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RESEARCH ARTICLE

STRUCTURAL SOCIAL CAPITAL OF PARENTS HAVING PERSON WITH DISABILITY IN CHANDIGARH

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Abstract

Structural social capital is understood as maintenance of connections, immense trust, following of certain rules and fulfilling certain commitments. It is pertinent to improve quality of life. The present research aimed to study the structural social capital of parents having persons with disabilities living in Chandigarh. The descriptive survey method with snowball sampling technique was employed. Twenty-five parents of persons with disability (N=25) having age group 20 to 55 years were in the sample. The questionnaire comprised of six statements and each statement had sub-items with the options of yes and no. Results showed that parents having persons with disabilities had good network ties with relatives, neighbours and friends but a few parents having persons with disabilities did not have good bondings. Besides, the majority did not participate in the activities such as social and cultural clubs, religious organisations, government schemes, local community functions and political organisations. The study recommends that support from the government, non-government organisations and community to provide financial, moral and psychological help to families of persons with disabilities is important for healthy development of all individuals of society.

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Introduction:-

A disability is defined as a condition or function judged to be significantly impaired relative to the usual standard of an individual or group. The term disability refers to an individual impaired due to physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness, and various types of chronic diseases. The present study is conducted to see the effect of structural social capital on parents having children with disabilities i.e. to see the day to day activities and social behaviour of parents having persons with disabilities.

There are mainly two dimensions of social capital which includes 1) structural social capital 2) cognitive social capital. Structural social capital is defined as the continued existence of network ties, rules, extensive trust, obligations and procedure. It is very important for improving the quality of life (Thuy & Berry, 2013), whereas, cognitive social capital is what and how people think and feel (Claridge, 2018).

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The child with disabilities has a profound effect on the entire family like the social and economic system of parents. On a positive side, it broadens horizons whereas, on the other side, it leads to a wide range of emotional, psychological, social, physical and financial problems in the life of persons with disability (PwD) and their families (Jayalakshmi & Aravindakshan, 2019). Studies indicated that parents of a child having a disability had a lower rate of social participation than parents having a child without disabilities (Reichman et al., 2008).

Lundy (2011) revealed that parents have difficulty in sustaining long-term friendships, as most of their time is invested in taking care of their child and working to maintain financial stability. It lessens their time to make friends and to do their leisure activities. Parents often need the support of their relatives in raising their children with disabilities and grandparents usually provide support to mitigate the stress levels. However, extended family members very rarely extend their support as they may not be emotionally attached to the children with disabilities (CwD) and it's family. Furthermore, friendships are another source of support to rely on parents as they help in lowering stress levels.

Giulio et al., (2014) revealed that parents face many challenges. The father of CwD has fewer emotional exchanges and the mother has poor social contact in terms of having feelings of emptiness, loneliness and rejection. It is very difficult to address the complex needs of a person with a disability (Reichman et al.). Each disability has a set of problems or areas to work. Eapen et al., (2014) stated that parenting a child with autism is socially, physically, financially and emotionally demanding. Researches have shown that parents with intellectual disabilities also tend to be isolated and have limited social networks (National council on disability, n.d.). Furthermore, caregivers who care for persons with mental illness face social and psychological turmoil. They feel resentment and guilt and face problems like coping with problem behaviours and feelings of isolation. It also becomes difficult to meet the personal needs of other family members (Kaufman et al., 2011). Having a PwD is also related to poor quality of life (Thuy & Berry). Persons with disabilities and their families face stigma and social exclusion. Family networks and support mitigate quickly (Thuy & Berry).

The relationship between parent, child and social ties outside family play an important role in creating a social structure (Edwards et al., 2003). Social capital has a great role in developing and sustaining the inclusion of families having people with disabilities in social life. Social capital generally includes relationships, support, trust, reciprocity, and the resources they can afford; these concepts and resources exist within communities and may also support the development of communities (Gotto et al., 2010).

Thuy and Berry reported that most of the mothers participated infrequently in community activities. A study conducted by Hansen et al., (2014) reported that family members, extended family and community didn't accept the condition of a child with disability easily. It reported that it was a burden to bring up a child with a disability alone.

It was found that very few studies have been conducted on the structural social capital of parents having persons with disabilities. Hence, the researcher endeavoured to study parents' social capital, particularly, structural social capital. The rationale behind conducting the present investigation is to understand the effect of structural social capital on parents having a child/person with a disability on their psychological behaviour and their social life pattern. Thus, the researcher in the present study tried to assess the structural social capital of parents having person/s with disability/disabilities.

Objectives of the study:-

Main objectives of the study were:-

- (1) To know the frequency of attending community-related activities by parents of persons with disabilities.
- (2) To study the frequency of visits to relatives, friends and neighbours' places by parents of persons with disabilities.
- (3) To assess the frequency of conversation with relatives, friends and neighbours of parents of persons with disabilities.
- (4) To know the challenges faced by the parents of persons with disabilities in the community.

Method and Procedure:-

A descriptive survey method was used which described the present status and situation of parents having persons with disabilities in a social setting.

Sample:-

The sample of parents having a person with a disability was selected through snowball sampling technique. Only those parents were considered who agreed to provide information as per the questionnaire. In total 25 parents were included in the study. The researcher personally collected the information from 25 parents of Chandigarh having a person with a disability.

Tool and Statistical Technique:-

The researcher adapted the social capital tools developed by Chen et al., (2009) and Onyx and Bullen (2000). The estimated reliability of Chen et al.,’s tool on social capital test was 0.87. The coefficients varied from 0.37 to 0.77 ($P < 0.01$ for all) for the overall Personal Social Capital Scale.

The researcher modified the questionnaire in Hindi. It contained six items. The statement was to be answered on a two point scale i.e. Yes/No. For calculation of the data, the researcher used descriptive statistics i.e. frequencies and percentages were calculated. Other information regarding social capital was also gathered from parents having PwD’s.

Results:-**Demographic details of Parents having Person with Disability:-**

Table 1: Demographic details of Parents having Person with Disability:

Demographic details	Frequency	Percent
Gender		
Male	09	36
Female	16	64
Age-wise distribution		
25 years and below	04	16
26 yrs - 35 yrs	02	08
36 yrs - 45 yrs	11	44
46 yrs -55 yrs	08	32
Qualification		
Illiterate	02	08
Below elementary education	02	08
Below higher secondary	08	32
Graduation	07	28
Post-graduation	05	20
Doctorate	01	04

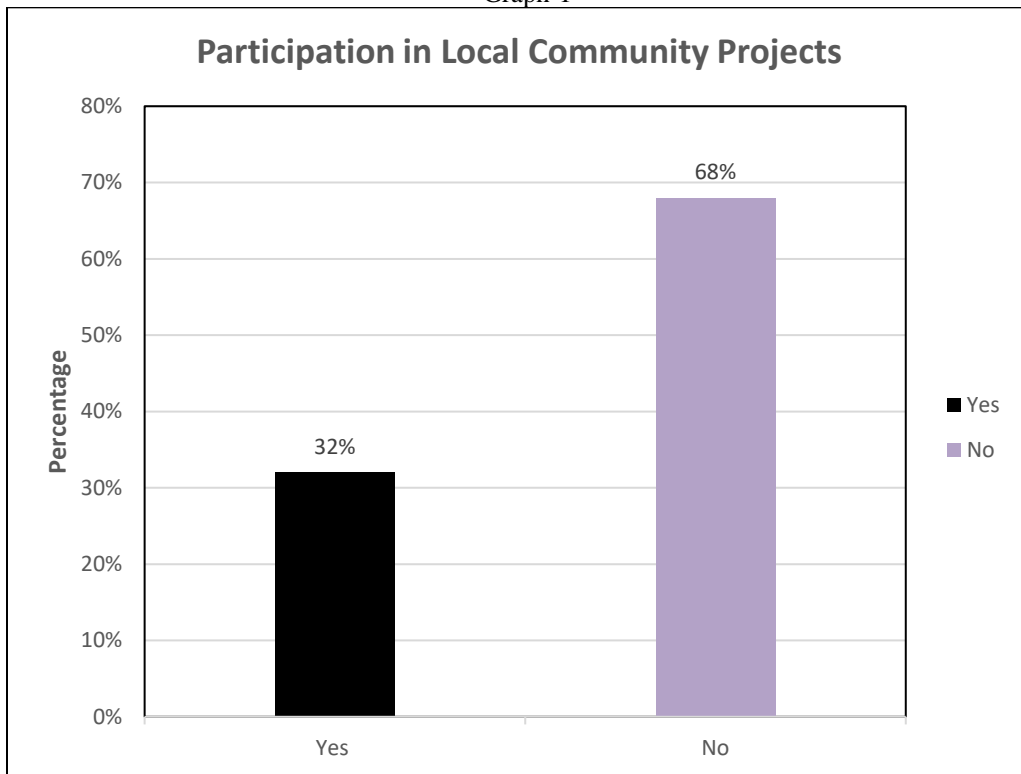
Information regarding Structural Social Capital:-

The researcher tried to find out the contact or relationship of parents having PwD with the community, relatives, neighbours and friends. The graphic representation of each item is as follows:

Item 1: Participate in Local Community Projects:

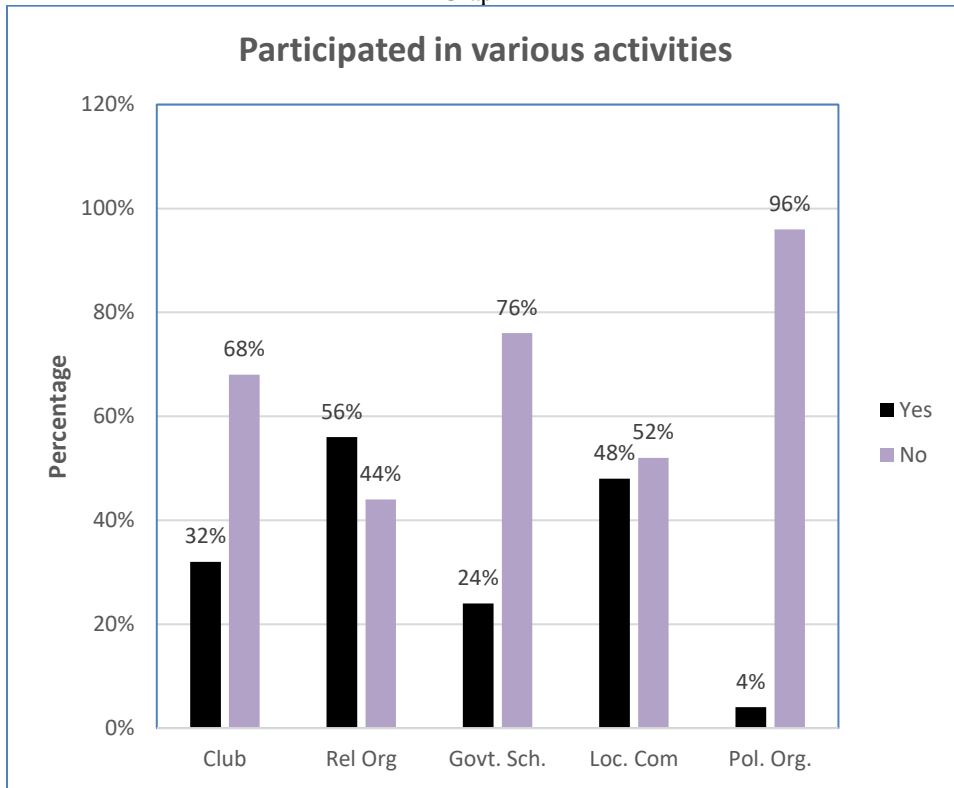
The parents were asked if they have ever participated in local community projects during the last six months. Following responses were given (Graph-1):

Graph-1

**Item 2: Participate in Activities during last three months:**

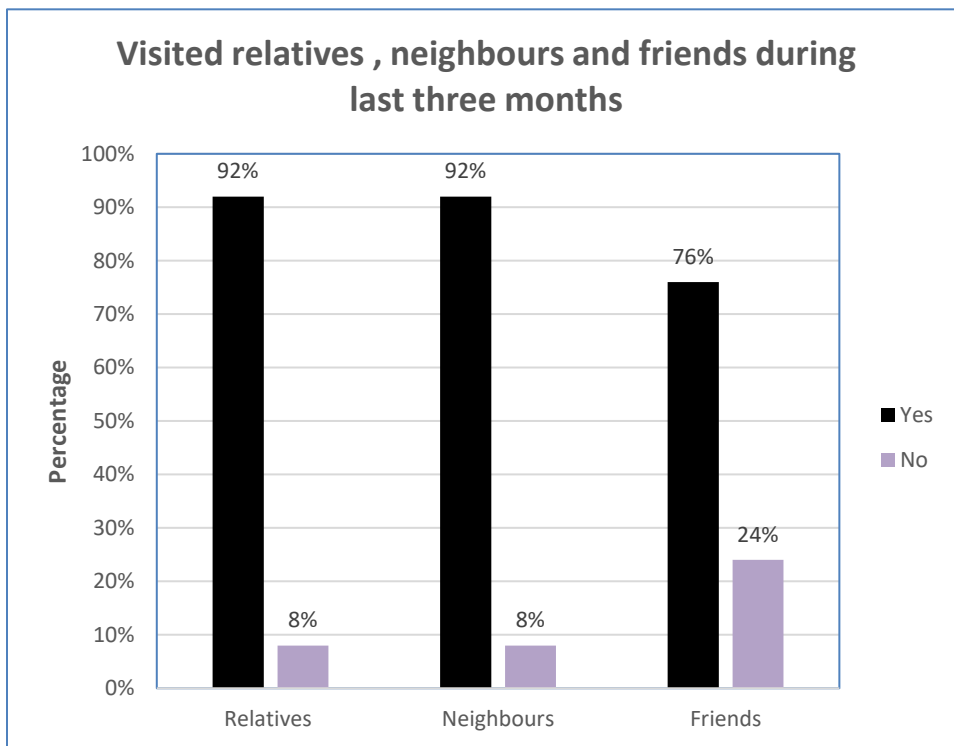
The parents were asked whether they had participated in the activities such as social and cultural clubs, religious organisations, government schemes, local community functions and political organisations during last three months. Following responses were given as depicted in Graph-2:

Graph-2

**Item 3: Visit different places during last three months:**

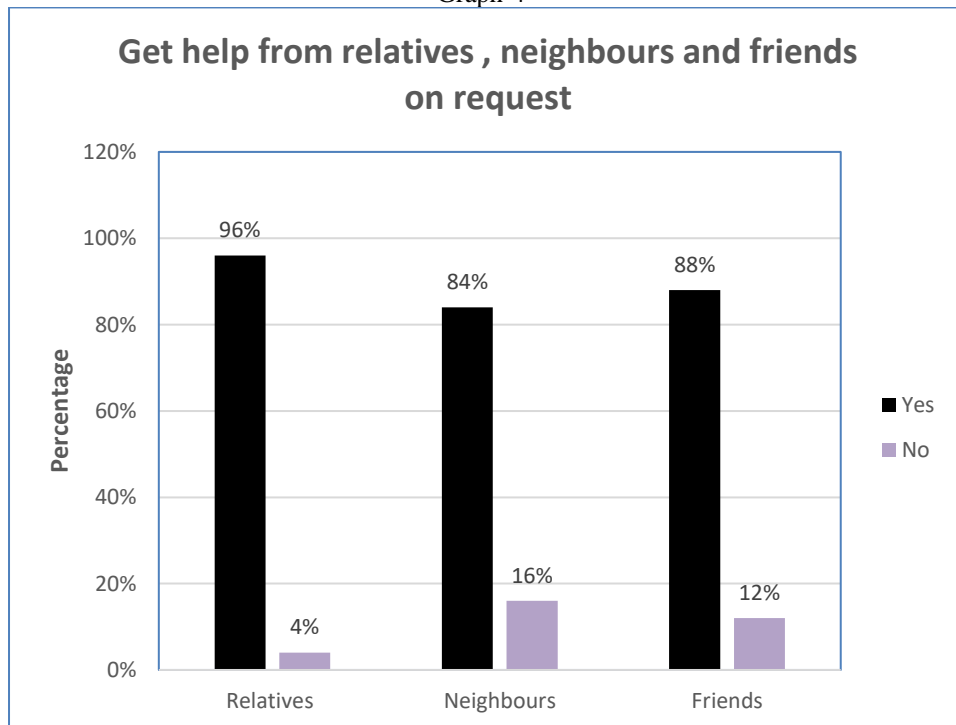
The parents were asked if they had visited their relatives, neighbours and friends during last three months. The responses are presented in Graph-3:

