

**Examining Available Behavioural and Social Interventions for Children with Autism
Spectrum Disorder in Developing Countries in Africa – A Scoping Review**

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Declaration

I declare that this research report is my own, unaided work. It is being submitted for the partial fulfilment of the degree of Master of Arts in Clinical Psychology at the University of the Witwatersrand, Johannesburg. It has not been submitted, in whole or in part, before for any other degree or examination at any other university.

A handwritten signature in black ink, appearing to read 'Kajal Maharaj', with a horizontal line extending from the end of the signature.

Kajal Maharaj

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Abstract

Autism spectrum disorder (ASD) is a prevalent neurodevelopmental disorder, but data on ASD presentation in developing countries is limited. This scoping review aimed to identify existing gaps in research on contextually relevant interventions, as well as examine available interventions, for children with ASD in developing countries in Africa. In addition, comorbid disorders in individuals with ASD are common. These comorbid disorders may perpetuate psychological distress and impact the quality of life for individuals with ASD. The Arksey and O'Malley (2005) framework with methodological enhancements by Levac et al. (2010) guided this review. Five stages were involved: identifying the research question, identifying relevant studies, screening studies, charting data, and summarizing results. A total of 2464 records were screened, and 19 studies met the inclusion criteria. The findings further highlight a lack of research on ASD interventions in developing countries, as well as barriers to accessing and implementing interventions. It also provided an overview of available interventions, including parent-mediated, professionally implemented, and other interventions. This review highlights the need for further research on effective and appropriate ASD interventions in developing countries in Africa, but also provides a foundation for understanding existing interventions and barriers.

Keywords: Autism Spectrum Disorder, Children, Developing Countries, Intervention, ASD

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Chapter 1: Introduction

The limited research pertaining to contextually relevant interventions for autism spectrum disorder (ASD) in developing countries is a concern. Affecting as many as 1.5% of individuals in high-income populations, ASD is a prevalent neurodevelopmental disorder. However, limited data exists on how ASD manifests in developing countries, creating a gap in available interventions (Guang et al., 2018; Lord et al., 2020; Lyall et al., 2019; Zwaigenbaum & Penner, 2018). Many individuals with ASD present with at least one comorbid disorder, which may stem from ineffective, inappropriate, or contextually irrelevant interventions. This can perpetuate psychological distress and ultimately decrease their quality of life (Cage et al., 2018; Rosen et al., 2018; Simonoff et al., 2008). Recognizing and addressing these issues is crucial for ensuring the health and well-being of individuals with ASD in developing countries and fostering a better quality of life.

Therefore, this scoping review will explore currently available behavioural and social interventions for children (aged 17 years or younger) with ASD in developing countries within Africa. These interventions, hereafter referred to as "interventions," are chosen because they aim to support children's communication, interpersonal relationships, and behaviour. These factors significantly impact how children perceive themselves and the world around them, ultimately influencing their mental health and well-being.

1.1 Background

From initially being described as a rare and narrowly defined disorder, autism spectrum disorder (ASD) has undergone a significant shift. Introduced by Leo Kanner in 1943 (Kanner, 1943), ASD is now recognized as a common, well-researched, and advocated-for neurodevelopmental disorder (Campisi et al., 2018; Lord et al., 2018). However, this understanding primarily stems from developed, high-income countries.

Characterized by social/communication deficits and restricted/repetitive behaviours, on a scale from mild to severe, ASD typically manifests in early childhood and can cause significant impairments in various domains of life, including social, occupational, and functional ability (American Psychiatric Association, 2013). Comorbidities such as anxiety, mood disorders, epilepsy, and immune deficiencies are also commonly associated with ASD (Lord et al., 2019; Lyall et al., 2019; Zaboski & Storch, 2018). These significant impairments in functioning, as well as common comorbidities, may perpetuate psychological distress for individuals with ASD.

Crucially, although extensive knowledge exists about ASD in high-income countries, information regarding its presentation and management in developing countries remains limited (de Leeuw et al., 2020; Durkin et al., 2015). This knowledge gap hinders efforts to effectively support individuals with ASD in these regions.

This review defines developing countries in Africa as those with underdeveloped infrastructure, limited access to resources, and low income, literacy, and life expectancy rates (United Nations, n.d.). Existing prevalence estimates are unreliable for developing countries. While the World Health Organization estimated a global prevalence of 0.76% in 2010 (Lyall et al., 2017), this figure is outdated and based on studies conducted in developed nations, representing only 16% of the world's children. A significant gap exists in prevalence data for developing countries. Furthermore, Hahler and Elsabbagh (2017) estimate that 200 million children in lower-income and middle-income countries have developmental delays or disabilities, potentially including ASD. Onoalapo and Onoalapo (2017) highlight the fluctuating nature of epidemiological data on ASD in developing countries. Despite suggestions of high prevalence, the accuracy of these estimates is questionable. This may be due to limitations in diagnostic tools, lack of awareness about ASD, or a combination of both factors. These issues lead to skewed data and inconsistent prevalence statistics across studies.

Therefore, existing statistics and knowledge about ASD in developing countries are likely outdated, broad, inaccurate, or lacking in detail. Consequently, interventions designed for children with ASD often draw upon research and data from high-income countries, leading to a scarcity of information on contextually relevant and feasible interventions applicable to developing countries in Africa. This lack of suitable interventions could contribute to the development of additional comorbid disorders and a decline in quality of life amongst children with ASD. Furthermore, inappropriate and irrelevant interventions may exacerbate associated psychological distress. This study aims to address this knowledge gap by exploring contextually relevant and feasible interventions for children with ASD in developing countries in Africa.

1.2 Theoretical/Conceptual Framework

This study will utilize the biopsychosocial model of health, developed by George L. Engel in 1977 (Engel, 1977), which emphasizes how biological, psychological, and social factors influence health and treatment effectiveness. However, in developing countries, cultural considerations are crucial for patient-centred care and successful health promotion efforts (Hilty, 2015; Napier et al., 2014).

Therefore, this study acknowledges the importance of the biopsychosociocultural model, which expands upon the biopsychosocial model by incorporating cultural and diversity factors critical to developing countries (Hilty et al., 2015). We will refer to both models throughout the study, often using the term, "contextually relevant" to encompass cultural diversity and other contextual factors. These models provide a comprehensive framework for understanding how health and illness present and evolve in developing countries, where biopsychosocial factors and contextual factors, such as culture and diversity, are essential for developing effective and appropriate interventions.

1.3 Rationale

1.3.1 Gaps in literature

Autism Spectrum Disorder (ASD) affects an estimated 1.5% of individuals in high-income and developed countries, with males diagnosed more frequently than females (Guang et al., 2018; Lord et al., 2020; Lyall et al., 2019; Zwaigenbaum & Penner, 2018). This statistic, however, only applies to these specific regions, creating a significant gap in our understanding of ASD prevalence and characteristics in developing countries (Abubakar et al., 2016; Franz et al., 2017; Marlow et al., 2019).

Furthermore, considering that 83% of the world's population resides in developing countries according to the United Nations Conference on Trade and Development (2022) (UNCTAD, 2022), the available statistics only represent roughly 20% of the global population, further highlighting this knowledge gap.

This lack of data on ASD in developing countries poses a significant challenge. Since existing interventions are often based on knowledge derived from high-income countries and their resource availability, low resource, developing countries may struggle to implement and sustain them. This scenario can lead to inappropriate or irrelevant interventions, ultimately impacting the quality of life for children with ASD in these regions.

Furthermore, diagnostic tools and markers for ASD may be influenced by various factors like ethnicity, language, socioeconomic status, and other biopsychosocial and diversity factors (Abubakar et al., 2016; Marlow et al., 2019). This creates challenges in developing countries where these tools might not be culturally appropriate, economically feasible, or effectively translated. Such limitations can further hinder awareness, diagnosis, and ultimately, intervention for children with ASD in Africa.

Inaccurate or skewed statistics are another concern. Limited knowledge about ASD, combined with the use of contextually inappropriate diagnostic tools, can lead to inaccurate or misleading data in developing countries.

It's also worth noting that some suggest rising ASD prevalence rates over time stem from increased awareness (Faras et al., 2010). However, in resource-limited rural areas of developing countries, awareness about ASD may be uncommon and difficult to obtain, highlighting another knowledge gap.

While the exact cause of ASD remains elusive, advancements in the past decade point to neurobiological and genetic factors as potential risk contributors. ASD is considered highly heritable, with environmental factors also playing a role (Lyall et al., 2019; Sealey et al., 2016). Perinatal factors like influenza, fever, foetal hypoxia, and exposure to environmental toxins are suggested risk factors (Fassett et al., 2017). Maternal age, health, and medication use may also be involved (Kim et al., 2019).

Crucially, diagnostic tools for ASD may be influenced by age, language, communication skills, socioeconomic status, and ethnicity (Zwaigenbaum & Penner, 2018). This is particularly concerning for developing countries facing these very challenges (World Health Organization, 2022). Diseases like malaria, HIV/AIDS, tuberculosis, and cholera are prevalent public health concerns in these regions. Additionally, socioeconomic stressors such as poverty and underdeveloped medical and waste facilities are widespread (World Health Organization, 2022). The combined effect of these biopsychosocial and diversity factors may pose an increased, yet unexplored, risk for ASD diagnoses in children from developing countries.

