RESEARCH ARTICLE

STRUCTURAL SOCIAL CAPITAL OF PARENTS HAVING PERSONS WITH DISABILITY IN CHANDIGARH

Ms. Parineeta Jindal¹ and Prof. Anuradha Sharma²

1. Research Scholar, Department: Department of Community Education and Disability Studies, Panjab University, Chandigarh, India.
2. Professor, Department of Community Education and Disability Studies, Panjab University, Chandigarh, India.

Manuscript Info

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 disability living in Chandigarh. The descriptive survey method with convenient 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, majority did not participate in the activities such as social and cultural clubs, religious organisation, government schemes, local community function and political organisation. The authors recommend that support from government, non-government organisation and community to provide financial, moral and psychological help to families of PWD is important for healthy development of all individuals of society.

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 disability 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).

Corresponding Author: Ms. Parineeta Jindal
Address: Research Scholar, Department: Department of Community Education and Disability Studies, Panjab University, Chandigarh, India.
A child with a disability (CWD) affects the social and economic system of parents. The child with disabilities has a profound effect on the entire family. On a positive side, it broadens horizons and on a negative 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, 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 disability (CWD) and its family. Furthermore, friendships are another source of support to rely on parents as they help in lowering the stress levels.

Giulio et al., (2014) revealed that parents face many challenges. The father of CWD has fewer emotional exchanges and 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).

Relations 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 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 children 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 persons with disability.

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' place 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 with the community.

Method and Procedure:-
Descriptive survey method was used which described the present status and situation of parents having persons with disability in 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 persons with disabilities.

Tool and Statistical Technique:
Researcher adapted the social capital tools developed by Chen et al., (2009) and Onyx and Bullen (2000). The estimated reliability of Chen et al., 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 adapted 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, researcher used descriptive statistics i.e. frequencies and percentages were calculated. Qualitative information was also gathered from parents having PwD’s.

Results:-
Demographic details of Parents Having Persons with Disability

Table 1: Demographic details of Parents having Persons with Disability.

| Demographic details | Frequency | Percent |
|---------------------|-----------|---------|
| **Gender**          |           |         |
| Male                | 9         | 36      |
| Female              | 16        | 64      |
| **Age-wise distribution** |    |   |
| 25 years and below  | 4         | 16      |
| 26 yrs - 35 yrs     | 2         | 08      |
| 36 yrs - 45 yrs     | 11        | 44      |
| 46 yrs -55 yrs      | 8         | 32      |
| **Qualification**   |           |         |
| Illiterate          | 2         | 8       |
| Below elementary education |   |   |
| Below higher secondary | 8        | 32      |
| Graduation          | 7         | 28      |
| Post-graduation     | 5         | 20      |
| Doctorate           | 1         | 4       |

Information regarding Structural Social Capital
The researcher tried to find out the contact or relationship of parents having children with disability 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 opinions were given (Graph 1).
Item 2: Participate In Activities During The Last Three Months:
The parents were asked whether they had participated in the activities such as social and cultural clubs, religious organisation, government schemes, local community function and political organisation during the last three months. Following opinions were given (Graph2).
Item 3: Visit the following places in the last three months:
The parents were asked if they had visited their relatives, neighbours and friends during the last three months. Following opinions were given (Graph 3):

![Graph 3: Visited relatives, neighbours and friends during last three months]

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

![Graph 4: Get help from relatives, neighbours and friends on request]
Item 5: Visited by relatives, neighbours and friends at their place during the last three months:
The parents were asked if their relatives, neighbours and friends visited their home during the last three months (Graph 5).

Item 6: Conversation with the following during the last 15 Days:
The parents were asked if they had conversations with their relatives, neighbours and friends in the last 15 days (Graph 6).

Qualitative Information given by Parents of Child/Person with Disability regarding Social Capital
1. A parent of a person with intellectual disability mentioned that they didn't go anywhere.
2. A parent of a person with an intellectual disability having autism replied that they always contribute in local community functions, however, due to illness in the family, the parents had not been able to participate in the projects or any other activities.
3. A parent of a person with visual impairment replied that she remained only at home.
4. A parent of a person with leprosy-cured informed that they are so busy that they were not engaged in a social and cultural club even held in their community.
5. A parent of a person with visual impairment revealed that they didn't go anywhere due to their disability in the family.
6. A parent of a person with hearing impairment said that they didn't have time to participate in various activities.
7. Parent of a person with hearing impairment mentioned that religious organisation was far from home, hence, it was difficult to participate in its activities regularly. A parent of a person with autism said that joining a club may be difficult for parents with low financial status.
8. A parent of a person with mental illness revealed that they didn't have friends. A parent of a person with hearing impairment also said that they didn't have friends.
9. Relatives did not like to come in their home due to the disability as per parent of a person with intellectual disability having autism.
10. A parent of a person with mental illness revealed that they didn't have any friends to converse with.

