

Siblings of children with disabilities: views from pilot study

Madhusudanan.S & Dr. R. Nalini

¹Ph.D. Scholar (UGC- JRF), Department of Social Work, Pondicherry University, Puducherry

²Associate Professor, Department of Social Work, Pondicherry University, Puducherry

Abstract: *The role of sibling relationship lasts for a life-time as the siblings spend more time with each other than with their parents. The sibling bond is a special one. This paper addresses the initial results from the pilot study (April- May, 2016) of the research on siblings of children with disabilities. Twelve face-to-face interviews were conducted with siblings without disabilities in the age group ten and nineteen. The purpose was to understand the social attitudes and relationship of the siblings without disability with their siblings with disabilities; besides knowing how well they understand their sibling's impairment. Nevertheless the pilot study highlighted the serendipitous finding on non-disabled sibling's psychological well-being. The initial result signals psychological aspects of distress, worry about future as well as their disabled sibling, lesser parental availability, confusion over their role, lack of communication between parents and non-disabled siblings. These siblings expressed positive, negative as well as mixed responses when they understood their sibling has some kind of disability. It is envisaged that the ultimate outcome of the research would lead to interventions for both the non-disabled siblings as well as the children with disabilities' well-being. The pilot study has shown that the well-being of siblings without disability should be taken into account because of the presence of a child with disability in the family.*

Keywords: *disability, mental health, sibling, sibling relationship*

I. Introduction

This paper addresses the initial results from the pilot study (April- May, 2016) of the research on siblings of children with disabilities. Twelve face-to-face interviews were conducted with non-disabled biological siblings in the age group between ten and nineteen. The purpose was to understand the social attitudes and relationship of the siblings without disability with their siblings with disabilities; besides knowing how well they understand their sibling's disability. Nevertheless the pilot study highlighted the serendipitous finding on non-disabled sibling's psychological well-being. This paper deals with the views and understanding of non-disabled sibling's towards their sibling with disabilities and tries to link the psychological well-being of siblings without disability through their views. It has been noted that "normal brothers and sisters are vulnerable to attacks on their psycho-emotional well-being" [1]. Healthy emotional development has strong ties with the adolescents' well-being, and also with their risk of developing behavioral and emotional disorders such as conduct disorder or depression [2]. Affective goals is one of the dimensions in Ford and Nichols taxonomy of human goal and happiness (a component in affective goals) is described as "experiencing feelings of joy, satisfaction, or well-being, avoiding emotional feelings of distress or dissatisfaction" (as cited in [3]).

1.2 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" [4]. Sibling relationship is defined as "an emotion-based special relationship which starts developing since birth and having a separate and stronger structure than the other relationship" [5].

1.3 Well-being

VandenBos (2015) defines well-being 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" [6]. Pollard & Lee (2003), defines wellbeing as "a complex, multi-faceted construct that has continued to elude researchers' attempts to define and measure" [7]. Dodge et al (2012) proposed wellbeing as "the balance point between an individual's resource pool and the challenges faced" [8]. The resources at one's disposal are psychological, social and physical. The challenges faced are psychological, social and physical. 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" [6].

It can be inferred by the definitions that both wellbeing and mental health are closely associated. Dodge et al (2012) in their article have said it is difficult to define wellbeing [8]. However, Dodge et al definition forms the basis for this article as studies and conventional knowledge indicate that siblings without disability face issues in all the three aspects namely psychological, social and physical because of the presence of a sibling with disability.

1.4 Views of siblings without disabilities

The pilot study captured the views of siblings without disabilities. The pilot study gave due importance to their understanding of sibling's disability, each interview was conducted for about 50-60 minutes in a conducive environment. The participants represented both urban and rural areas of Puducherry district and they were contacted through a special school. Ethical considerations are met out by explaining what the research is all about and the respondent's anonymity and confidentiality of data are strictly adhered. The verbatim responses of the respondents are presented under the following heads.

1.4.1 Knowing their sibling as children with disabilities

Negative

It was difficult, I prayed to god for his recovery.

Though it was difficult for me I didn't express my feelings to others

I cried

I pitied my brother

I was sad, he speaks only three words – father, mother, sister.

I thought how he will be when he grows up.

Seeing other people's normal brothers make me jealous, my brother does not play with me (elder sister, aged 15)

Positive

My brother is a 'special child' (elder brother, aged 11)

Persons with disabilities will be famous in something (elder brother, aged 11)

In future my brother will shine in some field (brother, aged 11)

I was courageous, I am confident that he will become good.

I believed, I can make him walk.

