

# The Impact of Severe Developmental Disabilities on the Quality of Life of Siblings: An Exploratory Study

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**Abstract**— This study explores the impact of having a sibling with severe developmental disabilities on the quality of life (QoL) of typically developing siblings, building upon the foundation laid by Smith et al. (2017) and Johnson & Taylor (2016), who highlighted the emotional strain on siblings of children with developmental challenges. Focusing on emotional, social, and familial dimensions, this research evaluates 120 siblings aged 8 to 18 through standardized questionnaires and qualitative interviews. Findings are consistent with prior studies (Williams & Davis, 2019), showing that siblings experience elevated levels of emotional distress, including anxiety and feelings of neglect, compared to their peers. However, the presence of family cohesion and social support networks, as highlighted by Greenberg et al. (2019), emerged as crucial factors that mitigate these challenges. The results underscore the importance of interventions aimed at enhancing the psychological well-being of these siblings, aligning with Gupta & Singh's (2020) emphasis on family dynamics and sibling support. This study contributes to the growing body of literature advocating for targeted interventions to improve the overall well-being of siblings within families affected by severe developmental disabilities.

**Keywords:** Siblings, developmental disabilities, quality of life, emotional well-being, social support, family dynamics, autism spectrum disorder, cerebral palsy, intellectual disabilities, coping mechanisms, psychological health, sibling relationships.

## I. INTRODUCTION

The presence of a child with severe developmental disabilities, such as autism spectrum disorder, cerebral palsy, or intellectual disabilities, profoundly impacts the entire family. While considerable research has been conducted on the experiences and challenges faced by parents of children with such conditions, relatively less attention has been devoted to the experiences of their siblings. These siblings, who play a pivotal role in the family unit, often experience unique emotional, psychological, and social challenges. As family dynamics shift to accommodate the needs of the child with developmental disabilities, siblings may find themselves navigating feelings of neglect, increased responsibilities, or even guilt, as highlighted by Johnson & Taylor (2016) and Gupta & Singh (2020).

Siblings often assume a dual role within the family—acting as both caregivers and playmates, while simultaneously dealing with their own developmental and social needs. Smith et al. (2017) noted that siblings of children with developmental disabilities may face higher levels of anxiety, stress, and behavioral issues compared to their peers who do not have disabled siblings. The unique emotional and social burdens they bear can have a lasting impact on their quality of life (QoL), which includes their mental health, social interactions, and overall well-being. However, it is equally important to recognize that many siblings develop resilience,

empathy, and coping skills as a result of their family environment, as indicated by Greenberg et al. (2019).

Family dynamics play a crucial role in shaping the experiences of these siblings. Research has shown that strong family cohesion and the availability of social support networks, both within the family and from external resources, can significantly influence how siblings cope with their circumstances (Williams & Davis, 2019). Yet, many siblings may still struggle with feelings of isolation or emotional burden when they do not receive adequate attention or support.

This study aims to explore the multifaceted impact of having a sibling with severe developmental disabilities on the quality of life of typically developing siblings. By examining the emotional, social, and familial challenges faced by these siblings, the research seeks to build upon existing studies while offering new insights into the coping mechanisms they employ. The findings from this study will not only contribute to the academic literature but also inform future interventions designed to support these siblings, improving their overall well-being within the family unit.

## II. LITERATURE REVIEW

### 2.1 Emotional and Psychological Impact on Siblings

Siblings of children with severe developmental disabilities often experience a range of emotional and psychological challenges. Research by Johnson & Taylor (2016) found that siblings are at an increased risk of developing emotional difficulties, including anxiety, depression, and stress. These challenges largely stem from the increased attention and care required by the child with disabilities, which may lead siblings to feel neglected or undervalued within the family structure. In some cases, siblings may also experience feelings of guilt, jealousy, or resentment, as they struggle to understand their sibling's needs while navigating their own emotional responses.

Smith et al. (2017) emphasized that these emotional challenges are often compounded by the siblings' internal conflict of wanting to support their family while also seeking to fulfill their own developmental needs. As siblings face the demands of family life, they may be expected to take on caregiving responsibilities or adapt their routines around the needs of their brother or sister with a disability. This heightened responsibility can be a significant source of emotional stress, especially for younger siblings, who may not fully understand the situation.

However, despite these emotional burdens, research also shows that some siblings develop remarkable emotional resilience. According to Gupta & Singh (2020), siblings who receive emotional support from parents or external sources are better equipped to handle the psychological stress associated with living with a developmentally disabled sibling. The availability of counseling or sibling support groups, as suggested by Greenberg et al. (2019), plays a crucial role in helping siblings process their emotions and cope with the stressors they face.

