

# **The Lived Experience of South African Mothers Raising a Child with Autism Spectrum Disorder (ASD)**

## **A Summary of the results**

### **Overview of the Study and Findings**

The research study aimed to describe and explore the lived experiences of raising a child with ASD from the perspective of South African mothers. A qualitative, exploratory and descriptive research design was adopted. Nine mothers who each had at least one ASD diagnosed child in grade R-7 participated in the study. Importantly, the ASD diagnosed children had received their diagnosis 2-3 years previously thus ensuring depth in child-rearing experiences. Participants were recruited by contacting independent remedial and special needs schools in Johannesburg and Cape Town as well as through the use of snowball sampling.

The study employed an ecosystemic framework and thus the lived experiences of raising a child with ASD were explored within the particular systems outlined through the bioecological model (Bronfenbrenner, 1979). In this way, the experiences associated with raising an ASD diagnosed child within the South African context were explored together with an examination of the influence that the mothers' perceived environmental interactions have on child-rearing experiences. Additionally, the participants' experiences of support systems available to them and the support systems that they would have benefitted from also emerged through the ecosystemic exploration of raising a child with ASD. In order to assist in analysing the mothers' child-rearing experiences further, theory on The Tasks of Parenting (Bradley, 2002), Coping Strategies (Hastings et al., 2005) and Well-being (Ryff & Keyes, 1995) were also employed in the study. These theories assisted in exploring how the mothers' interactions within the various systems promoted positive or negative child-rearing experiences.

In line with the primary aim of the research, the participants in the study described and explored their experiences of raising a child with ASD. Very broadly, the results of the study indicated that raising a child with ASD in South Africa poses significant context-specific challenges for the mothers which contributed to their description of raising a child with ASD as being difficult. In particular, difficulties pertained to the lack of awareness of ASD in South Africa and navigating the schooling system in this context was notable. Furthermore, it was made apparent that interactions within the various systems, and the influence of these on the mothers' well-being, coping strategies employed, and the ability to achieve fundamental parenting tasks, influenced their child-rearing experiences. It was evident that interactions within the mothers' microsystem (mother-child relationship, family system, school, diagnosis, therapeutic services), their exosystem (inclusive education policy) and macrosystem (South African society) significantly impacted on child-rearing experiences. As such interventions should be targeted within these systems. Through implementing interventions within the various systems,

the optimal functioning of the mothers, the child with ASD, and the family unit as a whole will be promoted.

