



# A transdisciplinary scoping review of social identity among African youths with autism\_\_\_\_\_\_

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© 2025. The Authors. Licensee: AOSIS. This work is licensed under the Creative Commons Attribution License. Seventeen studies were reviewed from twelve databases. Inclusion criteria were studies on ASD in Africa published in English between 2019–2024. Data were thematically analysed following a single approach. Results organised by themes indicated that youths with ASD in Africa: (1) were stigmatised and discriminated (2) have limited access to resources (3) are socially excluded and (4) have low self-esteem. The study's findings suggest that ASD in Africa still holds more of a negative identity.

Transdisciplinary contribution: The use of different studies in this study allowed integration of single-end single-end information of disciplinary.

integration of views, methods and information from a variety of disciplines. A detailed understanding of how youth with ASD aged 12 years—35 years negotiate their social situations and establish identities across varied in their cultural contexts is made possible by this comprehensive approach. This also facilitated the identification of research gaps and advocates for comprehensive interventions that acknowledge the distinct social realities faced by African youths with ASD.

Autism spectrum disorder (ASD) is an evolving concept in the neurodiversity community.

There is now a continuum of views ranging from biological through social models of which

the medical model views ASD as pathological rather than atypical and the social model views

disability as arising from the obstacles faced by individuals in societies. This qualitative study

used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) to

interrogate evidence on variations in social identity among youths with ASD living in Africa.1

**Keywords:** Africa; autism; discrimination; inclusion; neurodiversity; neurology; self-acceptance; social identity; youths.

# Introduction

Autism is the umbrella term for a group of conditions together described as the autism spectrum disorder (ASD)<sup>2</sup> Autism spectrum disorder is often identified between the ages of one and 2 years in developed countries. In developing countries such as in Africa, it can be identified as late as 9 years because of poor diagnosis as a result of underdeveloped healthcare systems.<sup>2</sup> Autism spectrum disorder is mostly characterised by repetitive behavioural patterns, such as lining up and stacking things, and communication impairments.3 Depending on the age and aptitude of a particular child, these early indicators of ASD may not be as noticeable.4 Autism spectrum disorder<sup>2</sup> may have a lifelong effect on a person's ability to form and sustain social relationships and carry out routine everyday chores. Even if the exact cause of ASD is yet unknown, it is often known that a child's susceptibility to the condition is influenced by a number of environmental and genetic risk factors.4 Among these risk factors are being born underweight, having a sibling and an elderly parent with ASD and having other genetic symptoms such as Down syndrome.<sup>5</sup> Autism spectrum disorder intervention strategies are tailored to each person's unique situation and should begin as soon as the child is diagnosed in order to minimise their challenges and teach them new abilities.<sup>6</sup> Because ASD is so diverse, there is not one specific intervention strategy that can be used; instead a variety of specialised intervention strategies that need to be closely monitored by trained professionals are combined.2 Males are more prone than females to be affected in the case of ASD, which is estimated to impact at least 1% of the global population. 5 Any individual, irrespective of their individual circumstances, such as their race, gender, religion or socioeconomic level, can be affected by ASD. Autism spectrum disorder presents challenges, particularly for youths<sup>7</sup> actually, about one in every sixty-eight youths in affluent nations such as the United Kingdom and the United States have ASD.<sup>8,9</sup> This indicates that, despite the lack of data on its true prevalence on the African continent, ASD is not just an issue in the third world. There has to be more investigation on the frequency of ASD in Africa.

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Many caregivers are reluctant to work with youths who have ASD because of stigma, discrimination, a lack of understanding and negative attitudes towards youths with ASD.<sup>10</sup> Despite these difficulties, youths with ASD and the challenges that their carers continue to encounter various forms of prejudice and stigma and ridicule from locals, who frequently blame superstitious beliefs circumstances.11 Autism spectrum disorder is seen as an embarrassing condition, causing parents to hide their youths with ASD from the public's critical gaze. Consequently, these youths are rarely seen in social events or public gathering spots such as markets and playgrounds. 11,12 The negative judgement and unfair treatment encountered by people with ASD cause them to keep their youths hidden who would otherwise have received any support to help them integrate into society. 13 Nevertheless, in recent years, there has been an increasing amount of literature and advocacy promoting an alternative view such as biopsychosocial model, which integrates diagnostic information with psychosocial aspects of life (e.g. personality traits, coping abilities and social support) giving equal considerations to all factors impacting health and functioning of youths with ASD.<sup>11</sup> Biopsychosocial and social models of disabilities acknowledge and embrace many ways that people with ASD experience and express themselves. This scoping review aims to investigate and assess the diverse perspectives connected to African youths with ASD from seventeen peer-reviewed researches carried in Africa. In particular, the research focuses on examining the social identities of youths aged 12 years to 35 years with ASD in Côte d'Ivoire, Eritrea, Ghana, Kenya, Malawi, Mali, Nigeria, South Africa and Uganda.

# Social identity

According to social identity theory, social identity is the part of a person's self-concept that comes from belonging to social groups. <sup>12</sup> In more recent research, social identity has been identified as a dynamic construct that includes not only group membership but also the importance and value that people place on these affiliations. <sup>12,13</sup> For youths with ASD, social identity is especially important because it affects their self-esteem, social interactions and general mental health. Research shows that a strong social identity can help youths with ASD become more resilient and develop coping mechanisms, which helps them deal with social complexities and creates a sense of acceptance and belonging. <sup>12</sup>

Youths with ASD develop social identities through interactions, experiences and understanding societal norms. Supportive environments, including friendships and inclusive activities, aid in self-expression and connections. According to Zeliadt, youths with ASD who participate in social activities are likely to form more lasting relationships. However, most youths with ASD find it difficult to form relationships because of social communication difficulties, a lack of understanding of social cues, limited empathy, repetitive behaviours, adherence to routines and intense interest. These restrictions negatively impact their abilities to engage in meaningful social connections.<sup>12</sup> Therefore,

knowing one's social identity helps youths with ASD as well as teachers and practitioners build inclusive environments that foster peer connections and social skills. Individualised therapies that take into account the social identities of youths with ASD can promote understanding and acceptance among peers, strengthening social bonds and eventually improving social outcomes.<sup>12</sup> Thus, it is crucial to acknowledge the significance of social identity for youths with ASD in order to promote their social growth and improve their quality of life.

# The significance of social identity formation of youth with autism spectrum disorder

The formation of social identity among youths with ASD is critical as it influences their self-perception, relationships and overall well-being.<sup>12</sup> Social identity is built through interactions with peers, family and community, and for youths with ASD, these interactions can be significantly impacted by their social communication challenges.<sup>13</sup> Research shows that a well-developed social identity can enhance self-esteem and foster resilience in adolescents, which is particularly important for those navigating the complexities of ASD.<sup>13</sup> However, youths with ASD often face unique challenges in this domain, including difficulties in understanding social cues, managing emotions and engaging in reciprocal interactions.12 These barriers can lead to social exclusion, isolation and a decreased opportunity for identity exploration and development, manifesting in higher levels of anxiety and depression compared to their neurotypical peers. 11,12,13 Furthermore, issues such as bullying and stigma can complicate their social experiences, forcibly shaping their identity in a negative context.12

To support social identity formation, youths with ASD require comprehensive interventions that address their unique needs. Support mechanisms may include social skills training, peer mentoring programmes and therapeutic interventions that promote emotional regulation and social understanding.12 Furthermore, fostering environments in schools and communities is vital to providing them with opportunities for meaningful social engagement.<sup>13</sup> Family involvement is also crucial, fostering open communication, acceptance and engagement within the family can help reinforce a positive self-view and identity for youths with ASD.14 Ultimately, promoting effective supports and interventions not only aids in the social identity formation of youths with ASD but also enhances their quality of life and empowers them to navigate the broader societal landscape with greater confidence and acceptance.