There are also concerns regarding the underlying theoretical models used to develop ASD interventions (Vivanti et al., 2017). These models may be outdated, potentially limiting

their effectiveness in the specific context of developing countries (Hilty, 2015; Napier et al., 2014). This highlights a gap in the development of contextually relevant interventions for children with ASD in these regions (Vivanti et al., 2017). Furthermore, Vivanti et al. (2017) argue that many existing interventions lack strong scientific evidence for their efficacy. This lack of evidence creates a significant gap in effective interventions for children with ASD globally, including those in developing countries.

The previously discussed gaps in statistics, diagnostic tools, knowledge on aetiology, and contextually relevant theoretical models for ASD intervention pose significant challenges for children with ASD in developing countries in Africa. These gaps may lead to the development of comorbid mental disorders due to interventions that are not based in contextually relevant research or that are inappropriate for the specific needs and resources of the region. Children with ASD often face difficulties in areas such as building and maintaining healthy relationships, communication, and behavioural functioning. These challenges can negatively impact their psychological well-being, potentially leading to comorbid conditions and a decline in quality of life.

Contextually relevant behavioural and social interventions have the potential to address these difficulties more effectively and appropriately. Appropriate and contextually relevant interventions could lead to improvements in social functioning, enhanced psychological well-being, a reduction in the risk of developing comorbid disorders, and overall, an improvement in quality of life for children with ASD in developing countries in Africa.

1.3.2 Gaps in literature - Implications

Acknowledging the aforementioned gaps is crucial, as they contribute to a critical concern: the potential decline in mental health and well-being of children with ASD in developing countries due to contextually irrelevant interventions. Research suggests a high

prevalence of comorbid mental health issues in individuals with ASD (Cage et al., 2018; Rosen et al., 2018). For instance, one study found that an estimated 70% of children with ASD have at least one comorbid disorder, with 41% experiencing two or more (Simonoff et al., 2008). Common comorbidities include mood disorders (53% lifetime prevalence) and anxiety (50% lifetime prevalence) (Cooper et al., 2017). Other potential co-occurring conditions include ADHD, oppositional defiant disorder, eating disorders, impulse control disorders, and substance use disorders (Hossain et al., 2020; Lai et al., 2019). These statistics highlight the concerning prevalence of co-occurring mental health issues, potentially exacerbated by interventions that are not adapted to the local context.

The presence of co-occurring mental health disorders in children with ASD, results in an array of psychosocial health implications. These include low self-esteem, difficulty finding/maintaining employment and relationships due to stigma, underdeveloped social and communicative functioning, suicidal thoughts and behaviours, as well as substance abuse and impulse control issues (Cooper et al., 2017; Hossain et al., 2020). Without contextually relevant and feasible interventions, which is crucial for appropriate care in developing countries (Hilty, 2015; Napier et al., 2014), these additional mental health disorders in children with ASD will persist into adulthood, creating a cycle of significant impairment on mental health and well-being, as well as quality of life (Lai et al., 2019).

This review highlights significant gaps in ASD research within developing countries. This limited knowledge often leads to interventions that disregard the unique biopsychosocial and cultural factors impacting individuals with ASD in these regions. Consequently, these interventions may be contextually irrelevant or inappropriate.

The lack of culturally appropriate social and behavioural interventions for children with ASD in developing countries can perpetuate a cycle of negative consequences. This includes

low self-esteem, unhealthy coping mechanisms, strained interpersonal relationships, and negative behaviours, ultimately contributing to comorbid mental health disorders and a decline in quality of life.

Chapter 2: Literature Review

2.1 Introduction

Several existing interventions aim to address the social/communicative deficits and restricted, repetitive behaviour patterns characteristic of ASD. These interventions strive to improve cognitive and social functioning in children diagnosed with ASD (Fernell et al., 2013; Orinstein et al., 2014). This study will focus specifically on behavioural and social interventions, as they target these areas directly and aim to enhance social behaviour, psychological well-being, and overall quality of life.

Early identification and intervention for ASD have been shown to have promising outcomes, with studies demonstrating improvements in functioning (Koegel et al., 2013). However, the effectiveness of most interventions remains largely unknown due to limited scientific evidence (Vivanti et al., 2014). This lack of data makes it challenging to determine which interventions are effective, when to implement them, and how to deliver them optimally.

Vivanti et al. (2014) further highlight the critical connection between understanding intervention efficacy and feasibility, and the subsequent development and implementation of contextually relevant interventions. This is particularly concerning in developing countries, where culturally appropriate and effective interventions are crucial for ensuring quality patient care (Hilty, 2015; Napier et al., 2014).

The literature review section of this study will begin by identifying existing interventions for ASD globally. It will then narrow the focus to interventions specifically available for children with ASD in developing countries, primarily those in Africa. These interventions will be further examined and evaluated in the data analysis and discussion sections.

2.2 Interventions

2.2.1 Applied Behaviour Analysis

Several behavioural and social/communicative interventions exist for children with ASD. One prominent approach is Applied Behaviour Analysis (ABA). Proponents of ABA emphasize its scientific foundation and effectiveness in promoting positive social and behavioural functioning through operant learning principles like reinforcement and stimulus control (Ivey & Schreck, 2017; Orinstein et al., 2014; Pellecchia et al., 2016). However, ABA therapy has also generated critiques.

Critics argue that ABA adopts a medical model, framing ASD as a condition requiring a "cure" or "treatment" (Chapman & Bovell, 2022; Kirkham, 2017; Milton, 2018; Rosenblatt, 2018). This perspective contrasts with the "neurodiversity movement," which views ASD as a natural variation, similar to race or gender. The neurodiversity movement advocates for policies that support individuals with ASD rather than seeking cures.

Furthermore, ABA therapy can be expensive, demanding to implement, and challenging to sustain (Solomon et al., 2014). These factors pose significant barriers in developing countries with limited resources, low literacy rates, and underdeveloped healthcare infrastructure. The high cost and logistical hurdles make ABA interventions difficult to maintain in such settings.

2.2.2 Early Intensive Behavioural Intervention

Another intervention similar to ABA, with potentially promising outcomes, is Early Intensive Behavioural Intervention (EIBI). EIBI builds upon ABA techniques to offer a comprehensive, individualized program for young children with ASD. This long-term (2+ years) program typically involves 20-30 hours of intervention per week (Klintwall et al., 2015;

MacDonald et al., 2014). However, it is crucial to note that the promising outcomes associated with both ABA and EIBI primarily stem from studies conducted in high-income, developed countries. Furthermore, the long-term nature of ABA and EIBI presents significant challenges for sustainability in developing countries. These interventions require substantial funding and dedicated time, resources that may be scarce in low-income settings. This reality significantly hinders the feasibility of implementing and sustaining these interventions on a large scale in developing countries.

2.2.3 Natural Developmental Behavioural Intervention

Another promising intervention combining ABA with developmental and relationship-based approaches is the Early Start Denver Model (ESDM) (Ryberg, 2015; Webb et al., 2014). ESDM falls under the category of Natural Developmental Behavioural Interventions (NDBI). It focuses on leveraging a child's natural environment to promote social skills, aiming for optimal outcomes in both the cognitive and social/communicative domains (Geoffroy et al., 2019; Fuller et al., 2020; Mirenda et al., 2022; Ryberg, 2015).

This emphasis on utilizing the natural environment holds particular promise for developing countries due to its lower resource dependency. ESDM utilizes existing environments and factors like culture and social dynamics (biopsychosociocultural factors) within the intervention process. Additionally, ESDM is considered more cost-effective compared to traditional ABA approaches. It requires fewer intervention hours and reduces the need for additional services like speech, occupational therapy, or further ABA, ultimately lowering overall costs (Cidav et al., 2017; Fuller et al., 2020; Mirenda et al., 2022). Therefore, ESDM presents itself as a potentially valuable tool for developing countries due to its cost-effectiveness. Fewer required intervention hours and the potential reduction of additional services make it a more feasible option in low-income settings.

2.2.4 Parent/Caregiver Implemented Interventions

Another type of feasible and cost-effective intervention that demonstrates efficacy are parent-implemented interventions (Solomon et al., 2014). It is suggested that individuals with ASD receive early, intensive intervention on a long-term basis, which is often very expensive and not feasible for many, especially for those who have limited access or unavailable resources (Kasari et al., 2013; Liao et al., 2014; Solomon et al., 2014). Thus, there is an emergence of parent/caregiver- implemented interventions, which establishes therapeutic intervention and recommendations into a child's daily routine (Kasari et al., 2013; Liao et al., 2014; Solomon et al., 2014). It has been suggested that the parent/caregiver – child relationship is extremely valuable in developing social and communicative skills and should not be overlooked as an intervention to the social deficits identified in relation to ASD (Liao et al., 2014). Thus, a social-pragmatic developmental approach to intervention has been recommended. This approach has been established on the developmental, individual difference, relationship-based (DIR/Floortime) model. This model uses a child's natural context to improve their social and language skills, as well as cognitive and emotional functioning, in order to develop meaningful relationships (Casenhiser et al. 2011; Liao et al., 2014). Another intervention similarly based on the DIR model is the play and language for autistic youngsters (PLAY) home consultation program, which aims to improve social reciprocity and/or developmental measures and has demonstrated results of increased functioning in social, cognitive, and emotional domains (Solomon et al., 2014).