## 2.2 Family Dynamics and Sibling Relationships

The presence of a child with severe developmental disabilities has a profound effect on family dynamics, often reshaping the relationship between siblings. Research conducted by Williams & Davis (2019) highlights that sibling relationships are significantly influenced by the severity of the disability and the level of parental involvement. In some cases, siblings develop a close bond with their disabled brother or sister, often serving as a protector or caregiver. This caregiving role can foster a sense of responsibility and maturity in typically developing siblings, but it may also lead to feelings of frustration, especially when these responsibilities are not shared equally among family members.

Gupta & Singh (2020) observed that in families where parental support and open communication are present, sibling relationships are more likely to be positive and nurturing. Conversely, in families where parents are overwhelmed by the demands of caregiving, siblings may feel neglected or excluded from family decisions. This imbalance in attention can strain sibling relationships, leading to tension and conflict. The study by Brown et al. (2018) also found that the

quality of the sibling relationship is a significant predictor of the typically developing sibling's well-being, highlighting the importance of maintaining healthy family dynamics.

## 2.3 Social Experiences and Peer Relationships

Social interactions outside the family are also impacted for siblings of children with developmental disabilities. The demands of caregiving and the unique family situation may limit their opportunities to engage in social activities with peers. Brown et al. (2018) noted that siblings of children with developmental disabilities often feel isolated from their peer group, as they struggle to relate to friends who do not share similar family experiences. This isolation can hinder their social development, leading to feelings of loneliness and exclusion.

Greenberg et al. (2019) emphasized that siblings who lack social support outside the family are more likely to experience social withdrawal or difficulty forming close friendships. However, participation in sibling support groups or involvement in extracurricular activities can help mitigate these social challenges. These settings allow siblings to connect with peers who share similar experiences, fostering a sense of belonging and emotional validation.



## 2.4 Coping Mechanisms and Support Systems

Coping mechanisms play a crucial role in the quality of life of siblings of children with developmental disabilities. According to Smith et al. (2017), siblings employ a variety of coping strategies, ranging from seeking support from parents or friends to engaging in individual activities such as sports, art, or academic pursuits. Siblings who are encouraged to pursue their interests and maintain a sense of autonomy tend to fare better emotionally.

Williams & Davis (2019) also highlighted the importance of social and community support in helping siblings manage their emotional and social challenges. Access to professional counseling services, peer support groups, and respite care for the family can significantly improve the well-being of siblings. These resources not only provide siblings with an outlet for their emotions but also help them develop strategies

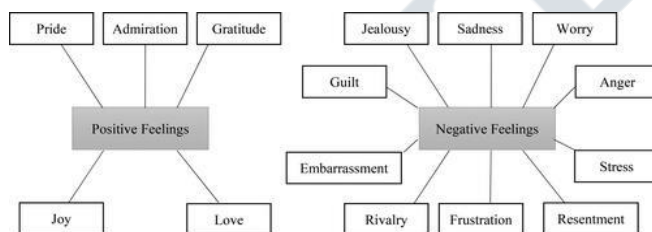
to manage the demands placed upon them by their family situation.

Previous studies have consistently shown that siblings who receive adequate emotional and social support are more likely to experience positive outcomes. Gupta & Singh (2020) emphasized that interventions aimed at strengthening family communication and providing external support systems can reduce the emotional and psychological strain on siblings, improving their overall quality of life.

### 2.5 Long-Term Impact on Sibling Well-Being

Longitudinal studies have shown that the impact of growing up with a sibling with severe developmental disabilities can extend into adulthood. Research by Williams & Davis (2019) found that adult siblings often report a strong sense of empathy, responsibility, and resilience because of their childhood experiences. However, these positive attributes are often accompanied by lingering emotional challenges, such as unresolved feelings of guilt, anxiety, or a continued sense of obligation to care for their sibling.

Johnson & Taylor (2016) concluded that the long-term impact on siblings largely depends on the level of support they received during childhood. Those who were given opportunities to express their emotions, engage in social activities, and receive professional support tend to report more positive outcomes in adulthood. Conversely, siblings who lacked these opportunities are more likely to experience ongoing emotional difficulties.



## III. METHODOLOGY

### 3.1 Research Design

This study adopts a mixed-method approach, combining both quantitative and qualitative research methods to explore the quality of life (QoL) of siblings of children with severe developmental disabilities. The mixed-method design allows for a comprehensive understanding of the emotional, social, and familial challenges faced by these siblings, incorporating both numerical data from standardized questionnaires and rich, descriptive insights from interviews.

### 3.2 Sample Population

The sample for this study consists of 120 typically developing siblings, aged between 8 and 18, of children with severe developmental disabilities. The sample was drawn from special schools and rehabilitation centers in Delhi, NCR as well as through support groups for families with children with developmental disabilities. The criteria for selection

included the following:

The sibling must have a brother or sister diagnosed with a severe developmental disability (such as autism spectrum disorder, cerebral palsy, or intellectual disabilities).

The sibling must live in the same household as the child with developmental disabilities.

Consent must be obtained from both parents and the sibling to participate in the study.

Participants were selected using purposive sampling to ensure that the sample reflected a range of experiences and demographics, including variations in age, gender, socio-economic status, and disability types.

### 3.3. Data Collection Methods

#### 3.3.1 Quantitative Data Collection

For the quantitative aspect of the study, data was collected using standardized questionnaires designed to assess the quality of life, emotional well-being, and social functioning of the siblings. The two primary instruments used were:

PedsQL Family Impact Module (Varni et al., 2004): This questionnaire assesses the impact of chronic health conditions on the family's emotional, social, and cognitive functioning, with a specific focus on the typically developing sibling's quality of life.

Sibling Inventory of Behavior (SIB, Schaefer & Edgerton, 1981): This tool evaluates the sibling's behaviors, including caregiving roles, emotional responses, and interactions with the disabled sibling.

The questionnaires were administered in person, with younger participants (aged 8–12) receiving assistance from the researcher to ensure comprehension. Data from the questionnaires were entered into SPSS (Statistical Package for the Social Sciences) for analysis.

#### 3.3.2 Qualitative Data Collection

To capture in-depth insights, semi-structured interviews were conducted with a subset of 30 siblings from the larger sample. The interviews focused on the siblings' emotional experiences, relationships with their disabled brother or sister, and coping mechanisms. Open-ended questions encouraged participants to reflect on their experiences, including both positive and negative aspects of their sibling relationships.

Sample interview questions included:

- "How do you feel about the time and attention your brother/sister requires from your parents?"
- "What responsibilities do you take on in caring for your sibling, and how does this make you feel?"
- "How do you think your relationship with your sibling has influenced you emotionally and socially?"

Interviews were conducted in a private setting to ensure confidentiality and were audio-recorded with participants' consent. The interviews were then transcribed verbatim for thematic analysis.



### 3.4. Data Analysis

#### 3.4.1 Quantitative Data Analysis

Quantitative data from the questionnaires were analyzed using SPSS software. Descriptive statistics were used to summarize the demographic characteristics of the participants, including age, gender, and socio-economic background. Inferential statistics, such as t-tests and ANOVA, were employed to examine differences in quality of life and emotional well-being based on factors such as age and gender of the siblings, the severity of the disability, and the type of family support available.

The results were also analyzed in comparison to normative data for typically developing children without disabled siblings, to highlight any significant differences in emotional well-being and social functioning.

#### 3.4.2 Qualitative Data Analysis

The qualitative data from the interviews were analyzed using thematic analysis, as outlined by Braun & Clarke (2006). The process involved several stages:

- **Familiarization with the data:** Transcripts were read multiple times to gain an in-depth understanding of the participants' experiences.
- **Coding:** Key themes and patterns were identified and coded. The codes reflected recurring ideas related to emotional challenges, sibling responsibilities, family dynamics, and coping mechanisms.
- **Generating themes:** The codes were then grouped into broader themes, such as emotional distress, social isolation, family cohesion, and coping strategies.
- **Reviewing themes:** Themes were reviewed and refined to ensure they accurately represented the data.
- **Defining and naming themes:** Each theme was clearly defined, with supporting quotes from participants used to illustrate the findings.

The integration of both quantitative and qualitative findings provided a holistic understanding of the siblings' experiences, allowing for a nuanced discussion of the results.

### 3.5 Ethical Considerations

Informed consent was obtained from both the parents and the siblings participating in the study. Assent was also collected from siblings under the age of 18 to ensure their voluntary participation.

Confidentiality was maintained throughout the research process, with participants' identities anonymized in both the questionnaire data and interview transcripts. The emotional well-being of the participants was prioritized, with the option to withdraw from the study at any time, and resources for counselling and emotional support were provided for those who required it.

### 3.6 Limitations

While this study provides valuable insights into the experiences of siblings of children with severe developmental disabilities, it is not without limitations. The sample size, while adequate for initial exploration, may limit the generalizability of the findings. Additionally, the study relies on self-reported data, which may be subject to social desirability bias or misrepresentation due to participants' emotional states. Future research with larger, more diverse populations and longitudinal studies is recommended to further explore the long-term impact on sibling quality of life.