# Medical model perspective on autism spectrum disorder spectrum disorders

The medical model of disability is a framework that provides a collection of rules and guidelines that subtly defines individuals with disabilities as being ill by assigning a sick role to people with barriers, it oppresses, dehumanises and controls them.<sup>15</sup> It absolves the (impaired) person of the responsibility to manage their own affairs. In fact, for the length of their barriers, it pushes them to accept their reliance

on the sick role as the norm. 15,16 To briefly put, the sick role seeks to deny an impaired person their autonomy the capacity to make decisions for themselves and their life, which is what makes a person a human. 15,16,17 The medical model serves as the foundation for the study and therapy for disorders associated with ASD, which entails determining the possible genetic, neurological and environmental variables that may contribute to the condition. Autism spectrum disorder has been related to a number of genes through research, indicating a complex genetic architecture. 18,19 Moreover, neurobiological studies have identified anomalies in the composition and operation of the brain in people with ASD, including differences in the amygdala, cerebellum and various cortical areas. The goal of the medical model is to enhance the lives of those with ASD and lessen their symptoms by focusing a great emphasis on early diagnosis and intervention.<sup>20</sup> Behavioural therapies, including applied behaviour analysis (ABA), are frequently used in early intervention programmes because they have been demonstrated to help youths with ASD with their social, communicative and adaptive skills.19 Furthermore, while comorbid problems such as anxiety and aggressive behaviours are typical among those who have ASD, pharmacological therapies are sometimes utilised to address them.

The medical perspective on ASD, which often emphasises deficits and abnormalities in neurological functioning,15 significantly shapes the social identity of youths with ASD in Africa. In many African cultures, autism is frequently misunderstood and stigmatised, resulting in negative perceptions among peers and communities. 16 This perspective can lead to labelling individuals with autism as 'disabled' or 'abnormal', which may impact their self-esteem and social interactions.<sup>16</sup> Consequently, youths may internalise these labels, leading to social isolation and disengagement.<sup>13</sup> In addition, the lack of awareness and acceptance of ASD within families and communities often results in limited access to educational resources and support systems, further marginalising these individuals.<sup>13</sup> However, as advocacy efforts increase and awareness of ASD grows, there is potential for reshaping social narratives and promoting a more inclusive identity that recognises the unique strengths and contributions of youths with ASD, fostering a sense of belonging and empowerment within African societies. The medical model is nevertheless essential to expanding knowledge of ASD, notwithstanding these critiques. New diagnostic instruments and biomarkers are being investigated as part of ongoing research in an effort to identify ASD earlier and more precisely. Research on single-nucleotide polymorphisms and copy number variations, among other genetic advancements, is helping to clarify the disorder's hereditary components and provide guidance for possible future treatments.18

# The social model perspective on autism spectrum disorder spectrum disorders

The social model of disability has completely changed how society views and understands disability. The social model stresses how societal constraints contribute to disablement, unlike the medical model that pathologises conditions such as ASD as a personal tragedy or individual handicap.<sup>14</sup> The shortcomings of the medical model caused the social concept of disability to emerge in the latter half of the 20th century. 14,15 This paradigm holds that barriers related to social, environmental and attitude are what cause impairment rather than being a feature of persons alone.<sup>17,21</sup> To accommodate a range of talents and promote inclusion, the emphasis should move from repairing the individual to changing social institutions. 16,22 The social model requires a distinction between disability and impairment.<sup>19</sup> The social model advances that disability arises from the obstacles faced by individuals in societies, and impairment refers to any physical, sensory, intellectual or psychological differences that an individual may have. 19,22 The social model acknowledges that impediments to communication, mobility and attitude all contribute to the construction of disability within society.<sup>22</sup> These obstacles can take the form of unwelcoming architecture, poor transit, a lack of educational possibilities, prejudice in the workplace and unfavourable preconceptions.<sup>15</sup> Society may establish an inclusive environment that allows people with disabilities to fully engage by addressing and removing these barriers.<sup>21</sup> The social model of disability emphasises that rather than being a product of personal failings, ASD results from society's inability to accept variety.<sup>22</sup> This change in perspective shifts the focus from 'fixing' or 'curing' people with ASD to society's need to provide accessible settings and opportunities. A culture of acceptance and respect is fostered by encouraging people to see others with ASD as an identity that is just as legitimate as any other. 17,23 Through acknowledging and appreciating the abilities and qualities of people with ASD, society may progress towards a future that is more fair and inclusive.

The social model perspective of disability emphasises the impact of societal attitudes, structures and barriers in shaping the experiences of individuals with disabilities, including youths with ASD.14 This perspective shifts the focus from viewing autism solely as a medical condition to understanding it as part of the diverse spectrum of human variation.<sup>16</sup> By recognising the societal barriers that hinder participation, educators and policymakers can create supportive environments that foster inclusion and acceptance.<sup>18</sup> This approach helps to empower youths with ASD, enabling them to develop a positive social identity. Consequently, supportive interventions can enhance their self-esteem and facilitate meaningful connections with peers, promoting overall wellbeing. It is crucial to recognise, although, that there are critics of the social model. Some contend that it oversimplifies the complexity of ASD.<sup>23,24</sup> But it offers an insightful viewpoint that encourages a more accepting and compassionate method of helping those with ASD spectrum disorders.

# Neurodiversity movement perspective on autism spectrum disorder spectrum disorders

There are various ways to frame ASD. Neurodiversity is connected to an 'ecological society' in which human variation is respected and assisted in identifying their niche.<sup>17</sup>

Neurodiversity is a scientific idea that suggests a different perspective on function and malfunction.<sup>17</sup> According to Kapp et al., neurodiversity movement is the fact that different people have different minds and brains; in the same way that 'biodiversity' is the fact that there are differences in biological makeup. In contrast to diseases that must be treated, neurodiversity movement promotes the understanding and acceptance of a range of neurological conditions, including ASD, as normal variations of the human experience. As stated by Australian sociologist Judy Singer and Kapp et al., the phrase neurodiversity was first used in the late 1990s and suggests that neurological variety should be treated with the same consideration as cultural and genetic variation. Therefore, the neurodiversity approach suggests that society should change to accommodate these variances rather than adhering to traditional medical models that aim to normalise or treat autistic features. Fundamental to this idea is the understanding that those with ASD have special talents, capabilities and perspectives on the world, and that these things should be valued and accommodated rather than pathologised and repressed.<sup>17</sup> This contrasts with the medical model, which encourages those with ASD to accept being sick as the standard. 18 In short, the sick role aims to deprive an impaired person of their autonomy – the ability to choose their own course in life and make decisions for themselves, which is what defines a human being.16 The idea of neurodiversity movement is for those with ASD to have an empowered social identity. The neurodiversity movement perceives ASD from the main principles of the biopsychosocial model of disability and healthcare.<sup>18</sup> It combines beneficial elements from the social and medical models,14 which integrates psychosocial elements of life (like resilience) with medical and psychosocial diagnostic data.<sup>14</sup> Social advocacy from organisations such as neurodiversity movements has completely changed people's knowledge and perception of ASD by denying the notion that ASD are a private characteristic of each individual and is instead the result of social, environmental and mental barriers.<sup>16</sup> These social advocacy's central idea is the ASD person's personal agency in overcoming social boundaries. Providing people with ASD dignity as the head of their own life is replacing the idea of 'fixing' or 'curing' them.

The neurodiversity perspective on ASD emphasises the recognition and validation of individuals with ASD as a part of human diversity, challenging traditional deficit-focused views.<sup>17</sup> This paradigm shift shapes the social identity of youths with ASD by fostering acceptance and encouraging self-advocacy. 18 By promoting an understanding of autism as a difference rather than a disorder, it enables these youths to embrace their unique neurological profiles, enhancing selfesteem and social connections,17 Support systems based on neurodiversity prioritise inclusive practices, empowering individuals to engage meaningfully within their communities and ultimately facilitating a more positive and integrated social identity that respects their experiences and capabilities. 19 However, others who oppose the neurodiversity movement contend that it may minimise the serious difficulties as some individuals with ASD require a variety of

forms of help and intervention strategies. <sup>14</sup> However, the idea of neurodiversity advocates still shapes the conversation about ASD and disabilities today, encouraging a more accepting and considerate view of individual variances in neurology. <sup>25</sup> It is critical to strike an equilibrium between knowledge of the range of requirements within ASD population and the promotion of acceptance and inclusion as research advances.