In conclusion, placing caregivers in the role of therapists can be both feasible and cost-effective. This approach, demonstrably improving social skills and emotional well-being, empowers caregivers to build stronger relationships with their children (Green et al., 2013;

Oono et al., 2013). This is particularly suitable for resource-limited settings, as it eliminates the need for specialized interventionists. Additionally, incorporating interventions into daily routines acknowledges and leverages the influence of biopsychosocial and cultural factors, further enhancing intervention effectiveness. Ultimately, this approach reduces overall costs and resource requirements.

2.2.5 Technology-Based Interventions

Technology-based interventions have also been proposed, driven by the challenges of accessing and affording traditional ASD interventions (Fletcher-Watson et al., 2016; Meadan et al., 2016). These interventions, developed for high-income countries with readily available technology, may offer some cost-reduction benefits compared to traditional methods like ABA, which remain problematic even in developed nations (further highlighting their unsuitability for developing countries). However, despite advancements, technology access remains uneven across developing regions (Dedrick et al., 2013; Naslund et al., 2017). Therefore, the utility of technology-based interventions may be limited to specific developing countries with advanced technological infrastructure and awareness.

Additionally, the potential benefits of technology for individuals with ASD are acknowledged. They may find these interventions engaging due to their structured nature, reduced sensory stimuli, and lower social demands compared to in-person approaches (Grynszapan et al., 2014). However, concerns exist around their potential drawbacks.

Firstly, overreliance on technology-based interventions could exacerbate existing social isolation and hinder social skill development in children with ASD (Grynszapan et al., 2014). This may be particularly detrimental in developing countries where communities and cultures often emphasize social interaction and "togetherness" (Mascayano et al., 2020; Rathod et al., 2017). Technology-based interventions, if accessible, could further contribute to social and

behavioural issues, potentially leading to worsened psychological well-being and a decline in quality of life. Secondly, the emerging nature of technology-based interventions raises concerns about their long-term effectiveness and validity, despite promising initial results (Grynszapan et al., 2014). Coupled with accessibility challenges in developing countries, the appropriateness of this intervention type needs careful consideration.

2.2.6 Alternative/Emerging Interventions

Beyond technology-based interventions, other emerging approaches to supporting children with ASD exist. One such option is animal-assisted intervention (AAI), as highlighted by O'Haire (2013) and O'Haire et al. (2017).

AAI proposes that interacting with animals can foster social and interactional skills in children with ASD. Animals may be more engaging than traditional toys or objects, potentially facilitating the development of relationships with animals. These relationships can then be leveraged to increase awareness and interaction with other individuals.

Furthermore, children with ASD often experience difficulty with peer relationships, leading to social stress and isolation. Studies suggest that AAI may increase a child's willingness to form and maintain peer relationships, potentially improving their overall interaction skills with others.

However, it's crucial to acknowledge that AAI remains an evolving field, with existing research often facing methodological limitations. Despite this, further exploration of AAI in developing countries may be valuable. This intervention holds promise due to its low-resource requirements and the potential accessibility of animals in many developing regions.

2.2.7 Eclectic Interventions

It is also important to note that different interventions are often used eclectically, meaning that several methods or approaches to ASD intervention are used simultaneously. For example, interventions mentioned above may also incorporate sensory integration therapy, which is conceptualized around sensory, neurological, and physiological processing theories. Sensory integration therapy aims to reduce self-injurious behaviour, improve attention and sensory motor functioning, as well as inhibit maladaptive behaviours (Case-Smith et al. 2015). Reportedly, it is a highly requested and common form of intervention and is widely used by occupational therapists however, there is a lack of consensus around its evidence base due to incomplete or contradictory findings (Case-Smith et al., 2015; Schoen et al. 2019). Moreover, eclectic therapies may also draw from ABA, speech and occupational therapists, developmental psychology, and other ASD specific interventional approaches (Howard et al., 2014). An example may be using parent-mediated ABA or teacher-mediated ABA (Smith & Iadolora, 2015). This is useful in low-resource setting, leveraging the use of readily available individuals, such as parents of caregivers, rather than scarce specialists. In addition, many eclectic approaches to intervention are often utilized in a community setting, such as group intervention, familial intervention or interventions in schools and clinics (Eapen et al. 2013; Nahmias et al., 2019; Rollins et al., 2016; Smith et al., 2015; Stadnick et al., 2015; Wood et al., 2015). This is motivated by its cost effectiveness, feasibility, and demonstration of promising results. (Nahmias et al., 2019; Stadnick et al. 2015). In developing countries, there is often a community-based, sociocultural lifestyle (Rathod et al., 2017), which may prove useful in administering eclectic approaches to intervention. The abovementioned authors further acknowledge that several factors influence the effectiveness of eclectic interventions. The intensity and method of delivery can vary depending on who implements the intervention, such as a parent versus a professional. Additionally, community settings may provide less individual

attention than one-on-one interventions, potentially leading to less optimal outcomes. While individualized, intense interventions may yield better results, community-based eclectic approaches can provide valuable alternatives when other interventions, like ABA or EIBI, are inaccessible or inappropriate.

This review examines the landscape of behavioural and social interventions for children with autism spectrum disorder (ASD) in developing countries within Africa. These interventions vary in their implementation, effectiveness, and resource requirements. Some approaches are well-established, while others are emerging. Notably, many interventions can be combined to create an eclectic approach tailored to individual needs. By considering the biopsychosociocultural factors unique to these regions, this study aims to identify which interventions are most accessible and adaptable for improving social and behavioural functioning, ultimately enhancing the psychological well-being and quality of life for children with ASD in Africa.

Chapter 3: Methods

3.1 Aims and Objectives

This scoping review aims to identify and analyse existing research gaps and available interventions for children (17 years old or younger) with autism spectrum disorder (ASD) in developing countries within Africa.

Limited data and research on ASD in these contexts necessitate this investigation. Understanding these gaps and interventions is crucial for informing the development and implementation of culturally sensitive, appropriate, and effective interventions.

This information will be used to inform the development of existing or emerging interventions. Contextually relevant interventions, which consider biological, psychological, social, and cultural factors (Biopsychosociocultural), are essential for reducing the prevalence of comorbid mental health disorders in children with ASD in Africa, improving their quality of life.

Therefore, this study has the following specific aims:

1. To identify and discuss the gaps in research concerning contextually relevant interventions for children with ASD in developing African countries.
2. To systematically collect and synthesize data on the nature, scope, and extent of existing behavioural and social interventions for children with ASD in these countries.
3. To analyse patterns and themes related to the feasibility of implementing these interventions in these contexts.

3.2 Research Design

This study utilizes a scoping review, a qualitative research methodology employed to explore areas of interest and identify and describe associated problems for interpretation and meaning making (Aspers & Corte, 2019; Hammarberg et al., 2016). Specifically, it aims to investigate and analyse gaps in the literature regarding behavioural and social interventions for children with autism spectrum disorder (ASD) in developing African countries, ultimately highlighting the importance of contextually relevant interventions.

Furthermore, scoping reviews serve the purpose of mapping and exploring the range, extent, and characteristics of existing literature on a specific topic, ultimately informing future research by providing a broad understanding of the field (Peters et al., 2015; Peterson et al., 2017; Pham et al., 2014). Therefore, due to its ability to identify and examine gaps in literature pertaining to contextually relevant interventions for children with ASD in developing African countries and subsequently report on these gaps to inform future research, a scoping review is well-suited for this study.

3.3 Protocol Design

The study utilizes the methodology for scoping reviews, proposed and organized by Arksey and O'Malley (2005), as well as the methodological enhancement suggested by Levac et al. (2010). These approaches were selected to yield broad, but rich and relative results for the current scoping review (Arksey & O'Malley, 2003). There are five stages described in the methodological process and these are as follows (Arksey & O'Malley, 2005; Levac et al., 2010):

Stage 1: Identifying the research question.

Stage 2: Identifying relevant studies.

Stage 3: Study selection.

Stage 4: Charting the data.

Stage 5: Collating, summarising, and reporting the results.

3.3.1 Stage 1 – Identifying the Research Question/s.

This scoping review has identified the following research questions, which directly align with the proposed aims and objectives:

1. What are the gaps in interventions for children with ASD in developing African countries?
2. What is the nature, scope, and extent of existing behavioural and social interventions for children with ASD in these countries?
3. What are the recurring patterns and themes related to the feasibility of implementing these interventions in these contexts?