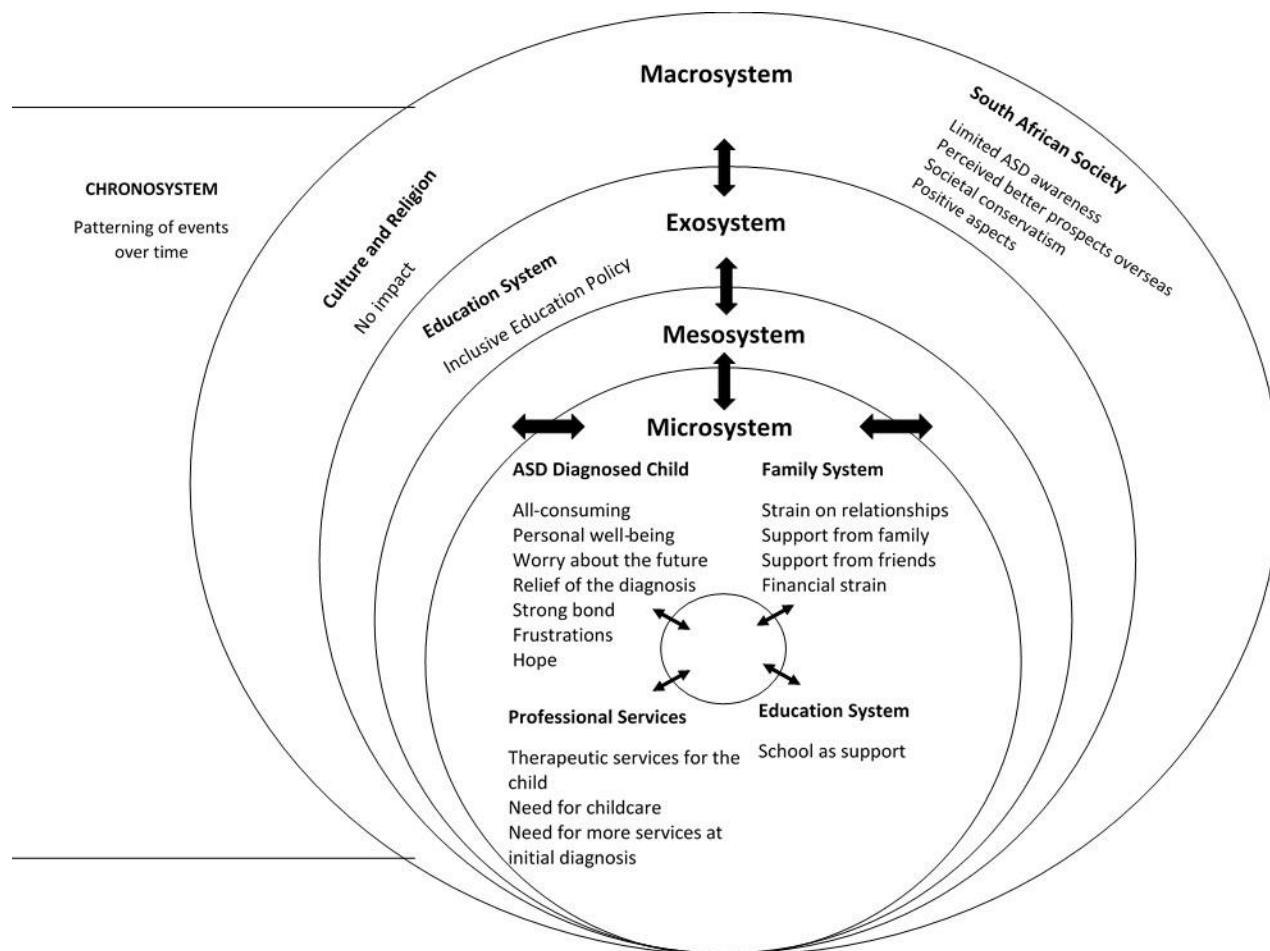
### **The Research Findings**

A summary of the themes and the sub-themes that emerged from the data analysis are outlined in the Table below. Thereafter, brief summaries of each theme is presented.

#### *Themes and Sub-Themes Emerging from the Data*

Theme	Sub-Themes
The mothers' experiences of the mother-child relationship	All-consuming experience Personal well-being Worry about the future Relief of the diagnosis Strong bond with ASD diagnosed child Frustrations in the mother-child relationship Hope
The impact of raising a child with ASD on the family system	Strain on relationships Support from family Support from friends Financial strain
Interactions with professional services	Therapeutic services for the child Need for childcare Need for more services at initial diagnosis
Mothers' experiences of the education system	School as support Views on inclusive education practices
The influence of culture and religion on the mothers' child-rearing experiences	
Raising an ASD diagnosed child in the South African context specifically	Limited awareness of ASD in South Africa Perceived better prospects overseas Societal conservatism Positive aspects of raising an ASD diagnosed child in South Africa <ul style="list-style-type: none"> <li>• Climate</li> <li>• Schooling</li> </ul>

The figure below presents the themes and sub-themes within the bioecological model as described by Bronfenbrenner.



### **Summary of the theme: The mothers' experiences of the mother-child relationship**

It was evident that interactions between the mother and the ASD diagnosed child influence child-rearing experiences. Specifically, the findings highlighted the all-consuming experience of raising a child with ASD and the impact it has on the mothers' emotional and physical functioning. The mothers experienced child-rearing to have impacted their careers and causes significant worry pertaining to the future of the child, resulting in feelings of exhaustion. While aspects within the mother-child relationship are experienced as frustrating, the mothers described having a close bond with the ASD diagnosed child. Mothers are able to see progress in their children, potentially influenced by the strong bond, which elicits feelings of hope. The findings also revealed that the ASD diagnosis was experienced as useful as it assisted mothers in knowing how to move forward.

### **Summary of the theme: The impact of raising a child with ASD on the family system**

The sub-themes revealed that raising a child with ASD is experienced as causing strain on all relationships- particularly relationships with spouses and friends. Suggestions pertaining to further support for the spouses and neurotypical siblings, due to the strain on these relationships, also emerged through the findings. Furthermore, the families expressed the

financial burden felt due to the support demands of the ASD diagnosed child. The mothers also explained that they feel supported by both family and friends provided effort is made to understand the child with ASD. Through this, it was made apparent that interactions within the family system, also comprising the microsystem, are influenced by the child's ASD diagnosis and this, in turn, impacts on the mothers' child-rearing experiences.

#### **Summary of the theme: Interactions with professional services**

It was made apparent that the mothers experience the therapeutic services that their ASD diagnosed child receives to be supportive and therefore beneficial. However, the mothers' described that one of the professional services that they would benefit from is that of child-care. This would allow the mothers to get a break which was expressed as a pressing need due to the all-consuming nature of raising a child with ASD. Adding to this, the findings of the study also demonstrated that the mothers would benefit from more support services during the initial diagnosis process.