# Autism spectrum disorder in the African context

The concept of ASD as it is widely applied in Western countries is not exclusive to the African context. Autism spectrum disorder is probably more of a functional than a neurological issue in many African countries.<sup>26</sup> Furthermore, studies have shown how crucial it is to include traditional African beliefs and practices in therapies and support services for people in these environments who have ASD.<sup>26</sup> Autism spectrum disorder are common in African societies and are often linked to spiritual or paranormal causes.<sup>26</sup> For example, a study by Bakae and Munir discovered that in some African cultures, developmental problems such as ASD are frequently linked to supernatural origins, including spiritual possession, curses or the anger of the gods. These ideas might cause people to turn to traditional healers rather than doctors for medical advice. The majority of indigenous African societies' beliefs or conceptions of sickness are supported by Bakare and Munir findings. As stated by,27 human health conditions, including ASD in Africa, are brought on by evil spirits. People who belong to these groups typically think that ancestral spirits or gods have the ability to determine an individual's issues and determine the best course of treatment.

Neither the ASD paradigm as it is known in the Euro-Western context nor any African language has any terms with a similar meaning that originated from Euro-Western countries.<sup>26</sup> Nonetheless, the majority of African societies view ASD as a health condition, similar to Western cultures, although they have different approaches to treating it. In Kiswahili, the term ASD is referred to as Usonji,26 which means disorders. The Chewa people of Malawi call individuals with ASD Osatha kulankula bwino, which translates to 'someone who cannot speak properly'.26 The term 'ukungashintshiswa'26 refers to ASD in isiZulu. Its literal English translation is 'not being changed' implying a condition or state that cannot be altered or modified. The Maasai of Kenya do not possess a term for ASD and that the closest the Maasai word almodai corresponds to the Western understanding of ASD, which means stupid.28 Also, for indigenous Zimbabweans, there are no terms in Shona, Ndebele or Kalanga that correspond to the Western definition of ASD.<sup>28,29</sup> The term 'haana kukwana' in Shona that most closely resembles ASD is 'not enough'. A person who is inadequate could find it difficult to participate in social activities and could require assistance.

The African perspective on ASD significantly influences the social identity of youths with the ASD, emphasising

community and cultural context over individualism.<sup>24</sup> In many African societies, ASD is often perceived through a lens of social relationships and communal responsibility, which can lead to varying interpretations of the behaviour and needs of individuals with ASD.<sup>25</sup> This perspective promotes a collective approach to support, encouraging families and communities to engage actively in the developmental journey of these youths.<sup>26,30</sup> By integrating cultural beliefs and practices into support mechanisms, African societies can foster a stronger sense of belonging and identity, ultimately enhancing the social integration and well-being of youths with ASD.<sup>27,29</sup>

# Social identity theory

In this section, we explain the theoretical framework that structured our study's argument. The theoretical underpinning for this study was social identity theory. Social identity theory is a useful theoretical framework for examining the social identities of young people with ASD in Africa.<sup>12</sup> Social identity theory was developed in the 1970s by Henri Tajfel and John Turner, and it centres on how people define themselves in relation to the social categories and groups to which they belong.12 This theory can assist researchers in comprehending how adolescents with ASD in Africa develop their sense of self in relation to their diagnosis and cultural background. In analysing the perspectives of those with ASD, recent research, such as Zeliadt, Msuda, Boone, Happé and Frith have emphasised the significance of taking social identity into account. Researchers can investigate how cultural values, societal norms and community perceptions impact the social identity formation of youths with disorders related to ASD utilising social identity theory in the African environment.<sup>13</sup> For instance, there may be differing degrees in acceptance and knowledge of ASD in many African communities, which can affect how those with ASD perceive themselves and are perceived by others. Furthermore, social identity theory can shed light on how youths with ASD negotiate social interactions and relationships in their communities.<sup>13</sup> Several studies, for example Zeliadt, Msuda, Boone, Happé and Frith have indicated that those with ASD frequently encounter issues with social skills and finding ways to interact with others. Through the application of this theory to the social identity of youths with disorders related to ASD, researchers can pinpoint important elements that support social integration and overall well-being in African environments. Interventions and support services that are customised to the individual requirements of youths with disorders related to ASD can be improved by having an enhanced comprehension of the ways in which social identity affects their experiences.14 Furthermore, the way that stigma and prejudice shape the identities of individuals with ASD in Africa can be better understood through social identity theory. According to recent studies, unfavourable preconceptions and beliefs about people with ASD could make them the target of stigma and prevent them from fully participating in society. In a study by Frith through examining the social identities of youths with ASD in Africa, researchers can find ways to

counteract stigma, encourage inclusion and improve the general well-being of people with ASD. A thorough framework for examining the social identities of young people with ASD in Africa is provided by social identity theory. Researchers can better understand how social identity impacts the sense of self of individuals with ASD and their interactions with others by taking into account the cultural, societal and individual aspects that define these people's experiences. The creation of culturally appropriate interventions and support services that enhance the well-being and social integration of youths with ASD in African communities can be influenced by this understanding.

# Aim of the study

This study aimed to undertake a scoping review on the social identity of youth with ASD in Africa. It seeks to respond to the following questions:

- What is the emerging evidence of social acceptance of youth with ASD living in Africa?
- How do youth with ASD in Africa experience social inclusion in their communities?
- How accessible are resources, opportunities and services for youth with ASD in Africa?
- What is the emerging evidence on self-advocacy and resilience among youth with ASD in African communities?

# **Methods**

# Research design

To compile information on social identity among youths with ASD in African, this study used a scoping review. A scoping review offers preliminary data based on an expanding amount of data in a field of study that has received little or no investigation.<sup>1</sup> The five steps were followed in this scoping review: (1) establishing the goals of the study, (2) finding pertinent studies, (3) selecting pertinent studies, (4) graphing the data and (5) drawing conclusions and presenting the findings.

### Search strategy

This study conducted searches in the following databases: the African Education Research Database (AERD) produced 5 articles, JSTOR 20, Scopus produced 10, Research Gate seventeen, Bielefeld Academic Search Engine (BASE) 8, SSRN 3, EBSCO Host 12, PubMed 10, Google Scholar 35, Web of Science 5 AJOL 6 and PsycINFO produced 15. The researcher first consulted the EBSCO Host using the study search terms. The EBSCO Host facilitated access to other databases such as the AERD, Scopus, the BASE and Google Scholar: ASD among youths in Africa. The following search terms were used:

- Self-identities of youths with ASD in Africa.
- Self-advocacy buy youths with Autism in Africa.
- Experiences of youths with ASD.
- · Identity negotiation among youths with ASD.
- Inclusion of youths with ASD in Africa.

- Social inclusion of youths with ASD in Africa.
- Resources, opportunities or services for youths with ASD in Africa.
- Self-acceptance and self-esteem among youth with ASD in Africa' (search terms are shown in Box 1).

#### **Inclusion criteria**

Applying the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) framework, 30,31 we included research that examined: (1) Social acceptance of youths with ASD; (2) access to resources, opportunities or services for youths with ASD; (3) social inclusion of youths with ASD and (4) youths with ASD sense of self-acceptance and self-worth. Additionally, we included empirical articles that were published in English between 2019 and 2023 in Africa that examined social identity among youths with ASD in African contexts for review. The convention on the Rights of Persons with Disabilities framework provides a comprehensive understanding of disability, including social aspects, and can be effectively used to analyse the social identity of people with ASD.

#### **Exclusion criteria**

We excluded studies on social identity of youths with ASD in Africa that were published before 2019. Selecting articles published within the last 5 years for a scoping review on social identities of youths with ASD in Africa was crucial to capture recent developments in research, societal understanding and policy changes. This timeframe ensures the inclusion of the latest cultural, environmental and contextual factors affecting these youths, reflecting their current experiences and challenges in the rapidly evolving landscape of ASD research. Our inclusion and exclusion criteria are shown in Table 1.

