

## Chapter 78

# “Intertwined Lives”: Narratives of Children With Disabilities and Their Siblings

**Shyamani Hettiarachchi**

*University of Kelaniya, Sri Lanka*

**Gopi Kitnasamy**

*Cerebral Palsy Lanka Foundation, Sri Lanka*

**Dilani Gopi**

*National Center for Cerebral Palsy and Developmental Disorders, Sri Lanka*

**Fathima Shamra Nizar**

*National Center for Cerebral Palsy and Developmental Disorders, Sri Lanka*

### ABSTRACT

*Sibling relationships are complex and unique, often spanning a range of deep emotions. The experiences of children with disabilities and their siblings are arguably seldom documented, particularly in the Global South. The aim of this chapter was to uncover the narratives of young children with disabilities and their siblings in Sri Lanka. Ten dyads of children with disabilities and their siblings and one quartet of siblings were included in this study. Opportunities were offered to the participants to engage in conversation aided by kinetic family drawings. An interview guide was used to support this process. The participant data were analyzed through the lens of the “lived experience” of family dynamics in the tradition of interpretative phenomenological analysis. This chapter will discuss the two complex broad themes of a surrogate parenting role and normative sibling relationships, which at times converge and at times diverge.*

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## INTRODUCTION

Siblings play a pivotal role in the lives of children with disabilities, in its best form, enabling powerful transformative bonds, assuming roles as parents, as well as taking on the roles of teachers and friends (Davidoff, 2006). The relationship between a child with disabilities and his/her sibling may be complex, given the level of dependence or independence, family dynamics and the socio-cultural realities the family has to contend with. Siblings of children with disabilities are often on the periphery of discussions; their views not always taken into account, particularly in the Global South, where children are meant to be ‘seen and not heard’. The experiences and views of children with disabilities and their siblings are often not documented or taken into account when deciding on intervention and management to support children with disabilities and their families (Young, 2007), even when therapy is family-centered. This chapter aims to document the lived experiences of children who have siblings with disabilities.

## BACKGROUND

While socio-economic background, family size and the severity of the disability, the attitude and expectations of the parents and the temperament of the child are said to influence the reaction of a sibling of a child with cerebral palsy, for instance, the type of disability is considered less pertinent (Gallagher & Powell, 1989). That said, the type and severity of cerebral palsy or disability may, in fact, require a high-level of care, which could influence the quality of life of the child individually as well as the family as a whole.

According to Zetlin (1986), five types of sibling relationships exist. The first relationship type is of warmhearted feelings and widespread involvement, with the role of surrogate parent or best friend adopted by some towards their sibling with a disability. The second and third are of warmhearted feelings but moderate or minimal involvement respectively. The fourth type of relationship is one of the resentful feelings and minimal involvement and the fifth characterized by no involvement. It is possible that siblings move between these relationship types with age and maturation.

An early view proposed by psychologists was the assumption that the presence of a child with disabilities at home disrupted or damaged the family unit (Kutner, 2016). More contemporary research has suggested that while there may be an increase in the levels of family stress or in siblings experiencing stress (Nunez & Rodriguez, 2005; Stoneman, 2005), having a child with disabilities may not result in disruption or damage but rather promote creativity and personal growth (Kutner, 2016). Growing up with a sibling with a disability could result in a range of mixed emotions, challenges and opportunities (Gallagher & Powell, 1989). Among the negative consequences and conflicting emotions uncovered within the literature are feelings of jealousy due to the attention received by their brother or sister (Boyse, 2009; Kutner, 2016; Schleichkorn, 1993) and as a result anger and resentment at the lack of attention received by them (Boyse, 2009; Russell, Russell, & Russell, 2003). In addition, children with siblings with disabilities may feel socially ostracized by peers resulting in loneliness (Russell et al., 2003) or be concerned that their sibling may not act in socially acceptable ways (Cuskelly & Gunn, 2006; Dew, Baladin, & Llewellyn, 2008). The child may also be worried and scared that they may lose their sibling or feel guilty for the negative feelings they carry towards their sister or brother or for being spared the same difficulties (Boyse, 2009). They may require reassurance for harboring feelings of their sibling’s

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