#### **Summary of the theme: Mothers' experiences of the education system**

Through exploring the mothers' experiences of raising an ASD diagnosed child within the educational system (micro- and exosystem), the mothers unanimously experienced the schools that their children attend as a major form of support. Adding to this, the findings indicated the mothers' apprehension pertaining to the inclusive education policy due to their negative experiences of the lack of support when their children were in mainstream environments. With this being said, the mothers felt that their children's current schooling environment was inclusive which reduced the mothers' worry as well as the need to advocate for the child within that space.

#### **Summary of the theme: The influence of culture and religion on the mothers' child-rearing experiences**

Based on the results it was made evident that the majority of the mothers in the current study do not believe their child-rearing experiences are impacted by cultural or religious beliefs. In support of this, the mothers described themselves as being very "open-minded". As demonstrated by two mothers, it was nevertheless suggested that if the mothers belong to specific cultural or religious groups, this will impact on their acceptance of the ASD diagnosis as well as how they respond to the diagnosis.

#### **Summary of the theme: Raising an ASD diagnosed child in the South African context specifically**

The results indicated that the South African context impacts on the mothers' experiences of raising a child with ASD. Specifically, the lack of ASD awareness is believed by the mothers to hinder their access to support resources and future employment opportunities for their child. Raising a child within this context is also experienced as challenging by the mothers due to the conservative nature of the South African society and the resultant judgement that accompanies this. The mothers did, however, acknowledge that the outdoor environment and the schooling opportunities in the country result in positive experiences of raising a child with ASD in this context.

### **Implications of the Results and Recommendations based on the findings**

The study makes a contribution towards addressing the paucity of ASD-related research within the South African context. In addition, few ASD-related studies in South Africa have examined the unique perspective of mothers, who are noted in the literature as typically being the primary caregiver of children diagnosed with ASD (Amrhein, 2016; Brewer, 2018). The study makes a further contribution to literature in this field as it is one of the few studies in South Africa that purposely examines the impact of environmental influences on child-rearing experiences using an ecosystemic framework (Bronfenbrenner, 1979). Through doing this, the support needs of the mothers within the various systems were made apparent and formed the basis for the identification and focus of several practical recommendations targeted at the various role players in this field. Adding to the unique nature of the current study, and its contribution to South African literature, the study utilised theory on well-being, parenting tasks and coping strategies which gave an indication as to why interactions within the various systems might impact on child-rearing experiences.

Based on the use of the ecosystemic framework in conjunction with the aforementioned theory, suggestions pertaining to how mothers, and families as a whole, raising a child with ASD can be supported, emerged as a key implication of the study. Facilitated by the ecosystemic framework employed in this study, recommendations are proposed within the various systems. As such, the study provides insight for role-players within the family system, the educational system, and South Africa as a whole, regarding ways in which they can assist mothers in raising a child with ASD. Furthermore, the results from the study provide health care professionals with an in-depth understanding of what families raising a child with ASD are going through. Through doing this, the ways in which the families can be supported are recommended.

#### **Microsystem.**

Despite the mothers' explanation that they received support from their extended family and friends, participants highlighted that the support they received was dependent on the level of understanding of ASD on the part of these role players. As a consequence of this, it is recommended that family and friends, comprising of the mothers' microsystem, take the time to understand ASD and communicate with mothers in terms of how they might effectively be able to assist. The type of support that they appeared to value is practical support. Therefore, if family and friends are able to look after the child with ASD for short periods of time, this will contribute to mothers feeling supported and will similarly allow mothers to have time for themselves.

While the mothers revealed that they felt supported by the schools that their ASD diagnosed children attended, which in this sample were mainly remedial and special needs schools, the schools can implement further strategies to ensure the child and the mothers feel supported within the school environment. The mothers explained that they find communication and feedback very helpful. Due to this, it is recommended that schools connect with the mothers of the ASD diagnosed child on a regular basis and collaborate with them in developing strategies to promote the optimal functioning of the child. In so doing, the schools might empower mothers with self-help skills. This will further promote optimal interactions within the

mesosystem. It was also shown that mothers have a desire to be connected with other mothers who are going through a similar experience. Therefore, schools could play a role in facilitating support networks for these mothers. For example, the schools can look into hosting a support group for the mothers where they might find the emotional space to express and share their experiences.