3.3.2 Stage 2 – Identifying Relevant Articles – Search Strategy

The scoping review identified relevant articles from open-access databases and databases subscribed to by the University of the Witwatersrand. Seven databases were chosen based on their potential to contain relevant literature: Google Scholar, DOAJ, JSTOR, ScienceDirect, PubMed, Wiley, and Taylor & Francis.

A keyword search was conducted using terms related to the target population, context, research questions, and conceptual framework (Arksey & O'Malley, 2005; Levac et al., 2010). These included "autism," "ASD," "developing countries," "children," "intervention," "social interventions," "behavioural interventions," "Africa," and other relevant terms. Boolean operators (AND, OR, NOT) were used to refine the search and ensure the selection of appropriate and relevant literature (Hollier, 2020).

Additionally, reference lists of identified articles were scanned for relevant research, and a search for grey literature (non-traditional publications like websites, conferences, and newspapers) was conducted to ensure comprehensive coverage of existing literature (Arksey & O'Malley, 2005).

3.3.3 Stage 3 – Study Selection (*Inclusion/Exclusion Criteria*)

Article/record selection was determined using inclusion and exclusion criteria, described as follows (Arksey & O'Malley, 2005):

Inclusion Criteria. This scoping review examined social and behavioural interventions for children with autism spectrum disorder (ASD) aged 17 or younger. This age range encompasses early and middle childhood through adolescence, which is when ASD onset or symptom identification typically occurs (American Psychiatric Association, 2013). The study included both male and female children with ASD in developing African countries, categorized as low- and middle-income countries. Articles on behavioural/social interventions were included, along with any traditional, contextually relevant, or emerging interventions targeting these domains. Additionally, the review considered children from various socioeconomic and racial backgrounds reflecting the diversity within developing African countries.

Both qualitative and quantitative studies were incorporated. Qualitative studies offer insights into beliefs, values, meanings, and perceptions, revealing deeper personal and subjective experiences (Hammarberg et al., 2016). Quantitative studies provide numerical data on variable relationships (Hammarberg et al., 2016). This combined approach provides a well-rounded perspective on the examined interventions, fostering a broader understanding (McKim, 2016).

Furthermore, grey literature relevant to the study was included. This refers to documents, literature, or media published outside traditional peer-reviewed journals,

potentially contributing valuable information (Adams et al. 2016). Open-access databases and authorized University of Witwatersrand databases were explored, alongside websites and other non-traditional mediums containing grey literature.

The review focused on articles published within the last eight years (2015-2023). This reflects the shift in ASD understanding, moving from a medical model to a biopsychosocial model emphasizing intervention to manage and improve symptoms, rather than cure or treat ASD (Rosenblatt, 2018). This timeframe also ensures article relevance by excluding outdated information.

Finally, only English-language articles or those translated into English were included. Articles required two or more relevant keywords for selection.

Exclusion Criteria. Articles/records irrelevant to the research context, population, aims, objectives, or questions, or lacking information related to the inclusion criteria, were excluded. Additionally, articles from non-African contexts and those outside the 2013-2023 publication timeframe were excluded. University dissertations were excluded due to practicality concerns regarding their volume and length.

Following Arksey and O'Malley (2005) and Levac et al. (2010), a multi-stage approach was used (Figure 1). First, articles were identified through keyword searches. Titles were then screened, duplicates removed, and abstracts reviewed for relevance. Finally, full texts were screened for final inclusion. It is acknowledged that relevant articles might be missed due to unclear titles or abstracts. A detailed analysis and summary of the selected articles will be provided in the next stage (Stage 4 – Charting the Data).

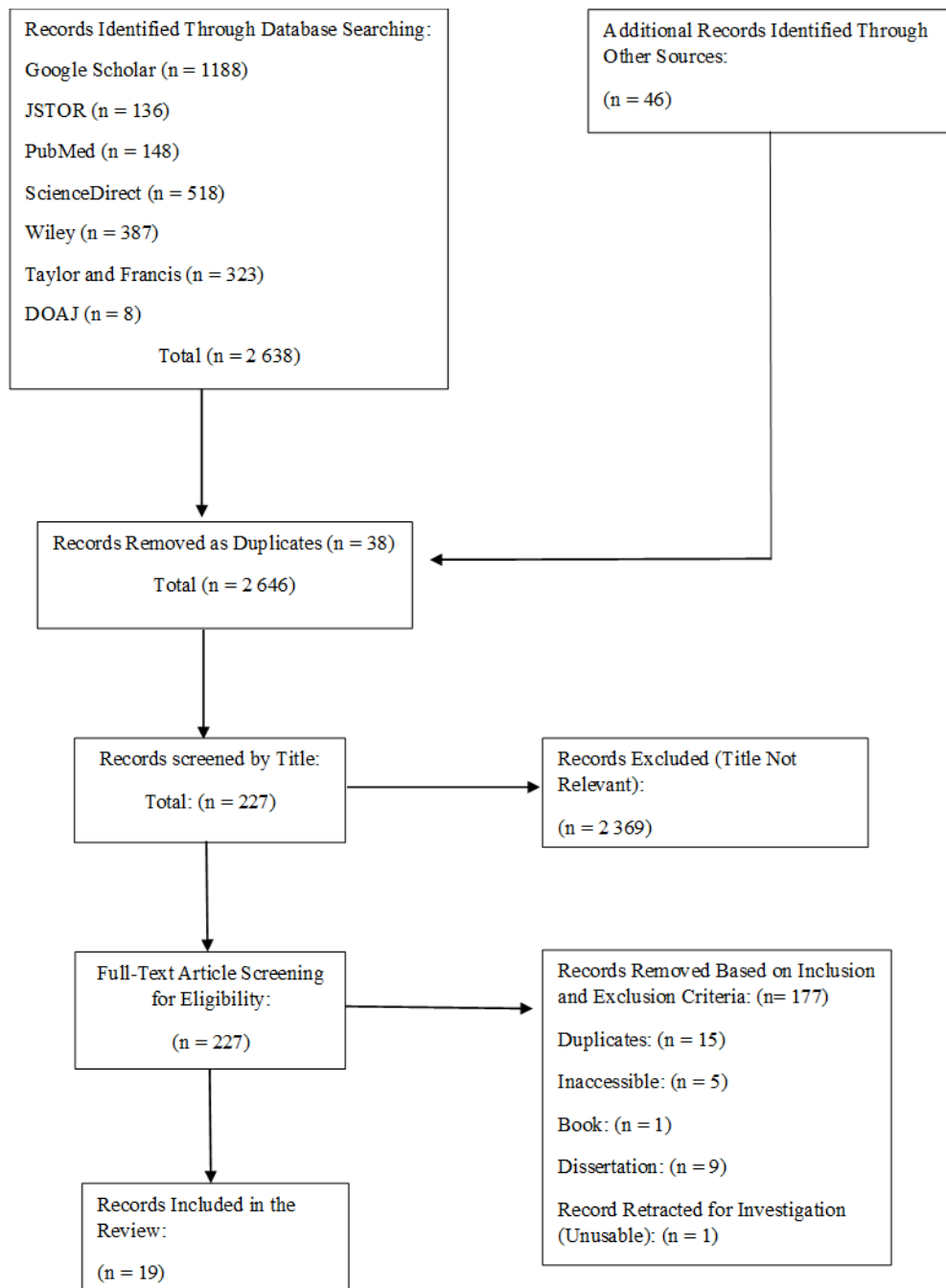


Figure 1: Flow Chart – Article Search Strategy

3.3.4 Stage 4 – Charting the data

This stage, as described by Arksey and O'Malley (2005) and Levac et al. (2010), includes charting the data, or extracting, collating, synthesizing, and summarizing key information obtained from the selected articles/records used in the current study. As reflected in *Table 1 – Characteristic Summary of Data*, the data has been extracted, collated, synthesized

and summarized based on location/contextual characteristics, sample characteristics, research design and intervention characteristics.