#### **Finding related studies**

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guided the research questions and

BOX 1: Final search strategy.

Key concept Search terms

Autism 'Autism spectrum disorder among youths in Africa',

'Self-identities of youths with ASD in Africa',

'Self-advocacy buy youths with ASDin Africa',

'Experiences of youths with ASD',

'Identity negotiation among youths with ASD',

'Inclusion of youths with ASD in Africa',

'Social inclusion of youths with ASD in Africa',

'Resources, opportunities or services for youths with ASD in Africa'

'Self-acceptance and self-esteem among youth with ASD in Africa'

ASD, Autism spectrum disorder.

TABLE 1: Inclusion and exclusion criteria.

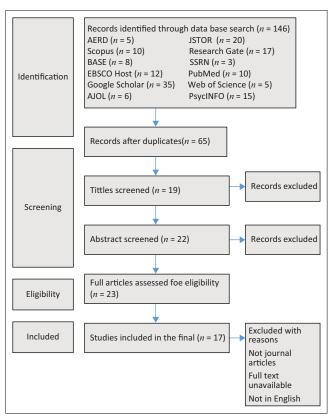
Concept	Inclusion criteria	Exclusion criteria		
Autism neurodiversity	Studies on social identity of youths with ASD conducted in Africa from 2019 to 2023 in English language	Studies on social identity of youths with ASD not conducted in Africa and not in English language and before 2019		

ASD, Autism spectrum disorder.

searching for this scoping review. The use of PRISMA helped in improving transparency and quality of systematic review and meta-analysis of this study. It provided checklist and flow diagram to ensure comprehensive reporting of the study methodology and findings<sup>1</sup> (See Figure 1). We carried out our first search in the AERD database for initial leads, progressing our search and identifying productive search terms. We then extended the search strategy with other chosen databases for the thoroughness of the investigation. The use of twelve databases in this study was essential for comprehensive capturing of relevant literature.1 Using twelve databases ensured broader and accurate coverage of literature, which is integral to scoping reviews.1 Twelve databases were enough to obtain a correct and richer understanding of how social identities are constructed and perceived across different contexts. The databases used by this study increased the study's rigour as it helped to minimise publication bias and risk of missing relevant literature as a result of using few databases. The final search technique that was employed during the process is shown in

# **Data charting**

A total of 146 articles were selected for screening after the publications were meticulously sorted according to the inclusion criteria. Of the 146 studies 65 were duplicates, which we eliminated. Eighty-one articles with suitable titles remained after we eliminated 19 articles in the title screening



Source: Adoped from Braun V, Clarke V. Thematic analysis practical guide. London: Sage; 2021 AERD, African Education Research Database; BASE, Bielefeld Academic Search Engine.

FIGURE 1: Preferred Reporting Items for Systematic Reviews and Meta-Analysis flow chart

because they were conducted out of Africa. Twenty-two articles were eliminated at the abstract screening stage of the next screening process because the abstracts were not sufficiently addressing self-identities of youths with ASD in Africa. Using the inclusion criteria for research that were released in English between 2019 and 2023, 23 articles were removed and 17 articles were found for the review.\(^1\) Using seventeen articles in this study was adequate because the articles collectively provided a comprehensive overview of social identities of youth with ASD in Africa. The articles provided satisfactory breadth over depth and were able to illuminate key themes of the study. The 17 articles were all focused, manageable and they ensured relevant information representation.\(^1\) Refer to Figure 1 for the PRISMA flow chart.

# **Data synthesis**

We plotted the results against the main inclusive community principles taken from the framework in order to synthesise the data. The UNCRPD's tenets are as follows: (1) Respect for dignity, (2) Non-discrimination, (3) Full and effective participation, (4) Accessibility, (5) Equality before the law, (6) Right to life, (7) Personal mobility, (8) Education, (9) Health and (10) Work and employment. However, results from this study were plotted against a summary of the UNCPRD because the reviewed articles examined social identities of youths with ASD outside the UNCRPD framework. In order to manage the study results, this scoping review only considered results related to UNCRPD framework because it provides a comprehensive legal framework that underscores the rights and dignity of individuals with disabilities, making it highly relevant for scoping review studies that explore selfidentities of youths with ASD in Africa and the tenets of study's social identity theory. The UNCRPD frameworkrelated themes from this study scoping reviews were as follows: (1) social acceptance; (2) access to resources, opportunities or services; (3) social inclusion and (4) selfacceptance and self-esteem.

#### **Ethical considerations**

An application for full ethical approval was made to the Zimbabwe Open University Ethical Review Board, and ethics consent was received on 08 June 2024. The ethics waiver number is 6001/123. The Zimbabwe Open University Ethical Review Board issued an ethics waiver for the study because the study does not include human participants.

### Results

Eight of the seventeen studies<sup>12,13,32,33,34,35,36,37</sup> that were evaluated revealed that youths with disorders related to ASD in Africa were not socially accepted in their communities, according to the summary of findings in Table 3. Four further studies that were evaluated<sup>12,13,14,37</sup> demonstrated that youths with ASD in Africa had limited access to resources, opportunities, and advocates for adequate supportive services. Nine studies out of seventeen examined research showed lower levels of

social inclusion of youths with disorders related to ASD in African communities. <sup>12,14,32,34,38,37,39,40,41</sup> The poor level of self-acceptance and self-esteem among young people with ASD in Africa was also found in seven of the seventeen evaluated research. <sup>12,38,39,42,43,44,45</sup>

# **Discussions of main findings**

This study provides a discussion of the main findings of results which are consistent with the social identity theory and the UNCRPD. Social identity theory provides a thorough framework for examining the social identities of young people with ASD in Africa. Social identity theory helps to explore how social identity impacts the sense of self of individuals with ASD and their interactions with others by taking into account the cultural, societal and individual aspects that define these people's experiences.

# Theme 1: Social acceptance

The results of the reviewed research show that social acceptance of youths with ASD in Africa is very low. 12,13,32,33,34,35,36,37 The review also showed that youths with ASD in Africa are stereotyped and infrequently observed at social events. 14

The findings of this study are in agreement with several other studies on the challenges faced by youths with ASD encounter, especially in Africa, particularly when it comes to social acceptance and inclusion. The complicated dynamic influenced by the junction of self-identity, discrimination and stigma affects the standard of living and overall wellbeing of youths with ASD in this area. According to research by Bakare and Munir, stigma and discrimination had a substantial impact on the feeling of self-identity of youths having in Ghana. Many youths with ASD experience unfavourable biases and preconceptions, which lowers their sense of value and self-esteem.46 Their general well-being and mental health are impacted by this feeling of otherness and isolation. In a similar spirit, a study carried out in Nigeria brought to light the widespread stigma connected to youths with ASD in that nation.36 The study discovered that prejudices against youths with ASD were frequently sustained by false information and misconceptions about the condition. Social inclusion and involvement are hampered by this climate of stigma and discrimination, which eventually affects how youths with ASD regarding oneself and their role in the community. Furthermore, studies conducted in Kenya provided insight into the internalised stigma that youths with ASD.35 The study found that a large number of people internalised the unfavourable opinions and attitudes of others, which resulted in emotions of guilt and self-blame. In another study,12 it was observed that despite the fact that a large number of African youths were having ASD, little is known about the disorder, which is sometimes associated with curses or demonic possession. Because of the myths and misconceptions surrounding this