Based on the results of the study, recommendations for health care professionals can be proposed. Due to the study falling within the educational psychology domain, the recommendations for health care professionals are targeted specifically at Educational Psychologists. From the study, it was evident that raising a child with ASD is challenging and has a significant impact on mothers, and the whole family unit. Therefore, in line with suggestions from the mothers, it is recommended that Educational Psychologists make a concerted effort to provide the whole family with therapeutic services. Specifically, the spouses and the siblings should be targeted for these interventions. Facilitating support groups might be an expedient way in which to provide support to the families as these may be more cost-effective for the families and will also connect families with others who are going through similar experiences-a need identified in the current study. Supporting the mothers therapeutically through helping them work through their emotions and introducing them to other parenting strategies should also be a key focus for Educational Psychologists practising in this domain. Educational Psychologists could also assist the families with feeling connected by putting the families in touch with each other.

As the need for more initial resources regarding ASD was mentioned by the participants in the study, it is recommended that Educational Psychologists educate themselves on the support services that are available for ASD. Through doing this, they should be able to provide mothers with a list of services and practitioners in the area that would be able to assist the ASD diagnosed children and the family as a whole. This could also be done on a larger scale by building a website where mothers can ask questions about services and ASD in general. In addition, information regarding services could similarly be listed on the website. Educational Psychologists could also explore working with software developers to develop an App that might contain relevant information on ASD as well as provide a platform through which mothers could connect. Addressing the lack of ASD awareness in South Africa could also form part of the role of Educational Psychologists. Specifically, they could provide training for educators and schools regarding how to support children with ASD within the classroom environment.

### **Exosystem.**

Through the study, it has been demonstrated that, due to the inclusive education policy implemented in South Africa, mainstream environments should be able to cater to the needs of children with specific barriers to learning. However, the mothers revealed that they experienced a lack of understanding pertaining to ASD in mainstream environments. This further resulted in more stress for mothers and unhappy children. As a consequence of this, it is recommended that mainstream schools employ a professional, such as an Educational Psychologist, who can ensure that teachers, and the school as a whole, are equipped to be able to cater to the needs of

every child within the school. It is further recommended that mainstream schools provide training to educators to equip them with the skills needed to be able to adequately support a child with learning difficulties within the mainstream class. Lastly, mainstream schools should also take cognisance of the recommendations, stated previously, for remedial and special needs schools. Implementing the above recommendations will ensure that children with ASD, and children with other learning challenges, together with their parents, feel supported by the school environment. Furthermore, through implementing these recommendations it is hoped that the school will be more equipped to be able to promote the optimal functioning of every child within the school.

As a consequence of the above, the Department of Education should review the policy on inclusive education and ensure that educators receive specific training regarding providing an inclusive classroom environment. In addition, the government needs to ensure that schools are equipped with the resources needed to be able to optimise the functioning of every learner within the classroom space. Specifically, the government could make certain that every school employs professional personnel, with knowledge of learning difficulties and skills to address these, who are equipped to support educators, parents, and children in the creation of an inclusive environment.

#### **Macrosystem.**

The results from the study have further implications for role players in the macrosystem such as the South African government- specifically the Department of Health. As the South African context significantly influenced the mothers' child-rearing experiences, suggestions as to how the government might ensure mothers of an ASD diagnosed child, and their families, are supported are important to consider. A prominent experience expressed by the mothers was the lack of ASD awareness within the South African context. While there is an Autism Awareness day, the government should target ASD awareness with more rigour. This might be done through government-sponsored advertisements that educate the general public about ASD and the steps to follow in the diagnosis process. Adding to this, the government might assist in ASD awareness by encouraging more researchers to conduct research in ASD in South Africa. Finally, to assist with the financial strain experienced by families raising a child with ASD in South Africa, the government could provide financial assistance to the families through social grants that are more readily accessible.

#### **Concluding Remarks**

The findings of this study provide an initial step towards revealing the mother's reality of raising a child with ASD within the South African context. Due to the study being conducted in the South African context, it addresses the paucity of research on ASD in this country and contributes to increased ASD awareness. From the findings, it is clearly evident that raising a child with ASD has a significant impact on the mothers' well-being and ability to provide important parenting tasks for the ASD diagnosed child. In addition, the study provided useful insight into interventions that might be initiated within the various systems to ensure the optimal functioning of the child with ASD, the mothers and the family unit as a whole. A

number of areas warranting further research also emerged through the current study and have the potential to make a meaningful contribution to the existing body of knowledge in this field.

In conclusion, through conducting the current study, it was apparent that raising a child with ASD is experienced as very challenging. The results of this study have significant implications for the family and friends of mothers with an ASD diagnosed child, schools, the South African government, and health professionals- especially Educational Psychologists. Embracing the recommendations suggested based on the findings of the study will contribute to ASD awareness and encourage different role-players within the various systems to work together to ensure mothers, families, as well as ASD diagnosed children, are holistically supported. The following quote captures the essence of this conclusion:

*“It takes a village to raise a child. It takes a child with Autism to raise the consciousness of the village” – Elaine Hall*