Table 1
Characteristic Summary of Data

Author	Location/Context	Sample	Research Design	Intervention/s
Dawson-Squibb & de Vries, 2020	South Africa	18 parents/caregivers participated in Early Bird/ Early Bird Plus and 11 parents/caregivers participated in Autism Cares.	Mixed - methods, quasi-experimental design	Parent Education and Training Programmes - Early Bird/Early Bird Plus and Autism Cares
Knochel et al., 2021	Ghana	4 Students, aged 7 - 17 years old with ASD and 4 classroom staff	Experimental Design	Culturally Focused Staff Training on delivery of praise and its effect on student behaviour
Harrison et al., 2016	Tanzania	29 families of children (average age: 7 years old) diagnosed with ASD	Experimental Design	Intervention designed to inform parents of ASD and empirically supported behavioural strategies.
Wannenburg & van Niekerk, 2018	South Africa	Case study participant selected via purposive sampling. Participant has been diagnosed with ASD	Qualitative, mixed-methods case study	Speech therapy, creative endeavours, human-animal interaction and mentorship
Hampton et al., 2019	South Africa	Three, male school-aged children (5-7 years old) diagnosed with ASD.	Experimental Design	Enhanced Milieu Teaching (EMT)

De Milander et al., 2016)	South Africa	2 case study participants. One female (9 years, 4 months old) and one male (8 years, 7 months)	Case Study, pre-post-test design, using quantitative data	Equine - Assisted Therapy (EAT)
Rieder et al., 2023	South Africa	Ten caregiver-child dyads and four non-specialists participated	Single- arm, pre-post design	Naturalistic Developmental Behavioural Intervention (NDBI)
Pierucci et al., 2023	Zambia	19 caregivers of children diagnosed with ASD, Down Syndrome or Cerebral Palsy (Mostly ASD)	Mixed - methods, pre-post design	Project ImPACT - Parent-mediated, NDBI
Kumm et al., 2021	Lower-middle income contexts and low-resource contexts	Sample details not provided	Narrative, feasibility evaluation	Six emerging technology-based interventions for ASD
Macmbinji & Hadi, 2019	Kenya	60 parents of children with ASD, 40 children with ASD and 20 occupational therapists	Descriptive, survey design involving both qualitative and quantitative approaches	Integrated therapy approach
Tekola et al., 2020	Ethiopia	Caregivers, professionals and stakeholders (participant details missing)	Mixed Methods design	The World Health Organizations' Caregiver Skills Training programme
Bello - Mojeed et al., 2016	Nigeria	20 mothers of children with ASD between the ages of 7 - 17 years old	Pre-post intervention pilot study	Weekly, manualized group-based interventions, including functional behavioural analysis and individualized behaviour management plans

Moosa et al., 2023	South Africa	20 Occupational Therapists	Descriptive, qualitative design using semi-structured interviews	Occupational therapists various assessments and interventions for ASD
Mathew, 2021	Africa	Sample characteristics not provided - Grey Literature	Research design details not provided - Grey Literature	Technology- based interventions
De Goede, 2023	South Africa	Sample characteristics not provided - Grey Literature	Research design characteristics not provided - Grey Literature	Animal-assisted intervention
Franz et al., 2023	South Africa	150 children with ASD (18 - 72 months) and their caregivers	Type 1 effectiveness-implementation hybrid design; assessor-blinded, group randomized controlled trial	NDBI
Aderinto et al., 2023	Africa	Review of 55 Articles	Review	Various interventions
van der Merwe & Yarrow, 2020	South Africa	45 children with ASD, aged 13 -17	Qualitative, exploratory, case study design	Waves for Change (W4C) - Surf-based therapy for ASD
Krynauw & Pedro, 2018	South Africa	10 neurofeedback practitioners	Qualitative, exploratory research design	Neuro-Feedback Intervention for ASD

The above table, *Table 1 – Characteristic Summary of Data*, shows that the majority of the selected articles/records were based on research conducted in South Africa. Research from the remaining articles is spread between different geographical regions within Africa. While there is considerably more information regarding available interventions in South Africa, the similarities across different geographical regions in Africa may imply the potential to generalize these interventions into different contexts however, more research into

generalizability needs to be conducted, as different biopsychosociocultural factors may exist within different countries. Samples in the records/articles included parents/caregivers of children with autism, children with autism themselves, and various health professionals. This sample range may be beneficial in providing a more holistic, and well-rounded overview of available social/behavioural ASD interventions for children in Africa from different perspectives of interaction and care. The interventions in the articles/records range from established interventions to emerging interventions. A detailed exploration and analysis of this data will be included in the results section.

3.3.5 Stage 5 – Collating, Summarising and Reporting the Results

According to the guidelines provided by Levac et al. (2010), the current review collates, summarises, and reports the results in three stages. The first stage is the analysis, or summative description of results through thematic, narrative analysis, which uses word and text to collate, synthesize and analyse data, finding emerging patterns or themes (Cruzes et al., 2015). The steps for achieving a thematic, narrative analysis are outlined by Butina (2015), and comprises of a) organizing and preparing the data, b) have a general understanding of the data, c) coding (processing and sorting) the data, d) categorizing data into themes, e) interpreting the data. Thereafter, Levac et al. (2010), suggest reporting the outcomes and results to address the aims and questions of the review.

3.4 Qualitative Rigour and Reflexivity

The current study was conducted by an MA Clinical Psychology student, with prior training in research methodology throughout her undergraduate and honours degrees. Moreover, methodological quality is enhanced by the researcher working collaboratively with a research supervisor (Gower & Taylor, 2019). Supervision is essential in ensuring transparency, accountability, and non-bias, as well as providing expert knowledge, skills, and

support, useful to conducting a valid and reliable review of high quality and sustainability (Gower & Taylor, 2019; Severinsson, 2014).

In addition, to ensure the reliability and transparency within the review, the methodological protocol set out by Arksey and O'Malley (2005), and Levac et al. (2010), was utilized and consulted throughout.

3.5 Ethical Considerations

Several ethical considerations were observed for the current study. Firstly, an ethical waiver of clearance was granted through the Human Research and Ethics Committee (non-medical), and the study commenced thereafter (See Appendix A for ethical clearance certificate). In addition, the study ensures that all published articles/literature used, and data gathered, follows the ethical principles of research, non-maleficence, beneficence, fidelity, autonomy, justice, and integrity (Gajjar, 2013) within their methodology and ethical considerations. The current study ensures that the published articles screened for use consider the vulnerable and minor age groups and ensures consent from parents/guardians was provided (Ketefian, 2015). It is noted that grey literature cannot be screened for the ethical considerations mentioned above, and the above only pertains to published, peer-reviewed, academic literature being used. Lastly, the researcher and supervisor will work collaboratively, acknowledging potential bias and aiming to reduce bias by ensuring openness, transparency, and congruence in the methodological approach of the current study (Smith & Noble, 2014).

Chapter 4: Results

4.1 Search and Selection of Articles and Records

Using the guidelines set out by Arksey and O'Malley (2005) and Levac et al. (2010), a search for records was conducted (*Figure 1*). A total of 2 638 records were identified through the database search and an additional 46 records were identified through other sources and included grey literature. Thereafter, 38 records were removed as duplicates, and the remaining 2 646 records were screened by title and abstract. Title and abstract screening of records resulted in the exclusion of 2 369 records based on relevance. The remaining 227 records underwent a full-text record screening for eligibility based on inclusion and exclusion criteria. From the full-text screening phase, a further 177 records were removed based on inclusion and exclusion criteria, 15 additional records were removed as duplicates, 5 records were inaccessible, a total of 10 records were removed, as the records were books or dissertations and lastly, 1 article was retracted for investigation and thus, unusable. The remaining 19 records were included in the current study.

4.2 Characteristics of Included Records

The general characteristics of the records included in the current scoping review are included in *Table 1*. All records included were published between 2016 and 2023. Ten studies were conducted in South Africa and 2 studies reported being conducted in the context of Africa as a whole. The remaining studies were conducted in Kenya, Nigeria, Ethiopia, Ghana, Zambia and Tanzania. One study focused on the general context of lower middle-income countries and low resource settings. Samples and participants included a variety of professionals in ASD treatment and intervention, teachers of children diagnosed with ASD, caregivers of children with ASD, and children with ASD themselves. Two records of grey literature did not have a specific population or participant group and one article included was a scoping review of 55

studies, and thus did not specify a participant/sample group. Research designs of all included records were qualitative or quantitative in nature, with a few mix-method research designs as well. Interventions reported included a range of parent-mediated, teacher-mediated, naturalistic interventions, as well as occupational therapy, behavioural therapy, analysis and management plans, eclectic therapies, animal-assisted therapy, surf-based therapy and technology-based interventions.

4.3 Findings

4.3.1 *Theme 1: Limited research on ASD in Africa*

A major theme identified across the included articles and records discuss the limited research, specifically regarding intervention, for lower and middle-income countries, or low-resource contexts, such as developing countries in Africa. (Aderinto et al., 2023; Bello-Mojeed et al., 2016; Dawson-Squibb & de Vries, 2020; Franz et al., 2023; Harrison et al., 2016; Knochel et al., 2021; Kumm et al., 2021; Macmbinji & Hadi, 2019; Matthew, 2021; Moosa et al., 2023; Pierucci et al., 2023; Rieder et al., 2023; Tekola et al., 2020; van der Merwe & Yarrow, 2020; Wannenburg & van Niekerk, 2018). Furthermore, the lack of research becomes more concerning with statistical suggestions that ASD in Africa is highly prevalent (with suggestions that the majority of individuals with ASD globally live in lower-middle income and developing countries) and moreover, that ASD prevalence may be increasing each year (De Milander et al., 2016; Franz et al., 2023; Krynauw & Pedro, 2018; Kumm et al., 2021; Pierucci et al., 2023; Rieder et al., 2023) However, there are also suggestions that estimates about prevalence, including increasing prevalence for ASD, are inaccurate. This inaccuracy, once again, stems from the lack of context-specific research and awareness regarding ASD and ASD intervention in developing countries in Africa (Aderinto et al., 2023; Harrison et al., 2016; Matthew, 2021). Furthermore, Aderinto et al. (2023), suggest that accurate prevalence rates for

ASD in Africa is essential in challenging the existing barriers to ASD intervention in these countries. In addition, Dawson-Squibb and de Vries (2020), discuss this limitation in research and suggest that the World Health Organization has highlighted the need for more context-specific healthcare research and delivery pertaining to ASD in developing countries, such as developing countries in Africa. Harrison et al. (2016), suggest that ASD research in Africa is largely understudied with limited research informing empirically supported interventions for ASD, specifically regarding children. This results in further challenges to ASD awareness, intervention and access to intervention, as explored in *theme 2: Challenges to ASD intervention, and access to intervention, in Africa*. Without research on ASD intervention for children in developing countries in Africa, there is a lack of dissemination of information improving awareness and access, which may result in delayed screening, delayed intervention, stigma, and limitations to intervention resources.

