education Act 2009 whereby no children including the specially-abled children will be denied education and every child will enjoy the same benefits. The schools have to equip themselves with trained special educator and infrastructural facilities so that these special children can avail the benefits. But in reality there exist a gap in the implementation. It is seen that these specially-abled children are subjected to humiliation for their conditions by their fellow classmates, apathetic attitude of teachers makes them miserable. In the present case studies, it can be seen that there is no proper rehabilitation centre in the entire district and there is only one day care centre which is an NGO helping the specially-abled children to engage themselves and teach them various activities. But the centre is not accessible in terms of distance and costing to every specially-abled child in the area and this is evident from the second case study. It can be formulated from the above cases that socio-economic factor puts a lot of strain on the well-being of those children as well as on the parents and eventually they are left out in the process.

Total Dependency on the Parents

The dependency of the children on their parents and more on the mother is another parameter which is quite evident among these specially-abled children. Sandhya, the mother of one of the children stated, "My life started to revolve round my son. I am very obsessed about him and I cannot leave him alone for a minute. I used to juggle between household chores and caring and nurturing him. Even when we admitted him to Ujjevan Spastic society I take him to his school which starts at 11 am and I sit there and bring him back at 2 pm. He starts crying if he doesn't see me around."

Similar situation is faced by the mother where she stated, “I cannot let my daughter stay alone. Earlier I used to carry her to my workplace. I had to keep a constant vigil on her as she is a girl and many people use to come to my workplace. There is a constant fear in my mind what if anyone does some wrong with her. None of my close relatives kept any contact with us because of her condition. But now as my other children are there so I leave her at home in their custody. They take care of their elder sister.”

The present case studies offer an insight into the lives of the parents and their children where they are completely dependent on their mother as their physical and mental condition does not permit them to work on their own. This takes a toll on the parents’ mental health as because they live in a constant state of worry about what will happen to them in absence of them. The trust issue is every common in both the cases where the parents are not willing to leave their child in other’s custody because of guilt consciousness and also lack of psychological support from relatives, neighbours and friends. Special attention can be drawn to the case of the girl where the mother lives in a constant state of worry and fear because of her gender. The girls who specially-abled face different set of problems other than their physical vulnerabilities. There are many underlying challenges such as menstruation, fear of sexual abuse, marriage, adding more stress and anxiety into the already existing set of difficulties of the girls and their parents. Furthermore, disability adds additional barriers to full participation and thus exacerbates other cause of exclusion.

It can be also seen that the parents of disabled children face difficulty in coping with their situation. Anxiety, over-protection, low level of coherence, less emphasis on personal growth within the family members is quite common. The parents experience stress and care-giving challenges related to health problems, depression than parents of non-disabled children. (Heiman, 2002).

Sobita (mother of Pooja) said on this issue, “With this condition of my daughter no one will ever marry her and in our society people don’t understand disability. For them she is a mental patient and I have this constant fear that because of her condition my other children might face difficulty in getting married.”

Emotional Management with Other Children

It is also seen that the having a specially-abled children in the family impact the lives of other siblings along with their parents. In the process of juggling between household chores and taking care of the child the other child is left out of the desired love and attention from the parents. This is another dimension which the parents face trouble in dealing with. In both the cases the parents shared their difficulty in managing the other siblings. Subir’s mother stated, “I can’t give my daughter proper time and attention because of my son. I had to take care of him all the time as he is completely depended on me. I cannot take my daughter to school or help her in her studies which her friends’ mother often do. This situation keeps mentally irritating her all the time as she is also a child and she wants the same attention and time which I give to her elder brother.”

Similar situation can be observed in the other study where the mother said, “Though my other children love their elder sister but sometimes they get angry because I focus more on her needs and save money her future. Sometimes I have to deny my other children stuff that they ask for. This situation leads to

chaos in my house where they shout and scream because in the process their needs and desire gets unfulfilled.”

Thus, it is apparent in both the cases where the younger siblings often feel that they are neglected of the care and attention as well as their demands are not fulfilled which their specially-abled sibling is receiving thereby creating a situation making them angry and irritable. The healthy relationship between the family members are distorted which leads to stressful and negative home environment.

Financial Burden

Financial constraint is another phenomenon adding to the stress and burden on parents. Poor socio-economic condition impacts the families with specially-abled children. Financial constraints often limits their reach for proper rehabilitation which might affect the child negatively. In both the cases, financial constraints stand as a hurdle for the parents. Sobita stated, “I earn a monthly amount of Rs. 4,000-5,000/- which does not suffice to our need. I feel dejected and helpless for my daughter. With this income I am unable to provide her any medication or better treatment which might improve her condition. This always keeps me sad and mentally frustrated.” Sobita further informed “As of now my daughter did not receive any financial help from the government. I don’t have much time and scope to go and register her name in any of the government schemes allotted to specially-abled children. But I am planning to apply for Deen Dayal Pension Scheme for her and if she gets the amount that would be great help to her. I could at least provide her with the required medication for her condition which might help her in improving her condition.”

The other case study same situation can be witnessed. Pradip (Subir’s father) said, “I earn only Rs. 5,000 to 8,000/- per month and is the only source of income for my family. My son did not receive any help from the government and I could not give him proper medical treatment because of my poor financial condition. There are some good rehabilitation centres in Guwahati but it is not feasible for me to take him there. My son did not receive Deen Dayal Pension Scheme from the government though I have applied for it.”

The present studies narrate the psycho-social condition of the parents who have children with disability. They are constantly living in a state of anxiousness over the uncertain future of their children and the fear as their present situation is not permitting them to provide them with better facilities. They are waiting for financial help from the government which is a pension scheme provided to specially-abled person that would help them in meeting their basic needs.

Suggestions

To address the psycho-social issues encountered by the specially-abled children along with their parents in a day to day basis requires holistic and inclusive solutions which need to be achieved not only through policy level but also through human rights approach. Some suggestions that can be gathered from the case studies conducted are:

- Sensitizing and spreading awareness among communities in treating specially-abled children with compassion and kindness and not as a curse or disease should be enhanced.

- Non-Governmental Organisations (NGOs) should actively engage themselves in providing support and awareness building in interior schools and within communities to build a positive environment for the specially-abled children.
- Informal support group can be organized by the NGOs with the help of community members who would help in connecting the parents of specially-abled children in the areas which would help them in interacting with each other thereby helping in forming a support group.
- Inclusive education should be promoted as per RTE 2009 and Rights of Persons with Disability Act 2016. Teacher's training at regular interval, appointment of special educators at schools, developing disabled friendly teaching-learning models for the specially-abled students must be encouraged for the success of inclusive education. Parental training programme would help parents to cope up with the situation.
- Day care centres with trained special educators must be opened by the government in the region with minimal cost so that parents can afford to bring their children.
- Government schemes and policies pertaining to specially-abled children must be spread through print and mass media which would help parents in accessing the benefits for the children with disability.

Conclusion

Disability is not only associated with stigma but also give rise to negative attitudes, preconceived perceptions and societal barriers leading to the deprivation of differently-abled people. Klasing(2007) "Disabled people in rural India are often excluded from education livelihoods, medical care and social life. But so are people from lower castes and poor people in rural India and in particular the girls and women among them". The families of children with disabilities experience stresses, anxiety and often suffer neglect, maltreatment and abandonment engendered by the condition.

Therefore, social inclusion of the children with disability is possible with the implementation of proper steps and policies at the ground level. Change in attitude and mind set of the people, empathetic behaviour, proper infrastructural support, strengthening informal support groups with proper policies and strategies at the governmental level can help in bringing a positive and supportive environment for the specially-abled children with their parents helping them in bringing out of their seclusion.

References

1. M. Antony Raj, M. Sivamoorthy. Psycho-Social Problems Faced by Mothers' of Children with "Attention Deficit hyperactivity Disorder". Jijnasa (ISSN: 0337-743X), 2021, 38(1), 100-105.
2. Y. Benderix, B. Nordstrom, B. Silverg. Parents, experience of having a child with autism and learning disabilities living in a group home A case study. SAGE Publications and The National Autistic Society, December-2006, 10(6), 629-641. <https://doi.org/10.1177/1362361307070902>
3. J. Blaceher, C.L. Neece, E. Paczkowski. Families & Intellectual disability. Curr Opin Psychiatry, September-2005, 18(5), 2005, 507-513.
4. B.A. Boyd. Examining the Relationship Between Stress and Lack of Social. Focus Autism Other Developmental Disability, 2002, 208-215.
5. S. DeZelar, E. Lightfoot. Parents with disabilities: A Case Study exploration of support needs and the potential of a supportive intervention. Families in Society: The Journal of Contemporary Social Services, 2019, 100(3), 293-304. <https://doi.org/10.1177%2F1044389419841172>

6. L. D'Mello, M. Monteiro, Govindaraju B.M. Psycho-Social Problems Faced by Person with Disability. International Journal of Management, Technology, and Social Sciences (IJMTS), July-2017, 2(2).
https://srinivaspublication.com/wp-content/uploads/2019/06/1.SocialProblems_FullPaper.pdf
8. Erving Goffman. Asylums: Essays on the Social situations of Mental Patients and Other Inmates. Cox and Wayman Ltd., 1961, 119-122.
9. Tali Heiman. Parents of Children with Disabilities: Resilience, Coping, and Future Expectations. Journal of Developmental and Physical Disabilities, 2002, 14, 159-171.
<https://doi.org/10.1023/A:1015219514621>
10. G.M. Monwar Hosain, David Atkinson, Peter Underwood. Impact of Disability on Quality of Life of Rural Disabled People in Bangladesh. Journal of Health, Population and Nutrition, December-2002, 20(4), 297-305.
11. C.Y. Hsiao. Family demands, social support and family functioning in Taiwanese rearing children with Down Syndrome. Journal of Intellectual Disability Research, June-2014, 58(6), 549-559.
12. K. Jayaseelan, C. Naomi. A Study on the Psychosocial Problems Faced by the Physically Challenged Children in Chaisa Compound, Lusaka. International Journal of Business and Administration Research Review (IJBARR), 2018, 2(21), 105-113.
<https://web.archive.org/web/20200715072726/http://www.ijbarr.com/downloads/0404201813.pdf>
13. Insa Klasing. Disability & Social Exclusion in Rural India. Rawat Publications, 2007.
14. Aditi Nath. Socio-Economic Situation of Persons with Disability in Cachar District of Assam. Educational Quest: An International Journal of Education and Applied Social Sciences, August-2017, 8(2), 575-581.
15. Prashant Srivastava, Pradeep Kumar. Disability, its Issues and Challenges: Psychosocial and Legal Aspects in Indian Scenario. Delhi Psychiatry Journal, April-2015, 8(1), 195-205.
16. Sheetal Thakur. Disability, Stigma and Social Exclusion. International Journal on Arts, Management and Humanities, 2013, 2(2), 48-51.
17. The Gazette of India. The Rights of Persons with Disabilities Act, 2016. 28-December-2016.
<https://egazette.nic.in/WriteReadData/2016/173326.pdf>
18. F. Zambelli, R Bonni. Beliefs of Teachers in Italian school concerning the inclusion of disabled students: A Q-sort analysis. European Journal of Special Needs Education, 17-February-2004, 19(3), 351-366.