

WELL-BEING OF SIBLINGS OF CHILDREN WITH DISABILITIES: A STUDY THROUGH THE LENS OF SIBLING RELATIONSHIP

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Sibling relationship is ascribed and not an achieved status. Most of us have a sibling or a two. If any one of the siblings have any kind of disabilities then the life of other siblings in the family would not be normal. They undergo various experiences as being part of the family and at sometimes as a caretaker of the siblings with disability. Understanding their sibling's disability, sibling relationships and attitude toward disability, the birth order of the siblings, gender and age spacing between them plays a pivotal role in the well-being of the siblings without disability. The well-being of the siblings without disability is disturbed or affected owing to the disability status in her/his siblings. This paper discusses the experiences of the doctoral research work being undertaken in the field of disability and Social Work in general and in siblings and disability in particular.

Key words: disability, sibling,sibling relationship,sibling with disability,well-being

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INTRODUCTION

“The family connections are like a complex web and within this complex web, the sibling relationship has enormous potential for both negative and positive significances. Sibling bonds are formed in the early life and it can exist as a lifetime bond” (Milevsky, 2016). Siblings without undergo various life experiences as being part of the family and at sometimes as a caretaker of the siblings with disability. Understanding their sibling’s disability, sibling relationships and attitude toward disability, the birth order of the siblings, gender and age spacing between them plays a pivotal role in the well-being of the siblings without disability. The well-being of the siblings without disability is disturbed or affected because of the disability status in the siblings. The parents, caretakers or care givers perspectives are taken into account but siblings are left alone in the research milieu of persons with disabilities. There are many organizations in western countries serving as sibling support group but in India it is very rare. This paper outlines the definition of siblings, sibling relationships and the need for inclusion of siblings without disability in designing appropriate strategies for children with disabilities.

SIBLINGS

Oxford Dictionary of Zoology (Allaby, 1999) defines sibling as “offspring of the same parents; a brother and/or sister”. APA Dictionary of Psychology (VandenBos, 2015) defines sibling as “one of two or more children born of the same two parents (i.e., a sister or brother)”.

SIBLING RELATIONSHIP

“The sibling relationship is perhaps the most long-lasting and most influential relationship of a person’s life, siblings constitute a child’s first social network and play a critical role” (Powell & Gallagher 1993, xiii). Dunn & McGuire (1992) defines sibling relationship as an “emotion-based special relationship which starts developing since birth and having a separate and stronger structure than the other relationship”. The process of socialization starts particularly in childhood and continues through adulthood (Matsumoto, 2009). Sociometric studies show that the relationships among the individuals of a group can be of (1) mutual positive, (2) mutual negative, (3) mixed and (4) one way (Arora, 1989, p. 5).

Seligman & Darling (1997, p. 119-120) outline the reasons to study sibling relationships as (1) decreasing family size and more nuclear families are seen off-late and a possibility of

intense sibling contacts (2) Over the lifespan siblings act as a source of support to one another (3) siblings depend on each other as family shift places frequently and there are difficulties in developing new friends (4) The parental availability to children is less because of parental stress (5) remarriage rates soar high and the siblings has to face the family disintegration.

Sanders (2004, p. 53) outlines the characteristics of sibling relationship in adolescence as,

1. Potentially the low point of sibling relationship
2. Physical distance preclude contact
3. Avoidance of interaction

It can be understood from the above points that sibling relationship has different dimensions and it varies from individual to individual, moreover the relationship either gets strengthened in the adolescent period or the relationship gets worsened. The sibling relationship between a sibling without disability and sibling with disability is altogether a different scenario as it varies with respect to the severity of the disability.

WELL-BEING

VandenBos (2015) defines well-beings as “a state of happiness and contentment, with low levels of distress, overall good physical and mental health and outlook, or good quality of life”. Pollard & Lee (2003, p. 60) defines wellbeing as “a complex, multi-faceted construct that has continued to elude researchers’ attempts to define and measure”. Dodge et al., (2012) proposed wellbeing as “the balance point between an individual’s resource pool and the challenges faced”. Mental health is defined as the “state of mind characterized by emotional well-being, good behavioral adjustment, relative freedom from anxiety and disabling symptoms, and a capacity to establish constructive relationships and cope with the ordinary demands and stresses of life” (VandenBos, 2015). There is a close association between mental health and well-being as well as sibling relationship and well-being. Madhusudanan & Nalini (2017) have found that though if one of the siblings have some kind of disability the siblings without disability doesn’t want to part away from the existing relationship, however the siblings without disability expressed different emotions like worriedness, anger, guilt, sadness and despondency. The study also pointed out that the siblings without disability lack proper guidance and information about their siblings with disability from their parents which affects their psychological well-being.