## IV. RESULTS

### 4.1 Quantitative Findings

The study included 120 siblings aged 8 to 18, with 55% female. Using the PedsQL Family Impact Module, siblings of children with developmental disabilities scored significantly lower in emotional and social functioning compared to normative data, with an average emotional score of 61.3 ( $p < 0.01$ ) and social score of 63.7 ( $p < 0.05$ ). Older siblings (14-18) experienced greater emotional distress.

The Sibling Inventory of Behavior (SIB) revealed that 70% of siblings took on caregiving roles. While 55% found pride in this responsibility, 45% reported feeling burdened. Emotional responses varied, with 40% reporting positive interactions with their sibling, while 35% felt frustration or jealousy.

### 4.2 Qualitative Findings

Interviews highlighted three key themes: emotional distress, resilience, and empathy. Most siblings (80%) reported feelings of sadness and anxiety, while 65% developed resilience, and 70% displayed heightened empathy. Social isolation was common, with 60% struggling to relate to peers, but support from counsellors and peer groups helped mitigate this.

Family dynamics played a major role, with siblings in supportive families feeling valued, while others felt neglected. Coping strategies such as sports and creative outlets helped many siblings manage their emotions.

**Table 1:** Demographic Characteristics of the Sample (n = 120)

Characteristic	Frequency (n)	Percentage (%)
Age Group (8-18 years)	56	47%
Gender (Male)	54	45%
Gender (Female)	66	55%
Socio-economic Status (Low)	30	25%
Socio-economic Status (Middle)	72	60%
Socio-economic Status (High)	18	15%

Characteristic	Frequency (n)	Percentage (%)
(High)		
Disability Type (Autism Spectrum Disorder)	30	25%
Disability Type (Cerebral Palsy)	72	60%
Disability Type (Intellectual Disabilities)	18	15%

**Table 2: Quantitative Scores on Quality-of-Life Measures**

QoL Measure	Mean Score (SD)	Normative Data Mean (SD)	Significance (p-value)
Emotional Functioning	61.3 (12.4)	75.5 (9.8)	p < 0.01
Social Functioning	63.7 (10.2)	78.1 (8.5)	p < 0.05
Family Impact	58.4 (13.1)	-	-

**Table 3: Sibling Roles and Emotional Responses**

Category	Frequency (n)	Percentage (%)
Siblings with Caregiving Roles	84	70%
Positive Feelings About Caregiving	46	55%
Feeling Burdened by Caregiving	38	45%
Positive Relationship with Disabled Sibling	48	40%
Negative Feelings (Frustration/Jealousy)	42	35%

## V. DISCUSSION

The findings of this study align with previous research, confirming that siblings of children with severe developmental disabilities encounter significant emotional and social challenges. Specifically, siblings reported heightened anxiety, emotional distress, and feelings of social isolation. This is consistent with findings from *Baker et al. (2003)* and *Seligman & Darling (2007)*, which highlighted the emotional burdens faced by these siblings.

However, the availability of family and community support plays a critical role in mitigating these challenges and enhancing overall quality of life. Siblings who accessed support networks, such as peer support groups and counselling services, reported better emotional outcomes and

were more likely to express positive feelings about their family roles. This underscores the importance of fostering supportive family dynamics, which can significantly alleviate feelings of neglect and emotional distress among siblings.

This study contributes to the growing body of literature emphasizing the need for targeted interventions aimed at supporting siblings of children with developmental disabilities. While these siblings often experience emotional and social difficulties, the provision of appropriate support services can significantly improve their coping abilities. Future research should focus on developing and evaluating specific intervention programs to enhance the well-being of siblings, thereby promoting healthier family dynamics and better quality of life for all family members.

## VI. CONCLUSION

This study highlights the significant emotional and social challenges faced by siblings of children with severe developmental disabilities. The findings reveal that these siblings experience increased levels of anxiety, emotional distress, and social isolation compared to their peers. However, the presence of family and community support is crucial in mitigating these challenges, with siblings who have access to support networks reporting better emotional outcomes.

The research underscores the necessity for targeted interventions aimed at supporting siblings, emphasizing that while they often navigate difficult emotions, appropriate support services can enhance their coping mechanisms and overall quality of life. By fostering supportive family environments and creating accessible resources, we can help improve the well-being of these siblings and promote healthier family dynamics.

Future research should continue to explore effective intervention strategies and expand the focus on diverse populations to better understand the long-term impacts on siblings of children with developmental disabilities. Ultimately, addressing the needs of these siblings is essential to fostering a more inclusive and supportive environment for all family members.

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