

# Parents' journey into the world of autism

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**Background.** Autism Spectrum Disorder (ASD) is a developmental disability that results in an impairment in an individual's social interaction and communication, as well as restricted, repetitive and stereotyped patterns of behaviour. Children with ASD display difficulties in the areas of social as well as communicative behaviour. Parents, caregivers and family members are the main communication partners of children with ASD. Living with a child with ASD can result in changes within a family system.

**Objective.** To describe the challenges and experiences faced by families in their interaction with their child with ASD, caregiver coping strategies and the success of these strategies, and the generalisation and carryover of therapeutic strategies provided by a speech language pathologist (SLP).

**Methods.** A qualitative descriptive research design was selected to explore the objectives of the study. Ten participants were recruited; all participants were parents of a child with ASD attending Learners with Special Educational Needs School in Gauteng, South Africa. Data were collected through a semistructured face-to-face interview survey comprising open- and closed-ended questions, and were analysed using thematic content analysis.

**Results.** The results revealed five main themes, namely communicative challenges, family experiences, communicative coping strategies, speech and language therapy services and strategies provided by the SLPs. Communicative challenges were experienced by parents of one child with ASD. The communication and behaviour of children with ASD were found to affect the daily functioning of the family. The majority of parents reported not learning a new mode of communication, but rather adapting and adjusting to the communication of their child. Communicative coping strategies were required for novel social settings. There were mixed responses with respect to parent's abilities to access and learn new communicative coping strategies. Speech and language therapy assisted in improving the child's communication skills, while strategies provided by SLPs were explained to be effective even though generalisation of strategies was limited.

**Conclusion.** This study concluded that parents and children with ASD experience challenges in communication and interaction. The family systems approach as well as the World Health Organization's International Classification of Impairments, Disabilities and Handicaps are two functional frameworks that can assist SLPs to provide intervention to children with ASD.

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Autism Spectrum Disorder (ASD) manifests as a qualitative impairment in an individual's social interaction and communication, as well as restricted, repetitive and stereotyped patterns of behaviour.<sup>[1]</sup> The core characteristics found in a child with ASD include difficulties in social communication, language and related cognitive skills, and behaviour, as well as emotional regulation.<sup>[2]</sup> Children with ASD can present with difficulties in all five aspects of language (phonology, semantics, syntax, morphology and pragmatic); these difficulties vary according to the particular diagnosis of each child. It is generally agreed upon that whatever the diagnosis of a child with ASD, deficits in pragmatic skills and theory of mind are always present. These social communication deficits of a child with ASD may create a limitation in social experience, contributing to impaired development and learning, and challenging behaviours. Thus, children with ASD require a clear and effective mode of communication.<sup>[3]</sup> Speech language pathologists (SLPs) play an important role in enhancing a child's daily language skills, but therapy needs to extend beyond the therapy environment as a means of improving quality of life and daily functioning. Disabilities with a social component (such as ASD) are transactional; this implies that the effect of the language deficit does not only affect the child but the communication partners as well.<sup>[4]</sup> Communication partners are required to modify their interactive style and the environment in order to ensure successful communication.<sup>[5]</sup> Consequently, SLPs should recognise the significance of family involvement in the therapy process. Together, the SLP and family members should assess and monitor the effectiveness of intervention

for the child with ASD;<sup>[5]</sup> because programmes that include parents/caregivers prove to be effective with the involvement of SLPs.<sup>[6]</sup>

The study conducted was undergirded by two theoretical frameworks, namely the family systems approach and the International Classification of Functioning, Disability and Health (ICF) for children. The family systems approach is based on the notion that an individual's behaviour should be viewed and addressed within the context of the family.<sup>[7]</sup> The family undergoes changes and development over time, through which they are able to achieve a state of homeostasis.<sup>[8]</sup> Children with ASD are faced with developmental challenges that affect parental and family functioning, resulting in significant stress for all family members.<sup>[9]</sup> ICF is an early classification scheme introduced by the World Health Organization; it defines disability under three components, namely impairment, activity limitations and participation restriction.<sup>[10]</sup> The ICF allows for individuals to be classified according to health domains (hearing, talking and memory) as well as health-related domains (education and social interaction).<sup>[10]</sup> The ICF classification allows for ASD to be classified as a disability, owing to the associated language impairment and limitation in activity participation. The ICF presents factors that result in functional limitations as well as factors that may enhance optimum functioning, thereby guiding SLPs to help children with language impairment to improve their daily functioning in terms of language, communication and interaction.<sup>[11]</sup>

The challenges experienced by parents/caregivers in raising a child with ASD have been documented mainly in England, North America and Australia.<sup>[12]</sup> In addition, research regarding the communicative

difficulties of children with ASD has been conducted,<sup>[13]</sup> however, there is a paucity of information within the South African (SA) context regarding the experiences and challenges that parents face when communicating with their autistic child. SA is culture rich, allowing for diversity in the experiences of parents/caregivers; therefore, research regarding families who are affected by ASD is essential.

## Objective

The objective of this study was to explore and describe the communicative experiences and challenges of parents/caregivers of a child with ASD within the SA context. An additional objective was to describe caregiver coping strategies and the success of these strategies in families with children with ASD, while determining the carryover of therapy strategies.

## Methods

A descriptive research design was utilised. Non-probability purposive sampling was used to recruit ten participants. The sample comprised parents whose children were currently attending Learners with Special Educational Needs (LSEN) School in Gauteng Province, SA. An inclusion criterion was formulated to establish the eligibility of the participants in the study. A semistructured interview survey comprising open- and closed-ended questions was used. Written consent was provided by the Gauteng Department of Education as well as the principal of LSEN School. Ethical clearance was granted by the University of the Witwatersrand Human Research Ethics Committee (H13/03/09). All participants in the study were fully informed about the nature of the study. Participants provided written consent for participating in the interview as well as for the recording of the interview. Interviews were transcribed and analysed.

## Results

### Description of participants

All participants were parents of children with ASD. Nine participants were female (mothers) and one was male (father). Nine of the participants had sons and one had a daughter. The average age of participants was 41.4 years. All parents reported having only one child with ASD. Seven participants were black, two were Indian, and one was white. The average current age of children in question in the study was 11.8 years. The average age of diagnosis was reported to be 2.7 years. At the time of the study, all children had access to speech and language intervention through school therapists.

Thematic content analysis revealed five main themes, namely:

### Communicative challenges (subthemes: parent challenges and communicative challenges)

All respondents indicated experiencing challenges in both the receptive and expressive language domains of communication. Four participants reported challenges in understanding the signs utilised by their child. Five parents indicated having difficulty in providing instructions and commenting about items or topics that were not present in the environment of the child. Due to the lack of social interaction, one participant reported challenges in receiving any form of communication from her son. One participant further explained challenges in understanding her child due to articulation difficulties. From the subtheme communicative challenges, it was found that five participants described communication in a social setting as challenging owing to the change of environment. Six parents reported that communicating in a social setting was more challenging than in the home environment, where factors can be controlled and the environment remains familiar. Four respondents further pointed out that communication with a stranger proved to be challenging, as people demonstrated difficulty in understanding the behaviour and communication of a child with ASD; one parent attributed this finding to the lack of education of the public regarding ASD.

### Family experiences (subthemes: daily functioning with family and communication with siblings)

Four participants reported that having a child with ASD had influenced the daily functioning of their family. Participants indicated that they were required to adjust their manner of communication as well as their daily activities. Five participants reported no difference in their daily functioning. All participants indicated that the child with ASD was unable to participate in family discussions. For the theme communication with siblings, two participants reported that their child with ASD could not communicate and interact with their sibling. Six participants' responses implied that siblings were able to communicate through signing or verbal means; however, their interactions through play and communication were limited. It was found that older siblings had a better understanding of ASD.