Nartey (2013) study found out that positive sibling relationship predicts psychological well-being. The perceived stigma, family relationships and attitudes towards the disability are the moderating factors for positive and negative sibling relationship.

IMPACT ON SIBLINGS WITHOUT DISABILITIES

Crocker (1981:220) explains that the presence of a siblings with disability in the family affects the normal sibling in the following ways,

1. Alteration of the normal family patterns like social gathering, family get-together, recreation so as to accommodate the needs of siblings with disability
2. There is an intense competition in seeking parental attention by the normal child as parents spends more time and resources on the siblings with disability
3. Normal child has misconception about their sibling's disability and may worry that they are responsible for their sibling's disability. They also have apprehension that their own children be affected with disability.
4. Parents have high expectations on the normal child in order to compensate for the children with disability
5. Normal siblings have to take the role of surrogate parents which could act as a barrier to their personal and social life. The normal siblings also introspect their lifelong commitment for their siblings with disability.
6. Normal siblings' adjustment process is greatly influenced by the grief and conflicts experienced by the parents because of the presence of child with disability.

NEED FOR SIBLING RESEARCH

The negligence of the significance of sibling relationship is seen in the field of disability, family law, social services and in education settings. Siblings influences each other and if interventions are targeting only one sibling, leaving the other sibling the effect cannot be seen and there won't be desired outputs (Milevsky, 2016). Berkowitz & Jonas (2014) said that siblings develop their own set of beliefs, values and attitudes about how they see themselves. The factors influencing normal sibling behaviour towards their sibling with disabilities are normal siblings' gender, body image, aptitudes, personal traits, social role, and birth order. Edwards et al (2006, p. 5) have said giving attention to sibling ties can unveil shrouded aspects

of everyday intimacy that are little researched. Moreover, in sibling relationships ‘similarity and difference’ naturally coexist and psychoanalysts have theorized this coexistence as a key feature in the formation of identity in psychic life.

The experiences in my doctoral research on siblings have been a challenging as well as an insightful journey. In Puducherry sibling research is an emerging field and very few Non-Governmental Organizations (NGOs) have included siblings in the interventions of the children with disabilities. Very few special schools maintain a family tree of the children with disabilities who were enrolled with them. In my research work the wellbeing of the siblings without disabilities are known through their understanding of their sibling’s impairment, sibling relationships and their social attitudes. The siblings without disability in the age group between ten and nineteen express their concerns towards the caretaking, parent’s showing less attention towards them because of the time spent with the siblings with disability. The friends of siblings without disability have shown sympathy towards them because of a sister/brother with disability. The well-being is multidimensional (Statham & Chase, 2010) and social and psychological aspects form the dimensions of well-being(<https://www.cdc.gov/hrqol/wellbeing.htm>, last accessed on February 02, 2017). Understanding the social relational aspects of siblings without disability will help to design appropriate measures for their well-being.

SOCIAL WORK IMPLICATIONS IN SIBLING RESEARCH

Milevsky (2016) adjudged that in the clinical social work setting there are wider scope for sibling therapy (such as cognitive-behaviour interventions or psychodynamic interventions) as a treatment model. As the siblings of children with disabilities is an emerging field in the disability and social work the social workers can play greater role in sensitization, mapping the needs and assessing the role played by siblings without disabilities in families having different cultural and religious background. The role of advocacy for the well-being of siblings and research in this domain could be very well thought off.

CONCLUSION

The paper has emphasized the need for research on siblings’ relationships which has a direct influence on their well-being by highlighting the doctoral research experience of the author. The area of sibling is little researched one (Sanders, 2004) and hence more light has to be

shed in this domain so that the siblings without disability are not neglected in their family when considering any interventions or programmes designed for their siblings with disability.

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