I am noting down his daily behaviour to understand my brother's disability (elder sister, aged 19)

My brother is brilliant but he can't walk

I will become a Doctor to cure my brother (respondent is sister, aged 13)

Mixed response

I am taking care but I am losing my patience with my brother (elder sister, aged 19)

Friends are sympathetic towards me and ask how you manage your brother? Because of my brother, I have enrolled in B.Ed. special Education in NIEPMD, Chennai (Respondent is sister, aged 19)

1.4.2 Parents communication with non-disabled children about their siblings with disability

I understood that my brother is disabled from the discussions of my parents.

My mother said to dad "Don't say anything about the disability"

My mother said "he will be okay as he grows up"

My father said, "You only should look after him", I felt bad when my father beats my brother.

1.4.3 Difficulties faced due to siblings with disabilities

He tears my papers and notebooks, during exam time it is very difficult for me.

My teacher said my sister is an idiot.

If I get anger, I will scold him and he beats me.

I am always thinking about my brother (sister, aged 14)

I didn't ask about my elder brother's difficulty to my father, I fear he would beat me up (youngest, aged 10)

Father scolds mother with bad words and my (disabled) sister uses the same bad words (elder brother, aged 12)

Friends asked me 'If you are looking after your disabled brother, who will take care of your children in future?' (elder sister, aged 19)

It was very difficult for me when I heard he is not like me, I thought I should not beat him anymore (youngest, aged 10)

1.5 Discussion for Inclusion of siblings without disability in disability services

The practice guidance, Assessing Children in Need and their Families [9] notes that "the siblings of children with disabilities have often been invisible to the professional eyes". Mental Healthcare Bill, 2016 of India also talks about rights of Persons with mental illness, Chapter V- Sec. 18(4) (c) which provides mental health services to support family members of person with mental illness.

1.6 Scope for Social Work Practice

The sibling research has ample of scope for social work practice. Milevsky (2016) claims that the significance of sibling relationship has been neglected in the field of disability and social services, family law and in education settings. He also posits that the interventions planned for long-term changes will not yield the desired results if the interventions are targeting only one sibling in the family as siblings influence each other [10]. Hence any interventions targeting for well-being of children with disabilities should encompass their non-disabled siblings too. Psychiatric social workers, community level rehabilitation workers, social workers in advocacy and research field could greatly contribute in the well-being of the siblings of children with disabilities as well as the children with disabilities. The roles of social workers such as enabler (helping a client to cope with various stresses in crisis situations), mediator (resolving conflicts arising in micro, mezzo and macro system and sorting out arguments in those systems), educator (providing information to parents, siblings about the necessary skills to tackle the situation), and as an advocate (working on behalf of the clients) [11] could very well be used for the psychological well-being of siblings.

II. Results

None of the participants said they want to leave away from their siblings. They have love and affection towards their siblings with disability and share a special bond with them. The siblings showed different emotions like sadness, anger, guilt during the interview process. It is clear from the pilot study that the non-disabled siblings lack proper guidance and information about their siblings with disability. This creates mixed reactions and emotions in them. All the respondents come from nuclear family and parents spends time with the child who has disability and respondents felt lesser parental availability. Birth order also plays a vital role in siblings with children with disabilities and they are disturbed by the role reversals. Powell & Ogle (1985) indicate that like parents who have children with intellectual disability, siblings having brothers and sisters with intellectual disability also need special attention, understanding and support (as cited in [12]). In addition to higher levels of independent and self-assertive behaviour (known as agency and communion) valuing interpersonal relationship, cooperation and caring, well-being can be improved for individuals [13]. Briefing paper on Childhood wellbeing in United Kingdom reveals a close association between childhood wellbeing and positive family relationships. It also points out the availability of limited data on childhood wellbeing with respect to the disaggregated data on the variables such as age, gender, disability and socio-economic status [14]. The disequilibrium in the psychological wellbeing of non-disabled siblings also thwarts their pyramid of 'love of belongingness' as suggested by Maslow. UNICEF has stated that adolescence as a crucial period in child's life, adoption of positive and negative behaviours in adolescent period has an impact in their adult life [15]. Moreover this has a direct consequence in their personal development too.

III. Conclusion

On the domains and measures of wellbeing, Statham & Chase (2010) has quoted that "there is some emerging consensus that childhood wellbeing is multi-dimensional, should include dimensions of physical, emotional and social wellbeing; should focus on the immediate lives of children but also consider their future lives; and should incorporate some subjective as well as objective measures" [14]. No one could say no to a positive psychological well-being. This paper has addressed the well-being of children who have siblings with disabilities and their views about their siblings are presented. Researchers have said the area of sibling relationship are little researched [16] and along with the psychological well-being, the research of 'well-being of siblings of children with disabilities' will emerge as a prominent area of social work research interest as Desai (2010, viii) points out "the psychosocial well-being in childhood needs person-centred, strength-based, participatory and empowerment focused social work approaches" [17].

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