

Family quality of life of South African families raising children with Autism Spectrum Disorder



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What did we aim to find out?

Families play a key role throughout the lifespan of people with autism. Only recently did researchers start to seek positive approaches that can help support these families. Family quality of life is an international concept that provides a way to think about the 'goodness of life' of the whole family. Our study was the first in South Africa to ask families who are raising children with autism about their quality of life.

We used the data that we collected in our 2015 study to explore the answer to this question. Our findings are important because it can help service providers to better understand the strengths and needs of families who are raising children with autism.



- How do families who are raising children with autism in South Africa feel about their family quality of life?

Who participated in the study?

There were **180 families** who participated in the research study

- 75%** of the families were **2-parent families**.
- 42%** of the families had **2 children**.
- The average age of the child with autism was **5 years**.
- 52%** of the families felt that they were **'struggling'** or **'just getting by'** with their monthly household income.
- 81%** of the families raised a **boy** with autism.
- 19%** of the families had a **girl** with autism.
- 52%** of families considered their child to have a **'moderate'** level of autism, while **35%** indicated a **'mild'** level of autism and **13%** indicated a **'severe'** level of autism.

This is the people who are closely involved in the day-to-day affairs of the household (therefore we considered grannies, friends, paid workers to be part of the family)

How did we measure family quality of life?

We used the Family Quality of Life Scale. A parent had to rate 25 items on behalf of the family. The options ranged from 'very dissatisfied' to 'very satisfied'. The 25 items relate to the family's interaction, parenting, emotional well-being, material/physical well-being and disability-related support.

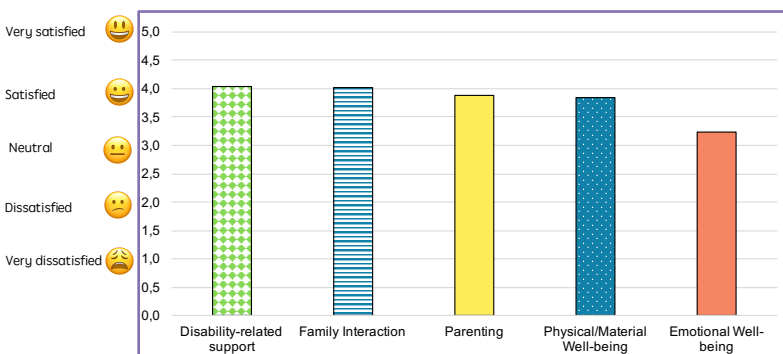
★ For example

My family enjoys spending time together

My family has a way to take care of our expenses

My family has the support we need to relieve stress

What did we find?



We found that the participating families felt most satisfied with the disability-related support that they received. This is important and highlights the potential vulnerability of those families who are not receiving any services for their child with autism. Families felt the least satisfied with their emotional well-being. This is similar to what other families living in other countries are reporting and stresses the need for services to be developed that support the emotional well-being of families.

What can we learn from all this?

- ✓ A **family quality of life approach** can help guide service providers to think about and work towards what brings satisfaction to the families that they serve.
- ✓ The **Family Quality of Life Scale** (freely available) can be used as a conversation starter to identify areas of family strengths and family needs.
- ✓ **Get to know** who the family considers being part of their family.
- ✓ **Empowering parents** with knowledge and skills can be valuable to all families.
- ✓ Supportive 'low-level' interventions such as **family support groups** can assist families, especially regarding their emotional needs.

A special word of thanks goes to the participating families and organisations who kindly devoted their time to participate in this study.

This easy-to-read version was created from the article called 'Family quality of life of South African families raising children with autism spectrum disorder' that was published in 2017 in the *Journal of Autism and Developmental Disorders* (doi: 10.1007/s10803-017-3102-8).

The published article was based on [Liezl's PhD study](#) - completed at the University of Pretoria. We created this simplified version to share what we have learned with service providers and families raising children with autism. Please contact Liezl if you are interested in the full version of the article - liezl.schlebusch@up.ac.za OR liezl@treesofhope.co.za

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