No	Source	Location	Study aim(s)	Methods	Participants	Condition under investigation	Study's outcomes	Study's recommendations
1.	Aderinto N, Olatunji D, Idowu O. 2023	S Africa	The article presented a narrative review of current knowledge on ASD in Africa, including prevalence, diagnosis, treatment and its impact of social and cultural factors.	Scoping review	No participants used	A comprehensive search was conducted using electronic databases, including PubMed, PsycINFO, Scopus, MEDLINE and Google Scholar.	The study found out that there was high level of: 1. Stigma 2. Discrimination 3. Weak social support 4. Ineffective inclusion 5. Weak service provisions	More education on ASD     Development of effective support services for youths with ASD.
2	Okurut E, Among H.2019	Uganda	This study examined the knowledge of ASD and its impact on youths with ASD development in Uganda.	Scoping review	No participants used	A comprehensive exploration of articles explored the understanding of the ASD and its effects on youths with ASD in Uganda.	The study revealed high levels of: 6 Prejudices 7 Youths with ASD are hidden away 8 Youths with ASD are almost never seen at social gatherings 9 Stigmatisation and discrimination. 10 Youths with ASD are stereotyped 11 They report low self-esteem and self-worth.	1. ASD awareness programmes 2 Development of effective support services for youths with ASD.
3	Nthibeli M, Griffiths D, Bekker T.2022	South Africa	This study looked into how much inclusion of youths with ASD in three Johannesburg schools.	Qualitative	20 youths (10 males and 10 females) teachers who work with youths with ASD in Johannesburg schools	The design chosen was interpretivist qualitative. Open-ended interview questions were used to interview teachers who assist youths with ASD.	The results show that a variety of instructional techniques, including differentiation and scaffolding are: employed to lessen.  12 Stigmatisation and discrimination.	1 ASD education among teachers 2 Training in inclusive pedagogies.
4	Muideen, O. et al., (2019)	Nigeria	This study carried a review of case reports and co-morbidities associated with knowledge, awareness and sociocultural factors affecting youths with ASD in Nigeria.	Scoping review	No participants	The literature search was conducted on PubMed and Google Scholar. The key words included ASD, autistic disorder, ASD and Nigeria.	The study found out that youths with ASD and intellectual disability felt there were:  13 Denied access to basic rights.  14. Face exclusion in employment opportunities.  15. Stigmatised and discriminated.	1 Further studies on family dynamics influence the social experiences of youths with ASD.
5	Onyishi C N, SefothoMM. 2019	Nigeria	This study examined the relationship between ASD and resilience in a group of Nigerian youths with high functioning ASD.	Quantitative	68 (34 males, 34 females) youths with ASD aged between 12 and 20 years from 20 inclusive education schools with high functioning ASD	Youths with high functioning ASD who were enrolled in school participated in a quantitative correlation research.	16 Social isolation is the biggest risk factor for depression among youths with high functioning ASD. 17 Youths with high functioning ASD experience depression and a negative emotional state 18 Inadequate abilities required for fruitful social interactions 19 Insufficient individual ability 20 An unsupportive cultural environment, including lacks, stigma, bullying and social isolation.	1 Evaluation on the effectiveness of social skills training programmes in enhancing the social identity of youths with ASD.
6	Myburgh Ll, Condy J, Barnard E.2020	South Africa	This study examined how three foundation phase teachers trained their learners in social skills, including independence, behavioural etiquette and self-esteem by providing them with explicitly structured classroom experiences. The learners were youths with ASD.	Qualitative	16 (8 males, 8 females) foundation phase teachers in South Africa's teaching youthful learners with ASD	This study used questionnaires to collect data on how foundation phase teachers in South Africa's youthful learners with ASD enhance social skills training through structured classroom experiences.	21 According to the study, while some youthful learners with ASD do become well-adjusted, others struggle to understand emotions or establish and maintain positive interpersonal relationships.	1 Exploration of how participation in inclusive education activities impacts the social identity of youths with ASD.
7	Amahazion F. 2021	Eritrea	In this study, youths with ASD from Eritrea were evaluated for the psychometric qualities of a translated version of the RSES.	Quantitative	20 (10 males, 10 females) Eritreans youths aged 13–35 years with ASD	Eritreans youths with ASD were given a sample of the translated RSES.	The findings suggested that Eritrean youths with ASD: 22 Have high SE.	Further studies should be conducted to evaluate how ethnic and gender differences affect youths with ASD from Eritrea were evaluated for the psychometric qualities of a translated version of the RSES.

Table 3 continues on the next page  $\rightarrow$ 

TABLE 2 (Continues ): Summary of the characteristics of the studies included in the final analyse the social identity of youths with ASD

No	Source	Location	Study aim(s)	Methods	Participants	Condition under investigation	Study's outcomes	Study's recommendations
8	O. A. Olusola, M. O. Ogunyemi, and A. L. Ajibola 2019	Nigeria	This study explored the experiences of youths with ASD in social settings and their perceived social identities.	Qualitative	15 (10 males 5 females) youths with ASD aged 13–18 years from various urban areas in Nigeria	Social skills, peer interactions and challenges faced in social settings.	23 Youths with ASD reported feelings of isolation and difficulties in peer relationships. They highlighted the importance of supportive friendships and family acceptance in shaping their social identities.	Further studies are recommended on how existing identity development frameworks help to better understand how social identities manifest in Nigeria African youths with ASD.
9	B. C. Kankam and J. S. Abekah 2020	Ghana	This study assessed the impact of community awareness programmes on the social integration of youths with ASD.	Mixed methods	100 (70 males, 30 females) youths with ASD aged 10–25 years and their caregivers in Accra, Ghana	Community perceptions of ASD, social acceptance and the role of awareness campaigns.	24 Increased awareness led to improved social acceptance and interaction opportunities for youths with ASD, enhancing their social identities.	More programmes targeting increasing awareness, social acceptance and interaction opportunities for youths with ASD in Ghana.
10	M. K. Adeyemo, F. S. Togun, and R. L. Adoo 2021	Nigeria	This research investigated the role of cultural beliefs in shaping the social identities of youths with ASD in Nigeria.	Ethnographic	50 families with youths diagnosed with ASD across different cultural backgrounds in Nigeria	Cultural beliefs, stigma and parental attitudes.	25 Cultural beliefs significantly influenced the social identities of youths with ASD, with stigma often leading to social exclusion in communal settings.	Further studies on how cultural beliefs can be used to influence the social identities of youths with ASD, with stigma in communal settings.
11	D. S. Motsoaledi and P. A. Matsela 2022	South Africa	This study explored how youths with ASD perceive their social identities in South Africa.	Narrative analysis	20 (8 males, 12 females) youths with ASD aged 12–20 years in Johannesburg.	Self-perception, social integration, peer relationships.	26 Participants expressed a desire for belonging and acceptance, with many sharing how they navigated social spaces to assert their identities despite challenges.	Exploration of communal activities that enhance desire for belonging and acceptance of youths with ASD.
12	F. O. Ige, T. B. Okwelle, and J. N. Okereke 2023	Kenya	This study evaluated the experiences of youths with ASD in inclusive educational settings in Kenya and how these environments affect their social identities.	Case study	30 (20 males, 10 females) youths with ASD aged 12–25 years enrolled in inclusive schools across Nairobi	Inclusion experiences, peer relationships, and teacher support.	27 Inclusive settings facilitated improved social interactions and fostered a more positive social identity among youths with ASD, provided that teachers were adequately trained and supportive.	Funding of inclusive education activities that sought to improve social interactions and fostered a more positive social identity among youths with ASD, in Kenya.
13	Mutharika, M., and Nguvumali, A. 2021	Malawi	This study investigated the experiences of youths with ASD in forming social identities in Malawi.	Qualitative	15 (5 males, 10 females) youths with autism aged 13–19 years and 10 caregivers	Social interactions at school, home and community settings.	28 Participants reported feelings of isolation and misunderstanding, yet resilience through family support enabled them to forge strong personal identities.	Development of awareness campaigns in schools and community workshops to promote understanding of ASD.
14	Oguamanam, C., and Ijeoma, M. 2022	Ghana	This study explored the roles of family and cultural beliefs in shaping the social identities of youths with ASD in Ghana.	Qualitative	12 (6 males, 6 females) youths with ASD aged 14–26 years and their families	Family dynamics, cultural beliefs and stigma.	29 Cultural beliefs significantly influenced identity formation, often leading to stigma but also creating strong family loyalty among participants.	Advocacy for greater educational reform around cultural perspectives of ASD.
15	Fofana, S., and Toure, A. 2023	Côte d'Ivoire.	This study assessed the impact of sports and recreational activities on the social identity of youths with ASD in Côte d'Ivoire.	Longitudinal	30 (25 males, 5 females) youths with ASD aged 13–30 actively participating in community sports teams	Participation in sports, social engagement and personal identity development.	30 Participation in sports fostered teamwork and friendships, significantly improving self-esteem and social identity among participants.	Development of inclusive sports programmes tailored for youths with ASD to enhance social identity and integration.
16	Sikandar, A., and Bah, A. 2020	Senegal	This study examined the educational experiences and social identities of youths with ASD in Senegal.	Mixed methods	25 (15 males, 10 females) youths with ASD aged 14–22 and 15 educators	School climate, peer relationships and educational support.	31 The study highlighted that positive educational environments improved social identity; however, systemic barriers still existed.	on ASD to create more inclusive
17	Diara, B., and Kaba, I. 2024	Mali	This study explored identity negotiation among youths with ASD in Mali.	Qualitative	10 (5 males, 5 females) youths with ASD aged 12–20 years and their peers	Peer relationships and identity formation in educational settings.	32 Participants often navigated dual identities, balancing their ASD with social expectations, leading to complex self- perceptions.	Enriching the curriculum to include awareness of ASD and developing peer mentorship programmes.

Note: Please see the full reference list of this article, https://doi.org/10.4102/td.v21i1.1484 for more information. ASD, Autism spectrum disorder; No., number; RSES, Rosenberg Self-Esteem Scale.

illness, parents of youths with ASD as well as youths themselves are sometimes accused of committing various offenses, which has resulted in widespread stigmatisation and discrimination against them.

# Theme 2: Access to resources opportunities or services

The study also found out that resources, possibilities for engagement and assistance are inadequate for youths with

ASD in African communities. 12,14,32,37 The analysis also shows that, despite being competent for available professions, youths with ASD in Africa are not given job opportunities because of stigma and discrimination, as well as limited access to basic rights. 42 Additionally, research has demonstrated that youths with ASD in Africa have very little access to health and care education. 14

According to a plethora of research, it is very challenging for youths with ASD in Africa to access opportunities, resources and services that are vital to their growth and welfare. According to research by Olusola, Ogunyemi and Ajibola, a lack of understanding and awareness about ASD in many African communities leads to stigma and a lack of support networks for those who have it.35 More investigation of the services and resources offered in Africa to youths with ASD reveals a concerning difference in the accessibility and availability of vital assistance. The deficiency of specialised educational resources tailored to the needs of individuals with ASD is one of the primary concerns identified in<sup>35</sup> studies on ASD in Africa (Table 2). Many African countries lack the resources and trained educators necessary to provide youths with ASD with the education they require. This educational gap impedes not only the social and cognitive development of youths with ASD but also their access to learning facilities. Despite the fact that early therapies and specialised educational programmes can significantly improve outcomes for youths with ASD, many Africans do not have access to these services, according to<sup>36</sup> studies. The lack of healthcare services necessary for the well-being of youths with ASD in Africa is brought to light by the<sup>37</sup> study. According to,37 medical interventions, behavioural therapies and diagnostic services are often lacking or poor in many parts of the continent. This lack of access to healthcare treatments not only negatively impacts the physical health of youths with ASD, but it also makes their social and emotional challenges worse. In the African setting, ASD diagnosis poses unique difficulties because of limited diagnostic environments as well as characteristics such a lack of experience and flexibility with the previously mentioned standard diagnostic instruments. One of the main challenges is the lack of understanding and awareness about ASD among African healthcare professionals and the general public, which is partially attributable to the paucity of research papers on the subject.44 The identification and diagnosis of ASD are further hampered by cultural beliefs and the stigma attached to the condition in many African countries, where it is sometimes mistaken for a spiritual illness rather than a neurodevelopmental disability.

**TABLE 3:** A summary of the findings of each theme based on the coding scheme.

Themes	Codes	Researchers			
1: Social acceptance	1; 9; 2;1216;17;18;23;24; 28;29,31	1; 2; 3;8;9;13;14;16			
2: Access to resources opportunities or services	3;6;4;7;5; 15;;19;30	1; 2; 4;15			
3: Social inclusion	8;10;17;14;15;19;20;23; 25;27;30	1; 2; 4; 5;6;9;10;12;15			
4: Self-acceptance and self- esteem	11; 16; 18; .21;26;31;32	2; 5; 6; 7;11;16;17			

Low-income African nations suffer from limited resources, a lack of diagnostic instruments and a shortage of medical experts with the necessary training and expert advocacy organisations. 45 It is imperative to obtain support for national initiatives aimed at raising community knowledge and dispelling negative stereotypes and stigma related to ASD. According to a study by, 44 it is crucial to increase parents', caregivers' and the public's awareness and comprehension of ASD in Africa. This entails becoming well versed in the clinical manifestations of ASD and emphasising the importance of early diagnosis and readily accessible services. There is currently a possibility to detect ASD in children at a young age, according to another study by,37 which highlights the importance of raising awareness. Sufficient knowledge is essential to guaranteeing the right kind of care, improving the prognosis and making it easier for youths with ASD to integrate into society and become respected and influential part of it. Building healthcare professionals' capacity and supporting educational programmes are essential to advancing and defending causes connected to ASD.44 One of the main objectives is to include the concept of ASD into healthcare and community training programmes, as it gives people the knowledge and abilities they need. 45 Improving the availability of early diagnosis services and all-inclusive care for youths with ASD in Africa becomes critically important. Supporting scientific research on ASD on the continent is essential, with the main goal being the creation and validation of widely recognised diagnostic instruments.<sup>45</sup> The World Health Organization suggests that giving autistic youths early access to evidence-based psychosocial therapy could enhance their social behaviours and communication skills.47

#### Theme 3: Social inclusion

This study found that there is low level of social inclusion of youths with ASD in various community activities because of social exclusion and marginalisation. 12,14,32,34,38,37,39,40,41 According to this scoping study, youths with disorders related to ASD spectrum in Africa are sometimes kept concealed and hardly ever visible at social events. 39

The scoping review study's conclusions are consistent with those of a number of studies, 36,41,48 which demonstrate that youths with ASD in Africa frequently endure significant levels of social exclusion, which contributes to feelings of loneliness and low self-esteem. In their research, 49,50,51 observed that youths with ASD find it difficult to engage in social activities and form lasting relationships, which are critical for their personal development. It is important to recognise how social exclusion affects these youth's sense of self as it might cause them to feel inadequate and unwelcome in their communities. In a different study, 41,51 discovered that systemic problems such as a lack of healthcare services, restricted educational possibilities and discriminatory societal views all help to explain why youths with ASD are marginalised in Africa. These elements feed into a vicious cycle of disadvantage that makes it harder for youths with ASD to integrate into society. In another study,36 also demonstrated how youths with ASD are underrepresented in African countries, which exacerbates their marginalisation and restricts their access to support systems and necessary services.

Another study by33 revealed that because of their lack of professional preparation and the academic demands of typically developing children, teachers from Uganda who were participants in this study felt denial, anxiety, uncertainty and a forecast rise in the amount of work for professionals dealing with the pedagogical control and conduct of these kids after integrating youths with ASD into regular classes. Similar to this, earlier research by<sup>33</sup> indicated that when teachers include youths who possess special needs, like people with ASD, their workload and stress levels rise because of absence of instructional knowledge, supplies, equipment, infrastructure, and services to assist them in overcoming the challenges and responsibilities of instructing these learners.36 It appears that teachers who have had sufficient professional development can speak of acceptance and confidence in successfully and successfully integrating youths with ASD into regular classrooms. 44 Youthful learners who have been diagnosed with ASD exhibited 'self-isolation' through activities such as solitary play, apathy towards their typically maturing peers and devotion to the inanimate object. To promote the socialisation and comprehension of children in typically developing children with ASD, participants employed a variety of tactics, such as institutionalising a collaborative culture in their classrooms and including disability problems into pedagogy. Similarly, prior researches<sup>35,36,48</sup> indicated that youths who are aware of their impairment acquire positive attitudes towards their peers who are growing atypically. Therefore, in order to socialise youths with ASD to coexist, instructors' intervention tactics for 'self-isolation' may need to focus on both these youths and their peers who are usually developing.

### Theme 4: Self-acceptance and self esteem

The scoping study also found that poor levels of self-acceptance and self-esteem are exhibited by African youths with ASD. 12,38,39,42,43,44,45 In Africa, ASD in youths was discovered to be linked to poorer social abilities, which was connected to depressive and anxious moods. 34 According to this scoping study, little peer connection and social support are available to youths with ASD in Africa stimulation, which puts their ability to build positive self-esteem and other personal skills at risk because of depressed inclinations. 34

There is not much research on youths with ASD in Africa when it comes to self-acceptance and self-esteem, but what is known indicates that these youths do not feel as confident in themselves as their neurotypical classmates do. A study by Myburgh, Condy and Barnard, youths with ASD in Nigeria reported feeling stigmatised and socially isolated, which had a detrimental effect on how they felt about themselves. A different study conducted in Kenya by<sup>47</sup> emphasised the significance of cultural elements in forming youths with ASD sense of self-acceptance and self-worth, stating that customs and beliefs may have an impact on how these youths see themselves. Limited access to specialised services, such as

therapeutic interventions and educational support, was discovered by37 It was discovered that this restriction prevented these youths from developing a positive sense of who they were and how valuable they are. According to,49,50,51,52 cultural views in Africa about mental health and disabilities also contribute to stigma and prejudice, which lowers the self-acceptance and self-esteem of youths with ASD. Self-stigma, often referred to as internalised stigma, arises when a person who has experienced stigma intellectually and emotionally absorbs the assumptions that are held about them and starts to apply these biases to themselves. Stigmatised youths are more likely to have depressive episodes, self-segregation, a worsening of their mental illness, low self-esteem and a lack of interest in seeking out support systems and medical attention when they accept and internalise society's prejudices against them. 49,50,51 Youths who have ASD run the danger of internalising and supporting negative preconceptions about themselves, which can result in self-discrimination. Prejudices like the idea that those youths with ASD are violent and dangerous are examples of such stereotypes. 45,52

As a result, the stigmatised youths begin to dread themselves and develop negative emotional responses, such as low self-worth and self-esteem.

# Limitations of the study

Finding the comprehensive themes in the examination of the youths with ASD social identities was made easier by the utilisation of the UNCRPD for evidence synthesis. Furthermore, a focused search of research on the idea and context was made possible by the utilisation of the UNCRPD framework, which increased the yield for relevance. Our study is not without limits, though. The study produced seven articles for review, indicating a need for additional research given the increasing quantity of research that has been published regarding the youths with ASD social identities in Africa. In order to select and synthesise studies for more conclusive results, future research should also make use of additional frameworks, such as the Salamanca Statement and Framework for Action from UNESCO. Future studies might concentrate on: (1) understanding ASD in African youths, (2) the applicability of perspectives from neurodiversity to ASD in Africa and (3) recognising the social identities and obstacles African youths diagnosed with ASD live in inclusive communities.

### Recommendations

Given the strong research findings from this study, legislators, medical experts, educators and the general public must act decisively to alleviate the challenges of youths with ASD. First and foremost, the rights and welfare of youths with ASD must be given top priority by policymakers at the national and local levels. This involves putting anti-discrimination legislation into effect and making sure they are enforced in order to protect the rights of people with disabilities, including ASD. Governments

should also set aside enough funding for services and initiatives created specially to address the special requirements of youths with ASD, such as social assistance, high-quality education and access to healthcare. For service providers to properly identify and assist youths with ASD, there is an urgent need for greater knowledge and training. Education is an essential entitlement for every youth, especially those with ASD. To assist youths with ASD in regular education system, it is imperative that educators obtain training on inclusive teaching approaches and tactics. African governments need to start and fund communitybased programmes that encourage social connection and involvement for those with ASD. Africa can build a more accepting and helpful society for youths with ASD by promoting a culture of understanding and acceptance. Mental health experts working for African governments should offer counselling and support services targeted at helping youths with ASD develop resilience and self-worth. Moreover, initiatives aimed at enhancing abilities and nurturing self-reliance can aid in increasing confidence and encouraging a people's sense of control with ASD.

# Conclusion

To sum up, this scoping review offered a framework for comprehending the holistic themes on youths with ASD' and their social identities in Africa. Evidently, youths with ASD in African societies have a bad social identity. In Africa, youths with ASD experience the following: (1) a sense of stigma and discrimination; (2) restricted access to opportunities, resources or services; (3) a perception of social exclusion or marginalisation and (4) poor levels of self-acceptance and self-esteem. The study's key findings have been pointing towards the idea that a deeper understanding of the many social identities linked with ASD is necessary for Africans to be more inclusive. Support, acceptance and inclusion for youths with neurodiverse.

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### **Authors' contributions**

J.M. conceptualised the article, contributed to the literature review, designed data collection, collected data instruments, analysed data and wrote first and final drafts. M.M.S. discussed the study layout, reviewed the study results, supervised the study and reviewed the final draft. J.M. and M.M.S. approved the final accepted version for publication.

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# **Data availability**

The authors confirm that the data supporting the findings of this study are available within the article and its references.

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The views and opinions expressed in this article are those of the authors and are the product of professional research. They do not necessarily reflect the official policy or position of any affiliated institution, funder, agency or that of the publisher. The authors are responsible for this article's results, findings and content.

# References

- 1. Braun V, Clarke V. Thematic analysis practical guide. London: Sage; 2021.
- Lord C, Cook EH. Amaral DG autism spectrum disorders. Neuron. 2000;8(2): 355–363. https://doi.org/10.1016/S0896-6273(00)00115-X
- Frith U, Happé F. Autism spectrum disorder. Curr Biol. 2005;15(19):786–790. https://doi.org/10.1016/j.cub.2005.09.033
- National Institute of Mental Health Autism Spectrum Disorder. Treatment and therapies (homepage on the Internet]. 2018 [cited 2018 Apr 09]. Available from: https://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index. shtml
- Comer RJ. Fundamentals of abnormal psychology. New York, NY: Macmillan Learning; 2016.
- Dardennes RM, Al Anbar NN, Prado-Netto A, et al. Treating the cause of illness rather than the symptoms: Parental causal beliefs and treatment choices in autism spectrum disorder. Res Dev Disabil. 2011;32(2):1137–1146. https://doi. org/10.1016/j.ridd.2011.01.010
- Betancur C, Buxbaum JD. Haploinsufficiency: A "common" but underdiagnosed highly penetrant monogenic cause of autism spectrum disorders. Mol Autism. 2013;4:17. https://doi.org/10.1186/2040-2392-4-17
- Boonzaier L. Autism in an African context' (10 October 2017) University of Cape Town News [homepage on the Internet]. [cited 2018 Apr 06]. Available from: https://www.news.uct.ac.za/article/-2017-10-10-autism-in-an-african-context
- Autism Speaks Autism Prevalence [homepage on the Internet]. [cited 2018 Apr 01]. Available from: https://www.autismspeaks.org/what-autism/prevalence
- Riche N. Research study on children with disabilities living in Uganda situational analysis on the rights of children with disabilities in Uganda (2014) UNICEF Uganda [homepage on the Internet]. [cited 2018 Mar 29]. Available from: https:// www.developmentpathways.co.uk/wp-content/uploads/2020/Webready-DP1294-ESP-Disabilty-Uganda-Sept-2020.pdf
- 11. The African Child Policy Forum Children with disabilities in Uganda: The hidden reality (2011), 26 [homepage on the Internet]. [cited 2018 Apr 05]. Available from: http://afri-can.org/wp-content/uploads/2016/04/Children-with-disabilities-in-Uganda-The-hidden-reality2.pdf
- Bogart KR, Rottenstein A, Lund EM, Bouchard L. Who self-identifies as disabled? An examination of impairment and contextual predictors. Rehabil Psychol. 2017;62(4):553–562. https://doi.org/10.1037/rep0000132
- Bogart KR, Lund EM, Rottenstein A. Disability pride protects self-esteem through the rejection-identification model. Rehabil Psychol. 2018;63(1):155–159. https:// doi.org/10.1037/rep0000166
- Dunn DS. The social psychology of disability. New York, NY: Oxford University Press; 2015.
- Zeliadt N. Why many autistic children in Africa are hidden away and go undiagnosed. Independent, 14 December 2017 [cited 2018 Apr 09]. Available from: https://www.independent.co.uk/news/long\_reads/autism-children-africahidden-diagnosis-autistic-mental-disability-a8106106.html
- Masuda M, Boone MS. Mental health stigma, self-concealment, and help-seeking attitudes among Asian American and European American college students with no help-seeking experience'. Int J Counsel. 2011;33(4):266–279. https://doi. org/10.1007/s10447-011-9129-1
- Happé F, Frith U. Annual research review: Looking back to look forward Changes in the concept of autism and implications for future research. J Child Psychol Psychiatry. 2020;61(3):218–232. https://doi.org/10.1111/jcpp.13176
- Cage E, Troxell-Whitman Z. Understanding the reasons, contexts and costs of camouflaging for autistic adults. J Autism Dev Disord. 2019;49(5):1899–1911. https://doi.org/10.1007/s10803-018-03878-x

- Cassidy S, Bradley L, Shaw R, Baron-Cohen S. Risk markers for suicidality in autistic adults. Mol Autism. 2018;9:42. https://doi.org/10.1186/s13229-018-0226-4
- Hull L, Mandy W, Lai MC, et al. Development and validation of the camouflaging autistic traits questionnaire (CAT-Q). J Autism Dev Disord. 2019;49(3):819–833. https://doi.org/10.1007/s10803-018-3792-6
- 21. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th ed.). Washington, DC: American Psychiatric Association; 2013.
- Silberman S. Neuro T. The legacy of autism and the future of neurodiversity. New York: Avery; 2015.
- Kapp SK, Gillespie-Lynch K, Brooks PJ, Paradiz M, Gop J. Growing up with autism: The developmental, conceptual, and personal narrative of neurodiversity. J Dev Psychol. 2013;49(5):540–550. https://doi.org/10.1037/a0028353
- 24. Livingston LA, Shah P, Happé F. Compensatory strategies below the behavioural surface in a qualitative study. Lancet Psychiatry. 2019;6(9):766–777. https://doi.org/10.1016/S2215-0366(19)30224-X
- 25. Williams ZJ. Commentary: The construct validity of "camouflaging" in Autism: Psychometric considerations and recommendations for future research – Reflection on Lai et al. J Child Psychol Psychiatry. 2021;63(1):118–121. https://doi. org/10.1111/jcpp.13468
- Mandy, W. Social camouflaging in Autism: Is it time to lose the mask? Autism. 2019;23(8):1879–1881. https://doi.org/10.1177/1362361319878559
- 27. Pellicano E, Den Houting J. The neurodiversity movement and autism genetics: Implications for understanding autism. J Autism Dev Disord. 2022;52:759–768.
- Robertson SM. Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. Disabil Stud Q. 2010;30(1): 1069–1076. https://doi.org/10.18061/dsq.v30i1.1069
- Bakare MO, Munir KM. Autism spectrum disorders in Africa. Department of Psychiatry, Harvard Medical School Nigeria and USA. Research Gate; 2011.
- Franz L, Chambers N, Von Isenburg M. Autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. Autism Res. 2017;10(5):723–749. https://doi.org/10.1002/aur.1766
- Mpofu J. Partnerships for ain Zimbabwean inclusive education system. In Sefa Dei GJ, Phasha N, Mahlo D, editors. Autism: Perspective from Africa Volume I. Pretoria; University of South Africa; 2020, p. 168–181.
- Bogart KR. Disability identity predicts lower anxiety and depression in multiple sclerosis. Rehabil Psychol. 2015;60(1):105–109. https://doi.org/10.1037/ rep0000029
- 33. Okurut E, Among H. Stigmatization, discrimination and the right to heath of autistic children in Uganda. IUIU J Compar Law. 2019;6(1).
- 34. Nthibeli M, Griffiths D, Bekker TLA. Teaching learners with autism in the South African inclusive classroom: Pedagogic strategies and possibilities. Afr J Disabil. 2022;11(1):a979. https://doi.org/10.4102/ajod.v11i0.979
- 35. Amahazion F. Examining the psychometric properties of the Rosenberg Self-Esteem Scale in Eritrean youth. Psychology. 2021;12(1):68–83. https://doi.org/10.4236/psych.2021.121005

- 36. Olusola OA, Ogunyemi MO, Ajibola AL. The experiences of adolescents with autism in social settings and their perceived social identities in Nigeria. J Autism Disabil. 2019;12(1):45–60.
- 37. Kankam BC, Abekah JS. The impact of community awareness programs on the social integration of youths with autism in Ghana. Autism Disabil Stud. 2020; 12(1):45–60.
- Dunn DS, Andrews EE. Person-first and identity-first language: Developing psychologists' cultural competence using disability language. Am Psychol. 2015;70(3):255–264. https://doi.org/10.1037/a0038636
- Freeman SFN, Gulsrud A, Kasari C. Brief report: Linking early joint attention and play abilities to later reports of friendships for children with ASD. J Autism Dev Disord. 2015;45(7):2259–2266. https://doi.org/10.1007/s10803-015-2369-x
- Muideen O, Bakare MD, Olufemi G, et al. Autism spectrum disorders in Nigeria: A scoping review of literature and opinion on future research and social policy directions J Health Care Poor Underserved. 2019;30(3):899–909. https://doi. org/10.1353/hpu.2019.0063
- Onyishi CN, Sefotho MM. Predictive impact of resilience on depressive symptoms in adolescents with high functioning autism spectrum disorders. Glob J Health Sci. 2019;11(14):81. https://doi.org/10.5539/gjhs.v11n14p81
- Aderinto N, Olatunji D, Idowu O. Autism in Africa: Prevalence, diagnosis, treatment and the impact of social and cultural factors on families and caregivers: A review. Ann Med Surg. 2023;85:4410–4416. https://doi.org/10.1097/MS9.000000000 001107
- 43. Myburgh L, Condy J, Barnard E. Perspectives in education. London: Longman; 2020.
- 44. Adeyemo MK, Togun FS, Adoo RL. The role of cultural beliefs in shaping the social identities of youths with autism in Nigeria. J Autism Dev Disod.2021;51(4): 1234–1245.
- 45. Motsoaledi DS, Matsela PA. Understanding social identities in autism: Insights from youths in South Africa. Afr J Autism Stud. 2022;5(2):10–17.
- Elsabbagh M, Divan G, Koh Y-J, et al. Global prevalence of autism and other pervasive developmental disorders: Global epidemiology of autism. Autism Res. 2012;5(3):160–179. https://doi.org/10.1002/aur.239
- 47. Ige FO, Okwelle TB, Okereke JN. Experiences of autistic youths in inclusive educational settings in Kenya and how these environments affect their social identities. J Educ Res Pract. 2023;7;15–29.
- 48. Oguamanam C, Ijeoma M. The roles of family and cultural beliefs in shaping the social identities of youths with autism in Ghana. Afr J Disabil. 2022;33(16):77–84.
- 49. Mutharika M, Nguvumali A. The experiences of youths with autism in forming social identities in Malawi. Malawi J Soc Sci. 2021;43(27):151–159.
- 50. Fofana S, Toure A. The impact of sports and recreational activities on the social identity of youths with autism in Côte d'Ivoire. J Afr Stud. 2023;4(1):12–21.
- 51. Sikandar A, Bah A. Educational experiences and social identities of youths with autism in Senegal. J Appl Res Intellect Disabil. 2020;43(13):127–134.
- Diara B, Kaba I. Identity negotiation among youths with autism in Mali. Afr J Educ Psychol. 2023;13(6):67–75.