4.3.2 Theme 2: Challenges to ASD intervention in Africa

Financial Constraints. The theme of limited financial resources in ASD intervention (development and implementation) is often mentioned in the selected articles/records. For example, these financial constraints are discussed by Knochel et al. (2021), who suggest that ASD centres/programmes in Ghana are reliant on international funding and support for ASD intervention and implementation. Wannenburg & van Niekerk (2018), provide a potential reason for limited funding for ASD intervention in Africa. They suggest that research and funding are focused on communicable diseases in Africa, as these are regarded as a major health concern in these contexts. This means that mental health and illness, as well as any other non-communicable disease are regarded as secondary concerns, as they have not been prioritized in policy and legislature in these regions. Furthermore, the cost of diagnostic and screening tools for ASD also place further financial constraints on ASD intervention and implementation in developing countries in Africa (Wannenburg & van Niekerk, 2018).

Similarly, a study conducted in Kenya further highlighted financial constraints and experiences of lack of support from the government, which results in limited and inadequate equipment for screening, diagnosis, intervention and intervention implementation (Macmbinji & Hadi, 2019). The lack of research on ASD in Africa impacts policymakers, health care providers, educators and communities in general. Without this research, appropriate interventions remain scarce and resources, specifically financial resources, may not be properly allocated, perpetuating the issue of financial constraints on ASD intervention (Aderinto et al., 2023).

Cultural/Contextual Adaptation. Many of the interventions considered to be available in developing countries in Africa are ones that have been developed in Western contexts with limited consideration for diversity factors mentioned within a biopsychosociocultural model (Hilty, 2015; Napier et al., 2014). There have been suggestions that these interventions, and the implementation of them, may not be culturally and contextually relevant or sensitive to lower middle-income and developing countries in Africa (Aderinto et al., 2023; Bello-Mojeeed et al., 2016; Dawson-Squibb & de Vries, 2020; Franz et al., 2023; Harrison et al., 2016; Knochel et al., 2021; Moosa et al., 2023; Pierucci et al., 2023; Rieder et al., 2023; Tekola et al., 2020; Wannenburg & van Niekerk, 2018). For example, higher income countries may develop interventions that are more costly, time-consuming, or that require access to professionals and infrastructure that developing countries in Africa do not have access to. As a result, there have been limited studies on the feasibility and efficacy of social and behavioural, ASD interventions for children in developing countries in Africa. This also impacts how information regarding ASD and ASD intervention is disseminated. A lack of research on ASD as a whole, results in a lack of awareness, understanding, diagnosis and ultimately, intervention. However, a study conducted by Dawson-Squibb and de Vries (2020), challenged the idea that Western-developed interventions may not be applicable to developing countries in Africa. These authors suggest that Western-developed interventions

are feasible and/or effective in developing countries in Africa when sufficient sensitivity is provided in adapting them to meet the diversity of these contexts and this was demonstrated in the results of their research. Knochel et al. (2021), also suggest that although there is still limited research of ASD and ASD intervention in developing countries in Africa, there has been some progress. The authors suggest that researchers are aware of this lack of cultural/contextual standardization, adaptation and sensitivity, and this awareness alone is crucial to the development of contextually relevant, emerging interventions.

Awareness and Stigma. Almost every article/record highlighted lack of awareness and stigma as a challenge to ASD intervention (Aderinto et al., 2023; Bello-Mojeed et al., 2016; Harrison et al., 2016; Knochel et al., 2021; Kumm et al, 2021; Macmbinji & Hadi, 2019; Matthew, 2021; Moosa et al., 2023; Tekola et al., 2020; van der Merwe & Yarrow, 2020; Wannenburg & van Niekerk, 2018). This relates to the sociocultural factors that impact intervention in the biopsychosociocultural model (Hilty, 2015; Napier et al., 2014). These authors have suggested that due to the lack of research regarding ASD intervention in developing countries in Africa, there is a lack of awareness about these resources. Furthermore, the lack of awareness perpetuates the issue of social/disability stigma associated with children who have ASD, as well as their families and communities. As a result of this stigma, it is easier and safer for families to avoid an ASD diagnosis, as well as intervention and implementation after a diagnosis.

Trained Professionals, Screening and Diagnosis. Harrison et al. (2016), highlights an important challenge to ASD intervention in developing countries in Africa. This challenge is the lack of trained professionals equipped in understanding and implementing ASD intervention. The authors share a statistic that in Sub-Saharan Africa, there is less than one psychiatrist for every million people. In the South African context, it is suggested that there are approximately 1 psychologist, and 1-2 social workers for every 400 000 people (van der Merwe

& Yarrow, 2020). This results in limited dissemination of ASD resources and intervention. Wannenburg and van Niekerk (2018), discuss how early intervention is imperative in preventing further developmental delays for children with ASD however, due to the lack of research, and dissemination of what information is available about ASD in developing countries in Africa, children are usually diagnosed at later stages. This may also be due to the lack of awareness and the stigmatization of individuals with ASD that obstruct the screening and diagnosis process, as well as the lack of professionals trained in the diagnostic and intervention processes. There have also been suggestions of inadequate screening and diagnostic tools that are culturally and contextually sensitive, as it has been explored that many of these tools have been developed in Western contexts (Wannenburg & van Niekerk, 2018).

4.3.3 Theme 3: Available Interventions and Outcomes

Parent/Caregiver Mediated Interventions. Parent/caregiver mediated interventions describe behavioural or social interventions for ASD that are implemented through the parents and/or caregivers of children with ASD, including teachers. This allows parents and caregivers to play a fundamental role in the planning and delivery of healthcare for their children (Fiest et al., 2018). These evidence-based interventions are usually referred to as naturalistic developmental behavioural interventions (NDBI). NDBI includes the key element of these interventions being naturalistic in nature, carried out spontaneously, in children's natural environments, such as their home setting or in school (Frost et al., 2020). An example of naturalistic intervention in a school setting can be found in a study conducted by Knochel et al. (2021), which implemented culturally focused classroom staff training on the delivery of praise and its collateral effects on student on-task behaviour. The results from this study were promising but only when culture and context were considered. Furthermore, classroom staff that participated found that when culture and context were considered, the intervention was acceptable and feasible (Knochel et al., 2021). An example of naturalistic intervention carried

out in a child's home environment can be found in the study conducted by Pierucci et al. (2023). In this study, a parent-mediated intervention training, more specifically, "project ImPACT" or "improving parents as communication teachers" was used. With this intervention, parents/caregivers would be trained to use their natural environment and daily routines to improve their child's social-communication skills. The parents/caregivers that participated in the study felt that the intervention and training was easy to understand and implement. Furthermore, the intervention also demonstrated improvements in the children's social-communication skills (Pierucci et al., 2023).

The majority of the included articles (10 of 19 articles) describe these parent/caregivers mediated interventions, suggesting that they are more feasible in the context of developing countries in Africa, and the outcomes are hopeful, demonstrating improvements in the behaviour and sociability of children with ASD (Aderinto et al., 2023; Bello-Mojeeed et al., 2016; Dawson-Squibb & de Vries, 2020; Franz et al., 2023; Harrison et al., 2016; Knochel et al., 2021; Pierucci et al., 2023; Rieder et al., 2023; Tekola et al., 2020; Wannenburg & van Niekerk, 2018). Rieder et al. (2023), succinctly describe this shared outcome of feasibility and improvement suggested throughout the abovementioned articles, stating that:

This type of approach, where the least resource-intensive service such as low intensity, non-specialist delivered interventions are offered first, may be particularly well suited to lower-middle income countries (LMIC) and other low resource settings. In low-resource contexts, innovative solutions involving redistribution of intervention services to both caregivers and non-specialist providers (e.g., ECD practitioners) may address the service gap impacting young autistic children and their families. Task-sharing may improve equity in access, and extend healthcare delivery, particularly in under-resourced contexts. This dual redistribution of roles from specialist to non-specialist providers, and from interventionist to caregiver, is responsive to the realities of low

resource environments. Task-sharing may be a key implementation strategy that advances accessibility, through principles of sustainability and scalability. (Rieder et al., 2023, p. 3)

For example, a study conducted by Dawson-Squibb and de Vries (2020), which used two Parent Education and Training (PET) interventions and tailored them to be more culturally and contextually sensitive. These interventions were found to be beneficial and acceptable in the South African context, as it considered cost of training, time constraints, language and other aspects of diversity that need to be accounted for when developing interventions for children with ASD in under-resourced contexts . The parents who took part in the study found that the programme was helpful and relevant. Similarly, other studies have stressed the importance of culturally sensitive and contextually relevant interventions (Aderinto et al., 2023; Franz et al., 2023; Harrison et al., 2016; Knochel et al., 2021; Macmbinji & Hadi, 2019; Moosa et al., 2023; Pierucci et al., 2023; Rieder et al., 2023; Tekola et al., 2020; Wannenburg & van Niekerk, 2018).