Graph-3

**Item 4: Got help from relatives, neighbours and friends:**

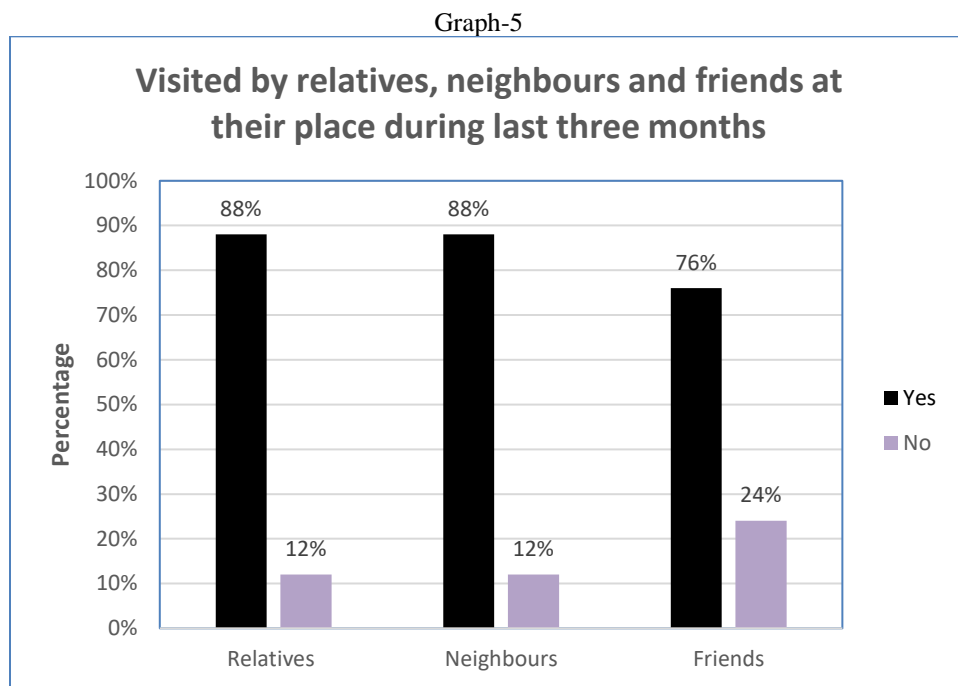
The parents were asked if they have got much help from relatives, neighbours and friends on request (Graph-4):