### Communicative coping strategies (subthemes: learning a new mode of communication; coping strategies adopted in a home setting v. the social setting; and access to communication strategies)

Three participants stated the need to learn a new mode of communication as a coping mechanism to communicate with their child. One parent reported learning the Picture Exchange Communication System (PECS) during her stay in the USA; this participant further reported abolishing the PECS system owing to it being time consuming and restrictive in a natural setting. The seven remaining participants reported not learning a new mode of communication; participants described adjusting and adapting to the communication of their ASD child as needed. In terms of coping strategies, six participants were required to adopt new strategies in a social setting in comparison with their home setting. Two parents specified that owing to the pressures of a social setting, they were required to be protective and supportive towards their child, whereas their child was expected to demonstrate more independence in a home setting. Settings that included individuals who were familiar to the child and who possessed knowledge regarding ASD proved to be less stressful. Four parents expressed negative responses regarding access to information regarding communication strategies in ASD. However, the remaining participants reported that they were able to find information through the LSEN School and networks such as Autism SA, Ernie Els Centre and social media groups.

### Speech and language therapy services (subtheme: improvement in speech and communication skills with therapy)

All parents believed that speech and language therapy resulted in an improvement in their child's communicative skills. Parents reported noting improvements in their child's verbal output, mean length utterances, signing and vocalisations.

### Communication strategies provided by the SLP (subthemes: type of communicative strategies provided and effectiveness of the strategy provided)

Eight parents reported receiving communicative strategies through meetings and workshops held by teachers and SLPs based at the school. Two participants reported not receiving communicative strategies from the SLP (reasons were not provided). From the responses, it was noted that parents were provided with strategies associated with the objectives of and activities conducted in therapy sessions. Parents explained receiving strategies in terms of encouraging vocalisations, the use of PECS and communication through Mekaton signing. It was further noted that the same strategies were provided for both home and social settings. Seven respondents indicated that they were pleased with the strategies provided by the SLP; however, carryover to the home environment was limited.

## Discussion

The communication challenges of children with ASD found in this study are an example of the manner in which language impairment affects a child's activity limitations and participation restrictions. These communication challenges are related to the ICF framework; language impairments are viewed as a disability in the ICF framework.<sup>[11]</sup> The findings of this study should be considered in conjunction with findings that indicate that children with ASD are faced with developmental challenges that affect family functioning.<sup>[9]</sup> The study demonstrated the importance of understanding the family systems approach in working with children with ASD. Having a child with ASD affects family functioning in areas such as family events, planning of activities (as parents are required to plan ahead), and the marital relationship.<sup>[14]</sup> The study also demonstrated findings with regard to sibling communication. Understanding the sibling relationship in the ASD population is important, as siblings become the main caregiver of their ASD brother/sister in cases where parents are no longer able to provide care.<sup>[15]</sup>

Previous studies have reported that families with a child with ASD adopt coping strategies such as distancing, escape and redefining personal goals as well as family priorities.<sup>[16]</sup> These findings were dissimilar to those of this research study, which described the communicative coping strategies which parents have adopted. Parents reported the need to adopt a new mode of communication, such as PECS, in order to communicate with their child. An SA study conducted by Travis and Geiger<sup>[17]</sup> indicated PECS to be a suitable system for parents, educators and children with ASD in terms of communicative functions such as requesting, which provided an explanation for the use of PECS by one participant in this study. Coping strategies were reported to be more significant in social settings compared with the home environment. Another study<sup>[18]</sup> reported that parents found themselves inadequate in dealing with the behaviours presented by the child with ASD, making social outings difficult for families. Participants explained that the lack of understanding regarding the ASD by the community resulted in families having limited contact with the community.

Speech and language services form an integral part in the remediation of a child with ASD. It is recommended that all children with ASD receive speech and language services owing to the nature of their social communication impairment.<sup>[19]</sup> Children with ASD are required to adopt various strategies to communicate. They may utilise PECS, sign language, gestures or a mixed system as a means of communication.<sup>[20]</sup> This was noted in the responses parents provided with regard to the areas of improvement that they had noted since their child had begun attending speech and language therapy. From this research study, it was found that improvement was noted in speech, language and interactive skills following speech and language intervention. However: 'the impact of speech-language services on language outcomes for individuals with ASD has not been systematically investigated.'<sup>[16]</sup> The current study revealed that eight parents were receiving communication strategies (from the SLP) that enabled communication and interaction with their child. This finding is encouraging, as it is essential that SLPs build partnerships with families to develop learning opportunities, provide information, teach strategies and offer feedback.<sup>[21]</sup>

### Theoretical/clinical implications of the study

In the current study, it was found that a child with ASD influenced the daily functioning of the immediate family members. The study indicated that the family system was influenced by a change brought about by one individual; the family was required to reach a new state of homeostasis. This finding implies the importance of considering the family system approach during the process of intervention. In addition, the study revealed the manner in which a disability such as ASD affects not only anatomical structures of the child but also

activity limitations and participation restrictions. This was noted in the restrictive communicative and interactive skills that the child with ASD displayed.

The ICF framework aspires to improve the quality of life of individuals with a disability.<sup>[11]</sup> The improvement in a child's quality of life is an important reflection that SLPs should consider when providing intervention. The ICF can be used as a framework during the intervention process, as its objective is to assist SLPs in understanding the factors that maintain functional limitations and those that facilitate optimal functioning. As a result, SLPs may help children with language impairments to improve functioning in their everyday life.<sup>[11]</sup> This study discovered that SLPs are providing communicative strategies for parents; however, strategies could not be generalised to all settings. This finding demonstrates the importance of providing home-based strategies that serve as a functional and realistic resource that can be utilised by parents in all settings. Additional clinical implications included the importance of considering the communication and interactive challenges faced by both the parent and the child with ASD. The family systems approach and the ICF are beneficial theoretical frameworks that SLPs should consider during the rehabilitation process of clients.

### Study limitations

The study involved a small sample size, which restricts the generalisation of findings to the SA population. The study did not include a comparison group of children who did not have access to intervention; therefore it cannot be concluded that improvement in the speech and language skills of the children in question (reported by parents) is attributed to SLP services. Participants were recruited from only one school, therefore responses were limited to therapy provided by the SLP present at the school. In addition, the social and economic demographics of participants in the study were not gathered; therefore findings cannot be generalised to all children with ASD within the SA context. This study involved an unequal number of races; as a result, it cannot be concluded that ethnic factors did not play a role in the responses provided. The study entailed a semistructured survey with specific questions chosen by the researcher; consequently, salient issues may have been neglected.

### Recommendations

Future research can expand on the interviews conducted in this study by using an explorative descriptive design with a larger sample size of participants from a variety of social and economic settings. This study involved participants who had access to SLP services within the school setting; however, future studies should consider children who do not have access to these services. As SA has a culturally diverse population, future research could further investigate the effect of culture on challenges and experiences of parents of a child with ASD. Another study could investigate the challenges and experiences that SLPs face in the therapy setting.

### Conclusion

The information derived from this study contributed to the limited information available pertaining to speech and language therapy services for children with ASD within the SA context. Furthermore, it provided an understanding of the challenges and experiences of parents of a child with ASD. Insight into the communication skills and needs of children with ASD without causing direct harm was gained. Children spend a large proportion of their time with their parents, who are their frequent communication partners. Parents encompass valuable information and insight regarding the difficulties and skills of their child. Professionals working with children with ASD should be made aware of the significant role parents play in their child's progression. This study demonstrated the important role of parents as well as the role of beneficial frameworks, such as the

family systems approach and the ICF. The results should contribute to the knowledge and clinical skills of professionals working to improve the quality of life of children with ASD.

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