Professionally Implemented Interventions. Professionally implemented interventions refers to interventions implemented by a professional in healthcare delivery, and may include occupational and speech therapists, behavioural analysts and specialists, or medical and other professionals. Four of the included articles discuss the usefulness of professionally implemented interventions, such as applied behaviour analysis (ABA), Speech and Occupational therapy and Neurofeedback interventions.

According to Aderinto et al. (2023) ABA aims to reduce maladaptive behaviours and increase desired behaviours through reinforcement. It assists by developing social-communication skills and aims to improve self-help skills. The authors suggest that ABA is a feasible intervention for developing countries in Africa, as it can be implemented by

professionals or non-professionals, who have been adequately trained, and it has demonstrated positive outcomes, as it is an evidence-based intervention (Aderinto et al., 2023). However, this contradicts with other authors who have suggested ABA to be a costly and time-consuming intervention that may not be appropriate for under-resourced countries (Solomon et al., 2014). This is not to say though that therapies like ABA cannot be adapted and changed to meet the cultural/contextual needs in developing countries in Africa, as Aderinto et al. (2023) have argued.

Speech and occupational therapies may also be useful in encouraging and promoting pro-social behaviours and reducing stereotypic or harmful behaviours demonstrated in children diagnosed with ASD (Macmbinji & Hadi, 2019; Moosa et al., 2023). A study conducted by Moosa et al. (2023), examined the current state of occupational therapy in South Africa, and the tools used in the assessment of ASD in children. The study demonstrated that occupational therapy is eclectic in nature, using different modalities and forms of intervention, such as play-based therapy or sensory integration therapy. Although the tools used for the assessment and intervention of children with ASD proves useful, it is noted that in under-resourced areas, awareness and access to these tools, assessments and interventions are limited. This is because of the financial cost of sourcing the necessary resources, as well as the time commitment necessary to implement them. Furthermore, there is acknowledgment that there are limited training opportunities for occupational therapists, and thus, there are not enough occupational therapists available, especially in under-resourced areas where this resource is needed (Moosa et al., 2023). In terms of speech therapy, although it is useful in developing social-communication skills in children with ASD, it has similar limitations to occupational therapy and in addition, speech therapy is often used in conjunction with other forms of ASD intervention, such as ABA therapy, as it may not demonstrate as effective results on its own.

This may create additional expenses and become more time consuming in itself (Macmbinji & Hadi, 2019).

Neurofeedback is a personalized brain training system, aimed at reducing an individual's sensitivity to certain stimuli, in order to encourage desired, adaptive behaviours. This intervention has to be conducted by a healthcare practitioner, and thus may also be less accessible for many families (Krynauw & Pedro, 2018). Neurofeedback interventions are often used in conjunction with occupational therapies or other, homeopathic interventions but this is not necessary. Krynauw and Pedro (2018), conducted a study on neurofeedback, which demonstrated that it is useful in reducing anxiety and aggression in children with ASD, as well as in improving communication, behavioural regulation, and quality of life. Although, the results are promising, the intervention itself requires access to resources that many developing countries in Africa do not have. This means that although beneficial, this intervention is one that is not necessarily generalizable to under-resourced areas in Africa.

Integrated or Emerging/Alternative Forms of Intervention. Integrated forms of therapy may include the use of several interventions at once. For example, using speech and occupational therapy in conjunction with ABA and parent/caregiver mediated interventions. Krynauw and Pedro (2018), mention this by describing how neurofeedback is often used in conjunction with occupational therapy. Furthermore, Macmbinji and Hadi (2019), also discuss how speech therapy is often used in conjunction with ABA therapy. The reason for this is to optimize the intervention for ASD, providing as much exposure to, and learning of as many new skills, as possible.

In addition, there are emerging/alternative forms of therapy including animal-assisted therapy, technology-based interventions, and surf-based therapy. These are yet to be proven as evidence-based interventions, as research into these interventions are limited, but these

interventions may be useful in under-resourced countries in Africa until further research is conducted (De Goede, 2023; De Milander et al., 2016; van der Merwe & Yarrow, 2020).

Animal-assisted interventions (AAI) are increasing in popularity as a cost-effective and accessible form of intervention for children with ASD. De Goede (2023), describes AAI as a therapeutic intervention that incorporates an animal, such as a dog, cat, horse, or bird, into a specialised, individualised treatment plan, that has specific and measurable goals. The bond that is created and sustained in the dyad between animal and child improves communication skills and reduces anxiety. Furthermore, it is suggested that the oxytocin produced in animal interactions may assist in reducing harmful behaviours demonstrated in children with ASD. Similarly, De Milander et al. (2016), conducted a study looking at equine-assisted intervention for motor proficiency in children with ASD. This intervention used horses as part of the 10-week intervention programme. The results demonstrated improvements in behavioural/motor proficiency for the children who participated in the research. Thus, AAI may be a beneficial intervention for children with ASD in under-resourced, developing countries in Africa, as it can be tailored to meet the needs of the child/family, is cost-effective and sustainable. However, it is still acknowledged as an emerging intervention with limited research in its efficacy and feasibility (De Milander et al., 2016).

In terms of technology-based interventions, two articles describe how technology can be used as an intervention, specifically in raising awareness, disseminating information, screening, as well as in improving social-communication skills in children with ASD (Kumm et al., 2021; Matthew, 2021). Matthew (2021) discusses how certain applications and e-tools can assist in teaching social-communication skills through technological devices. It can also assist in skills training and development for parents/caregivers of children with ASD with more efficiency. For example, assisting parents/caregivers to learn skills as part of parent-mediated interventions. Similarly, Kumm et al. (2021) recognizes these benefits, adding that it may also

assist with screening processes and awareness. However, overall, it seems that technology-based interventions although useful in some areas in Africa, may be inaccessible in other areas, where internet connectivity is reduced or non-existent, access to technological devices is scarce, and the knowledge to utilize these technologies is limited. Technology-based intervention can become costly, which is not feasible for most individuals in developing countries in Africa. Thus, although it could prove to be a useful and accessible intervention resource for some in developing countries in Africa, it is not the case for most (Kumm et al., 2021).

The last emerging intervention that was a standalone intervention in the selected articles for the current study, was surf-based therapy, proposed in a study conducted by van der Merwe and Yarrow (2020). The authors suggested a 12-month programme that consisted of 3-hour, weekly sessions at the beach, engaging in surf lessons, as well as connecting with the surf instructors, mentors and peers. The aim of surf-therapy is to help in emotional and behavioural regulation, social-communication skills, and to create a sense of belonging, community, independence and confidence. Despite hopeful results, this is also an emerging therapy that needs more investigation and one that may not be applicable to many developing countries in Africa, as there are resources needed that are not available in many parts of Africa. In addition, this would prove to be a costly and time-consuming intervention (due to the time length of the therapy, the professional skills needed to implement the therapy, and the resources needed to conduct the therapy) that may not be feasible for many individuals in under-resourced areas in Africa (van der Merwe & Yarrow, 2020).

Chapter 5: Discussion

A scoping review was conducted, aiming to identify, synthesize, and report on the available behavioural and social interventions for children (17 years old or younger) with autism spectrum disorder (ASD) in developing countries in Africa. The current scoping review contributes to an essential area of research that may inform emerging or existing, contextually relevant interventions for children with ASD in developing countries in Africa. Contextually relevant interventions are necessary in order to improve the quality of life for children with ASD.

The limitations to ASD research in developing countries in Africa are evident and many authors have discussed these limitations (Aderinto et al., 2023; Bello-Mojeeed et al., 2016; Dawson-Squibb & de Vries, 2020; Franz et al., 2023; Harrison et al., 2016; Knochel et al., 2021; Kumm et al., 2021; Macmbinji & Hadi, 2019; Matthew, 2021; Moosa et al., 2023; Pierucci et al., 2023; Rieder et al., 2023; Tekola et al., 2020; van der Merwe & Yarrow, 2020; Wannenburg & van Niekerk, 2018). In the current scoping review, a total of 2 464 records were screened and analysed, with only 19 studies identified as meeting the inclusion and exclusion criteria for the review, further emphasizing the lack of research in this area. Thus, the breadth and depth of research gathered from this review may still be limited by the amount of research available, which may impact the results and implications of the current review. More research into this area would provide a more comprehensive understanding of available interventions for children with ASD in developing countries in Africa, which could further inform feasible and contextually relevant interventions.

