

Towards the Development of a Framework of Care: Considering the Primary Caregivers of children with Autism Spectrum Disorder in a South African context

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Introduction: Primary caregivers (PCG) are often “silent” patients as their needs and quality of life are overlooked. In relation to parental stress, Autism Spectrum Disorder (ASD) is one of the most stressful childhood conditions given its pervasive nature, limitations in communication, lack of emotional expression and difficult behaviours. Although parenting stress in ASD is well-documented there are few interventions that cater for the PCG. Most interventions directly benefit the child with ASD (CASD) and benefits for parental well-being are secondary outcomes. To this end, this study aims to develop a framework of care in an attempt to improve the quality of life of PCG of CASD.

The **objectives** are reflected in four phases: preliminary information gathering and item generation; establishing consensus for inclusion; framework construction and feedback on the proposed framework.

The **methodology** follows a systematic approach as to achieve a sustainable and efficient framework of care. An exploratory sequential mixed methods design embedded with interactions for collaboration with PCG, health care professionals and other stakeholders within the field of ASD has been implemented. Collaborations will ensure the relevance and acceptability of the proposed framework of care within a South African context. Ethical clearance has been granted. The first phase is near completion.

The findings will be presented per phase giving the progression of the framework development with specific reference to the South African context.

Conclusion: The framework will bridge a gap in intervention for the PCGs of CASD providing a platform for implementation of the proposed framework.