Conclusions:
From the above results, it is seen that more than half (70%) 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 (70%) parents had relatives, neighbours and friends visiting them in their home during last three months; majority of parents with persons with disability talk or conversed with relatives, neighbours and friends in the 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 qualitative 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 organisation, government schemes, local community function and political organisation was also less.

Suggestions:
The study suggests that community participation of parents having persons with disabilities is quite less. 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 and their families do not face social exclusion rather they should get full support. The Non-Government Organisations should be created so that families are not only provided financial support but also moral and psychological support; arranging counselling sessions is important; organising rehabilitation therapies for persons with disabilities also assistance in solving other problems of the families. The community must also come forward to support the families of PWD for the healthy growth and development of all individuals living in society.

References:
1. Chen, X., Stanton, B., Gong, J., Fang, X., & Li, X. (2009, April). Personal social capital scale: an instrument for health and behavioural research. Health Education Research, 24(2):306–317. doi:10.1093/her/cyn020. Retrieved from https://academic.oup.com/her/article/24/2/306/573546 doi:10.1093/her/cyn020
2. Claridge, T. (2018, January). Dimensions of social capital-structural, cognitive and relational. Social Capital Research.Retrieved from https://dlfs2th61pid.ml.cloudfront.net/wp-content/uploads/2018/01/Dimensions-of-Social-Capital.pdf?x91095
3. Eapen, V., Crnec, R., Walter, A., & Tay, K. P. (2014, March). Conceptualisation and Development of a Quality of Life Measure for Parents of Children with Autism spectrum Disorder. Autism Research and Treatment. Retrieved from https://doi.org/10.1155/2014/160783.
4. Edwards, R., Franklin, J., & Holland, J. (2003, February). Families and social capital: Exploring the issues. Families & Social Capital ESRC Research Group, South Bank University: London .www1.lsbu.ac.uk/ahs/downloads/families/familieswp1.pdf
5. Giulio, P. D., Philopov, D., & Jaschinski, I. (2014). Families with disabled children in different European countries. Wittgenstein Centre for Demography and Global Human Capital (Iiasa, Vid/Öaw, WU),23.
6. Gotto, G. S., Calkins, C. F., Jackson, L., Walker, H., & Beckmann, C. (2010, September). Accessing social capital: Implications for persons with disabilities. Whitepaper. A National Gateway to Self-determination.[PDF document]
7. Hansen, A. M. W., Siame, M., & Van der Veen, J. (2014). A qualitative study: barriers and support for participation for children with disabilities. African Journal of Disability, 3(1): 1-9. https://doi.org/10.4102/ajod.v3i1.112
8. Jackson, J., Williams, T. L., McEachern, M., Latimer-Cheung, A. E., & Tomasone, J. R. (2019, April). Fostering quality experiences: qualitative perspectives from program members and providers in a community-based exercise program for adults with physical disabilities. Disability and Health Journal, 12(2): 296-301.
9. Jayalakshmi, V., & Aravindakshan, M. (2019). Emotional intelligence, psychological distress and coping among mothers of mentally challenged children. Disabilities and impairments, 33(1): 67-74.
10. Kaufman, A. V., Scogin, F., Macneil, G., Leeper, J., & Wimberly, J. (2010, October). Helping Aging Parents of Adult Children with Serious Mental Illness. J Soc Serv Res, 36(5): 445–459. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2952971/
doi:10.1080/01488376.2010.510949
11. Kazak, A. E., & Marvin, R. S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 33: 67-77. doi: 10.2307/584591
12. Lundy, H. F. (2011). Parental stress, socioeconomic status, satisfaction with services, and family quality of life among parents of children receiving special education services. Doctor of philosophy dissertation Georgia state university. Retrieved from https://scholarworks.gsu.edu/cgi/viewcontent.cgi?article=1068&context=cps_diss.
13. National council on disability (n.d.). Supporting Parents with Disabilities and Their Families in the Community. Chapter 13 Retrieved from https://www.ncd.gov/publications/2012/Sep272012/Ch13/
14. Onyx, J., & Bullen, P. (2000). Measuring social capital in five communities. The Journal of Applied Behavioral Science, 36(1): 2342. Retrieved from https://www.researchgate.net/publication/246794501_Measuring_Social_Capital_in_Five_Communities.doi:10.1177/0021886300361002
15. Reichman, N. E., Corman, H., & Noonan, K. (2008). Impact of child disability on the family. Matern Child Health J, 12(6): 679683. Retrieved from https://www.medscape.com/viewarticle/581577_2
16. Thuy, N. T. M., & Berry, H. L. (2013, February). Social capital and mental health among mothers in Vietnam who have children with disabilities. Glob Health Action, 6(1). Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3570571/ doi:10.3402/gha.v6i0.18886.