

# Understanding the Responses, Roles and Responsibilities of Parents and Siblings towards CwASD

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## ABSTRACT

Children with Autism have unique educational, social, sensory, behavioral and communicative needs. They lack eye contact; have deficient theory of mind, display echolalia and often engage in stereotyped and restrictive behavior. This adversely impacts their socialization and mainstreaming. These further cause parenting burdens and parents often find themselves ill trained to cope with numerous demands and parenting support needs. The present paper attempts to understand the responses, roles and responsibilities of parents and siblings towards the target group through content analysis approach. It also aims to understand the responsibilities and roles of siblings and parents towards children with Autism. The in-depth and extensive review of literature reveals that parents have unique responsibilities towards their child with ASD. Similarly siblings of CwASD often face several challenges and suffer from anxiety due to their inability to understand the problems faced by such children. The study sheds light on the multiple roles played by parents of such children such as: care giver, parent, educator and advocator. Thus this study will help to sensitize care givers, educators, trainers and therapists to sensitize, train and allow parents to facilitate effective rehabilitation of the target group.

**Keywords:** Parents of CwASD, Siblings of CwASD, Responsibilities, Challenges, Roles, Emotional well being.

## INTRODUCTION

Parents and siblings of children with autism spectrum disorders face multitude of challenges ranging from several unmet support needs to distinctive parenting demands due to the three affected core areas - social behaviors, communication limitations and restrictive and repetitive behaviors (Hartley & Shultz, 2015). Parents are considered the primary caregivers for their children from birth to adolescence and even beyond. They act as the essential link between home and school environments and this demands time, dedication, energy and financial resources. Parents of children with autism have unique knowledge and experiences about their children.

If parents learn about the condition of their child and are trained in appropriate skills, it is seen that they feel empowered to manage their children's needs in an efficient manner. Hence parent training is considered an important component of successful intervention programs.

Research also shows that children and adolescents with ASD often have Intellectual Disability as an associated condition, which further multiplies the care giving demands and needs placed on guardians. Such support needs often go unaddressed further making parents highly vulnerable to depression, anxiety, stress and emotional disturbances. They find it difficult to cope with the daily needs of their wards with special needs and other family-wide effects. Research studies indicate that parents of CwASD often depend on both formal and informal sources of support for assisting their children. This includes:

- **Formal support needs:** This includes advice and suggestions provided by trained professionals and therapists. Such support team includes trained special educators, therapy providers like physiotherapists, speech and language pathologists and occupational therapists.
- **Informal support needs:** This includes recommendations provided by families, friends and sensitized community members.

Prata et. al. (2018) has highlighted the importance of parental training programs in their study. The study reveals that parental training, guidance and counseling programs help the parents to support their child with Autism in a better way by raising their self confidence, imparting essential skills, promoting stress management and improving parental responsiveness. Such programs equip parents of CwASD with skills to handle and manage their wards efficiently by imparting better emotional regulation, child care and related skill training. The study also points out several challenges faced by parents in parental training programs such as lack of time commitments, lack of trained professionals, lack of child care, limited financial resources, long queues, lack of parental motivation and poverty.

Wetherston et.al. (2017) have highlighted the lack of parental satisfaction with the treatments and therapies received by their children. Parents often withdraw their children from various therapies due to lack of satisfaction, lack of knowledge and lack of funds. There is urgent need to improve the levels of parental awareness regarding various aspects of therapies for their children such as - nature, need, benefits and risks of various therapies towards betterment of children.

Milbourn et al. (2017) explored the presence of various stressors on families of children with ASD such as difficulties in diagnosis and access to services. The study suggests that Early and accurate diagnosis and appropriate intervention can improve child-specific outcomes and remove some of the stressors impacting family relationships and quality of life.

Irene (2015) mentions that the behaviours of parents are affected by their children's behavior and vice versa. The study reveals that positive emotions and reinforcement strengthen the child and create a secure loving environment while lack of reinforcements creates a negative environment for the child. The study further highlights the impact of children's behavior on the parental attitude and coping behaviours.

Tripathi (2015) highlights major concerns of parents having CwASD in northern India such as "what after me?" The study findings reveal that most parents with autistic children are in clinical range of stress and are in dire need for counseling services; parents of children with severe autism reported higher levels of stress

compared to parents of children with mild/moderate levels of autism; mothers reported more permissive parenting compared to fathers and parents reported more stress while dealing with adolescents having ASD and resorted to mostly authoritarian style of parenting.

## RESEARCH METHODOLOGY

The present study utilizes content analysis technique in which in-depth and extensive review of literature was conducted for research studies spanning past ten years (2009-2019). Keywords used for the review of literature includes: parents of children with Autism, siblings of children with Autism, responses of parents, challenges faced by parents of children with Autism. The data sources utilized for the present study includes secondary data sources accessed from open national and international data sources:

*Table-1: Data sources for the study*

<b>National sources</b>	Shodhganga
	Shodhgangotri
	National Digital Library
<b>International sources</b>	NCBI
	IEEE explore
	SAGE
	ERIC

## FINDINGS

### Responses of parents towards CwASD

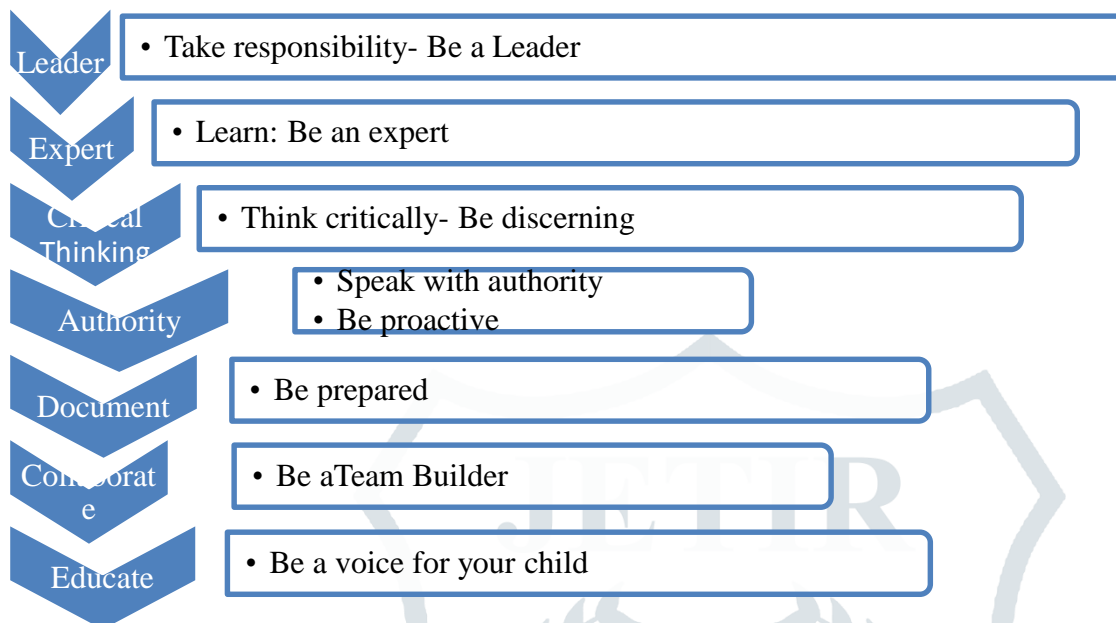
Reviewed literature indicates that children with Autism Spectrum Disorder (ASD) experience difficulties in communication, socialization and have distorted sensory perceptions which adversely impact the way they respond to social situations in everyday life. Parents of such children knowingly or unknowingly have to shoulder the responsibility of being the first care giver of their child with unique autistic needs and thus act as a link between home, school and community. Parents feel stressed, burdened and immensely pressurized in trying to divide their time between performing household tasks, management of their child with special needs and handling other daily activities. They are less inclined to socialize and share their feelings with others. This leads to greater isolation, feelings of intense worry about future of family and child leading to endless anxiety and stress. They feel the need for gaining support - physical, emotional, financial, social and factual in order to cope with challenges of managing their child with autism.

### Role and Responsibilities of parents towards CwASD

Parents of CwASD have to act as a connection between the society, home and school. They need to be equipped with certain skills and knowledge which will help them to meet the everyday needs of their

CwASD in a better manner. The numerous roles played by parents range from being a care giver, therapist, trainer and an advocate for their child. Martin () mentions seven principles which help parents to act as effective service providers for their child. These principles are:

*Figure-1: Seven principles for parents to acts as effective service providers for CwASD*



**Taking responsibility:** Parents of children with autism should learn about available therapies and treatment options emerging from evidenced based practices through books, discussion with experts and internet based resources. They should keep themselves up-to-date with latest knowledge and resources available for CwASD in order to facilitate better service provision and management of such children.

**Learning and gaining knowledge:** Parents of children with autism have to keep themselves up-to-date with the latest knowledge and learn from more sources of information such as books, journals, articles, internet sources. Parents should collaborate with other parent groups so that they do not feel left out and burdened with their child's problems alone. Other parents will be able to share their tips and provide referrals thereby providing a reassurance to new parents.

**Being proactive and speaking with authority:** Parents have to take the responsibility of their thoughts, ideas and feelings and try to be a leader and advocate for their child's rights. They have to stop blaming themselves and refuse to take anything personally. They should be able to seek help for all their care-giving and family support needs. They should be able to collaborate and with care givers.

**Being prepared with proper documentation:** Parents of children with autism have to keep ready some of the latest and proper documents like disability certificates, medical reports, school records which will help their wards to gain timely services such as medical, educational, social services etc.

**Using collaborative approaches:** Parents have to build a support system by seeking support from local groups and parent networks. They have to be proactive and speak with authority for their child's needs. Collaboration with service providers is the need of the hour.

**Educating the child and being a voice for the child:** Such children often need advocates. Parent is the best advocate for their child as he/she is the primary care giver and understands the unique needs of their child. The parent is an important part of the IEP team and plays an important role in taking decisions regarding advocating effectively for their child.

**Responses of siblings towards CwASD**

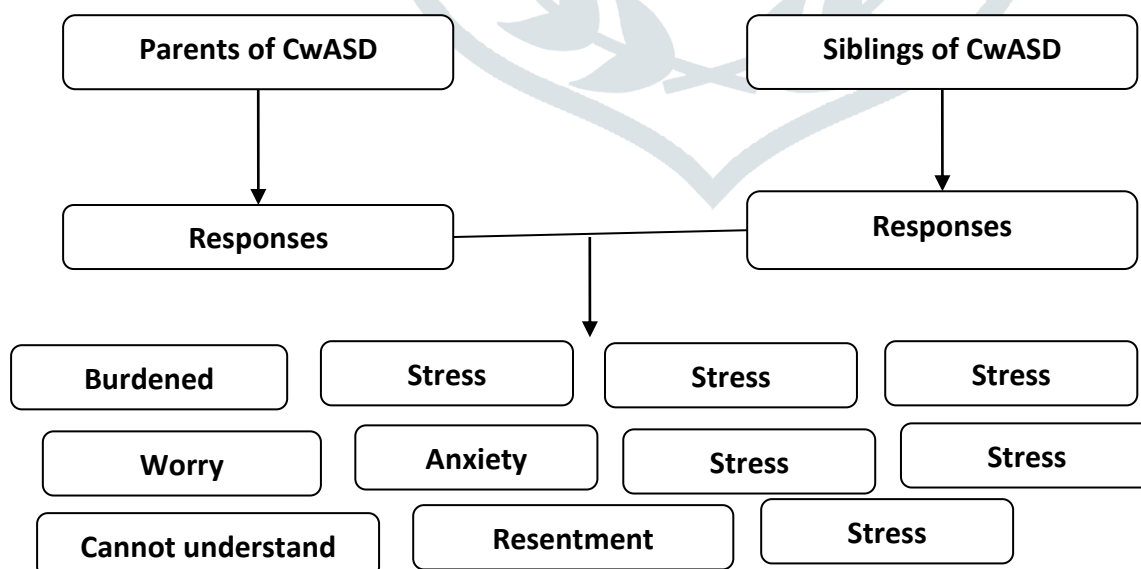
The siblings often react adversely towards their brother or sister having ASD due to their inability to understand the problems faced by them. Findings of previous research studies are indicative of feelings of stress resulting out of their own set of challenges. They display anger, jealousy and resentment over unequal treatment and more affection showed to them. They face embarrassment in social situations with friends and strangers due to unusual and often socially inappropriate behaviors displayed by their autistic sibling. Siblings of CwASD sometimes secretly worry about their brother or sister with special needs and other family members affected by the disorder which causes frustration, delinquency and stress.

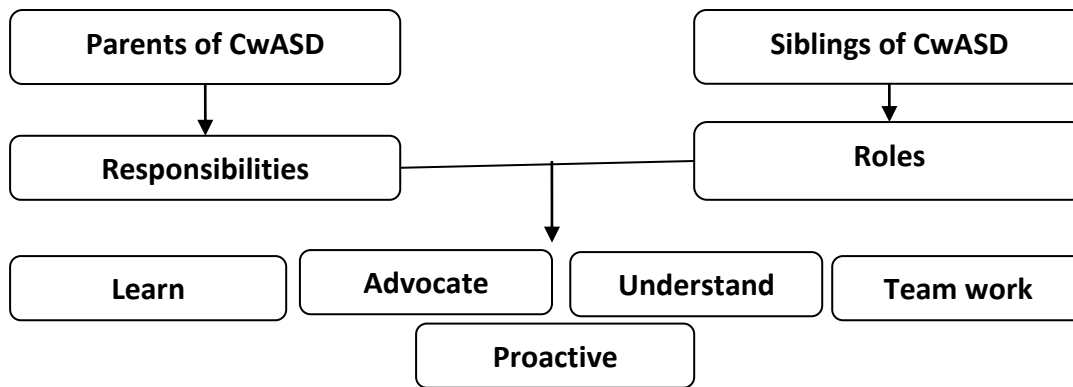
**Roles and Responsibilities of siblings towards CwASD**

The siblings of CwASD have the following role:

- Better sensitization
- Acquiring knowledge and learning
- Understanding the emotions of their sibling with ASD
- Talking to parents and care givers about their fears and frustrations

*Figure-2: Reaction and Responses of Parents and Siblings of CwASD*



**Figure-3: Roles and Responsibilities of Parents and Siblings of CwASD**

## CONCLUSION

The paper attempts to review the available literature – both national and international in order to understand the unique responses of parents and siblings towards CwASD. The findings suggest that more research needs to be done in the area of parents and siblings of CwASD to meet their unique needs, support needs and strengthen their resilience. There is need to develop training package for parents and siblings of CwASD to facilitate effective handling and management of the target group considered for the present study. This study indicates implications for future research as: greater need for raising awareness among families of CwASD, involvement of families and siblings of such children in intervention and therapeutic management programs, need for training for parents to use more effective styles of parenting for their CwASD.

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