Graph-4

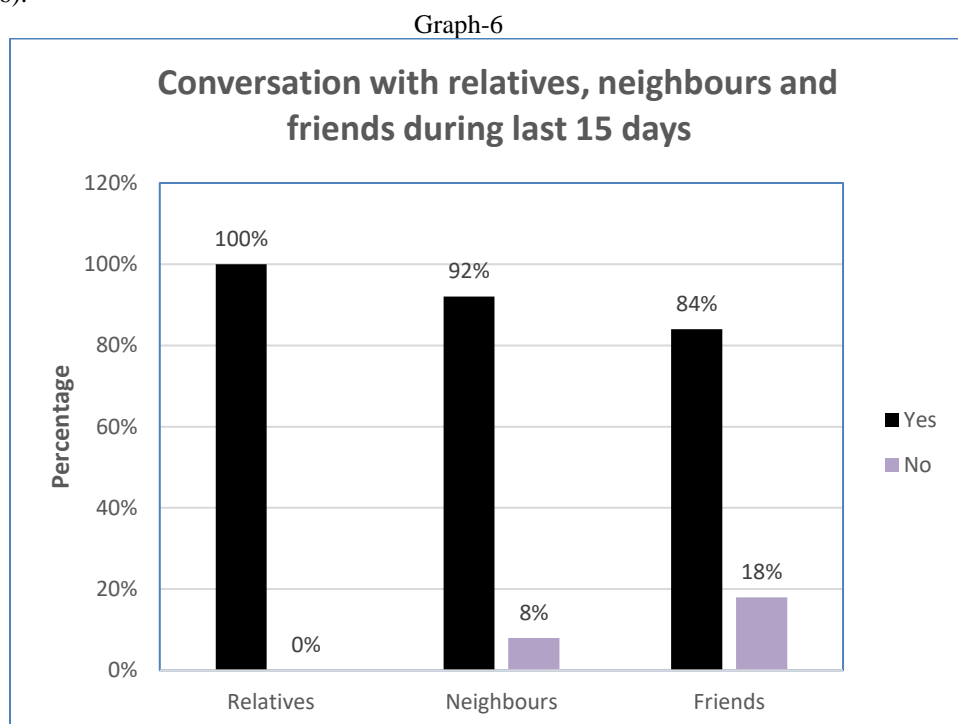


Item 5: Visited by relatives, neighbours and friends at their place during last three months:

The parents were asked if their relatives, neighbours and friends visited their home during last three months, for this purpose responses are presented in Graph-5 below:

**Item 6: Conversation during last 15 Days:**

The parents were asked if parents had a conversation with their relatives, neighbours and friends during last 15 days (Graph-6).



Other information regarding social capital given by Parents of Child/Person with Disability regarding Social Capital:-

1. A parent of a person with an intellectual disability and visual impairment mentioned that they didn't go anywhere and remained at home.
2. A parent of a person with an intellectual disability having autism revealed that they were unable to participate in any community related projects or any other activities.
3. A parent of each person with hearing impairment and leprosy-cured informed that they are so busy that they were not engaged in a social and cultural club even held in their community.
4. Some of the parents of a person with a disability mentioned that religious organization was far from home; joining a social club is difficult because of financial constraints (low economic status); having no friends.
5. Relatives did not like to come to their homes due to the intellectual disability and mental illness in their home/family.

Conclusions:-

From the above results, it is seen that more than half of parents of persons with disabilities visited their relatives, neighbours and friends during last three months; majority of parents got help on request from their relatives, neighbours and friends; more than half parents had relatives, neighbours and friends visiting them in their home during last three months; majority of parents having persons with disability talked or conversed with relatives, neighbours and friends in last 15 days. On the whole, it is concluded that majority parents having persons with disabilities had good network ties with relatives, neighbours and friends. But as reflected from other information given by parents it is analysed that there were a few parents of PwD's who did not have good bondings. Besides, involvement in activities such as social and cultural clubs, religious organisations, government schemes, local community functions and political organisations was also less.

Suggestions:-

The study suggests that structural social capital is important for mental health, lowering stress and living a good quality of life. Programs must be framed to educate the community and family members about disability so that persons with disability/disabilities and their families do not face social exclusion rather they should get full support. The government and non-government organisations should be established to provide financial support, hospital facility, moral and psychological support to families of PwD's; organizing counselling sessions is important; organising of rehabilitation therapies for PwD's and assistance in solving other problems of their families free of cost from time to time must also be carried out. The community must also come forward to support the families of PwD's for the healthy growth and development of all individuals living in society.

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