The current scoping review highlighted themes around the limitation of ASD research in Africa, as well as challenges to access and awareness of ASD interventions in Africa, such as financial constraints, contextual/cultural adaptation of interventions, awareness and stigma,

and a lack of trained professionals in the implementation of ASD intervention. All of the above pose a realistic barrier to ASD intervention for children in developing countries in Africa. These barriers need to be accounted for and addressed in order to make ASD intervention feasible in the current context. The biopsychosociocultural model of health may be beneficial in informing contextually relevant and appropriate interventions, as it considers the diversity, and challenges associated with diversity and cultural adaptation, highlighted within the findings of the current review.

In terms of available interventions and outcomes, some interventions are more established than others. For example, parent-mediated/caregiver-mediated interventions and professionally implemented interventions are available, feasible and demonstrate positive outcomes in the social and behavioural domains of children with ASD. Emerging interventions such as animal-assisted interventions, are still widely under-researched, but available research does demonstrate potential feasibility as an intervention in the current context.

Chapter 6: Conclusion

6.1 Summary of Findings

Autism spectrum disorder is a prevalent neurodevelopmental disorder, affecting many individuals worldwide. In Africa, there is limited research into ASD intervention for children. These gaps in ASD intervention research may be the result of multiple biopsychosociocultural factors, including barriers/challenges to access and awareness, such as financial constraints, stigma or a lack of trained professionals. These gaps may impact the well-being and quality of life for many children and families affected by ASD. Currently, there are limited available interventions for children with ASD in developing countries in Africa that demonstrate positive outcomes and are contextually feasible. These interventions include parent/caregiver-mediated interventions and professionally implemented interventions, such as applied behaviour analysis or neurofeedback. There are also emerging interventions that are eclectic in nature, using a combination of different strategies from various interventions, as well as other emerging interventions, such as animal-assisted intervention or technological-based interventions. More research into ASD in developing countries is needed to build a more in depth and comprehensive understanding of the state and implementation of contextually relevant interventions.

6.2 Strengths and Limitations of the Study

There is a major challenge in the limited amount of available research for interventions for children with ASD in developing countries, or ASD in developing countries in general. This made it difficult to provide a broad, but detailed and in depth, overview of available research, as a scoping review aims to do. However, it is also important to acknowledge that some records including relevant information may have been excluded in the current review. If a record/article did not have a comprehensive title, the record/article would have been excluded in the title screening, despite the possibility of meeting other inclusion/exclusion criteria.

Future research may want to do a title and abstract screening in a single step, to minimise exclusions. Furthermore, there is a limitation in accounting for the use of traditional medicine and healers, which many individuals in developing countries in Africa may consult regarding their health and care. Further research may want to observe and research the impact, relevance, use, and contribution of traditional medicine and healing in ASD intervention and care.

In addition, there is a level of subjectivity and bias that may exist in scoping reviews, specifically regarding the article selection, inclusion and exclusion criteria, and analyses. The assistance of a research supervisor assists in limiting this bias however, it may be beneficial for future studies to have multiple researchers to mitigate potential bias.

Lastly, this scoping review may not be generalizable to other developing countries. As mentioned above, each country may have their own specific challenges, or cultural/contextual differences (biopsychosociocultural factors) that may impact ASD research and intervention. In addition, many of the studies in the current review were conducted in South Africa, with its own range of diversity in access and resources. Thus, these available interventions for children with ASD in developing countries in Africa may not be generalizable. Further research will need to be conducted in order to determine generalizability.

However, the current scoping review provides a foundation for much needed, further research into ASD interventions for children in developing countries in Africa, by collating, summarizing and analysing the current, available interventions in the current context.

6.3 Implications of the Study

6.3.1 Research Implications

This review underscores significant gaps in research and literature concerning ASD interventions in developing African countries. The limited data emphasizes the critical need

for further research in this area. However, the review also provides a valuable overview of these research gaps, highlighting the existing barriers and challenges hindering further exploration.

Furthermore, the review identifies specific areas to improve the state of ASD intervention research in this context. Notably, it emphasizes the importance of considering biological, psychological, social, and cultural factors (biopsychosociocultural factors) when developing and implementing interventions for children with ASD in Africa.

While the review acknowledges the relevance of the biopsychosociocultural theoretical model in non-Western contexts, it acknowledges limitations in its current conceptualization compared to broader biopsychosocial models (Hilty, 2015; Napier et al., 2014). The review demonstrates the significant role of culture and context in developing appropriate interventions, highlighting their impact on awareness, acceptance, and access. This was further emphasized by themes identified in the review, suggesting that emerging and existing interventions should prioritize cultural and contextual factors to better serve children with ASD in developing African countries.

6.3.2 Theoretical Implications

Building upon the identified benefits of the biopsychosociocultural model for developing culturally relevant interventions for children with ASD in Africa, the review also highlights the significant research gap in ASD research for developing countries. Most existing literature originates from high-income, developed nations (Abubakar et al., 2016; Franz et al., 2017; Marlow et al., 2019). This necessitates further critique and adaptation of existing theoretical frameworks to better suit specific African contexts. The current review provides a valuable starting point by outlining potential areas for such adaptations.

6.3.3 Practical Implications

The current review provides clinicians, researchers and caregivers with an overview of the barriers/challenges to ASD awareness and access to intervention. This may be beneficial in navigating barriers/challenges, motivating for policy changes to bridge existing gaps. Some practical solutions may include motivating for more research to be conducted pertaining to the current topic, as well as awareness campaigns, community involvement, or increased government funding where feasible. Without the acknowledgement and understanding of barriers/challenges, contextually relevant and appropriate ASD intervention may be difficult to implement and research, impacting not only future empirical research and practical implementation of interventions, but the quality of life and well-being for children with ASD and their families.

6.4 Recommendations for Future Research

The current review demonstrates a need for more empirical research to be conducted to support existing theoretical evidence for the feasibility of the abovementioned ASD interventions in developing countries in Africa. However, even the existing theoretical basis for these interventions may need further development, strengthening and adaptation to the context of developing countries in Africa, as many of these theoretical underpinnings are formed in the context of developed countries. Therefore, it is essential for theoretical underpinnings to be evaluated and compared against the contextual differences in developing countries in Africa, in order to inform further relevant, and feasible, empirical research.

In addition, the majority of studies included in the current review were conducted in South Africa. Future research should aim to expand and conduct research in other developing countries in Africa. It is important to note that although South Africa is regarded as a developing country, South Africa still has more access and awareness to health care resources

than other developing countries in Africa (Daucy, 2023; Statista, 2023) . Furthermore, although developing countries in Africa can be grouped as one, there are many contextual and cultural differences within different countries that may impact the state of ASD and ASD intervention, such as the use of traditional healers or other belief systems that may impact access to care (Kumar, 2019). In order to understand and implement ASD intervention for children in developing countries in Africa that are effective and contextually relevant, further research into individual biopsychosociocultural differences in these developing countries may need to be conducted (Hilty, 2015; Napier et al., 2014). This additional research could create more individualized and holistic ASD interventions in these contexts, as well as determine the most pertinent and specific barriers in each developing country, assisting in bridging the gaps in literature, policy and care/intervention in specific ways determined by the research conducted in the specific developing country. Moreover, it may be beneficial for further research to be conducted into emerging ASD interventions for children in developing countries, such as animal-assisted interventions (De Goede, 2023; De Milander et al., 2016) or technological-based interventions (Kumm et al., 2021; Matthew, 2021), as these demonstrate positive outcomes and may be feasible. In terms of the differences that may exist within each developing country, the more research on effective and feasible interventions may mean there are more options for ASD interventions, which can be implemented based on different contextual needs and challenges.

Moreover, developing countries in Africa experience multiple barriers and challenges to ASD awareness and intervention. The barriers and challenges highlighted in the current review are necessary considerations for future research, as it assists in ensuring the adaptability and feasibility of interventions in the current, complex context. In addition, the barriers/challenges highlighted are also beneficial for clinicians/caregivers acting within intervention implementation, as it is essential for clinicians/caregivers to acknowledge and

understand potential barriers and challenges in order to develop solutions to mitigate them and provide informed, sensitive and contextually relevant care. Furthermore, parents may benefit from being educated on certain challenges and barriers, assisting in navigating them and providing a sense of autonomy in their understanding and problem-solving regarding their children's care.

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Appendix A – Ethical Clearance Certificate



SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE **CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)**

CLEARANCE CERTIFICATE

PROTOCOL NUMBER: MClin/23/03W

PROJECT TITLE:

Examining Available Behavioural and Social Interventions for Children with Autism Spectrum Disorder in Developing Countries in Africa – A Scoping Review.

INVESTIGATOR

Maharaj Kajal (2539667)

SCHOOL/DEPARTMENT OF INVESTIGATOR

SHCD/Psychology

DATE CONSIDERED

16 May 2023

DECISION OF THE COMMITTEE

Approved unconditionally

RISK LEVEL

No Risk

EXPIRY DATE

31 December 2025

ISSUE DATE OF CERTIFICATE

23 May 2023

CHAIRPERSON


(Dr Aline Ferreira Correia)

cc: Prof. Zaytoon Amod (Supervisor)

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I/we fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved, I/we undertake to submit an amendment of the protocol to the Committee.


Signature

Date

01 / 06 / 2023

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES