# The Role of Social Work in Advancing Capacity in Autism Spectrum Disorder in the Kingdom of Eswatini

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## Abstract

This reflection article, which positions itself within an ecological systems approach, focuses on advancing the capacity for effective responses to autism spectrum disorder in Eswatini. Autism spectrum disorder is a neurodevelopmental disorder with impacts ranging from mild to severe. Knowledge about this condition in Africa is limited, as exemplified by a very small body of research conducted in African countries. This article presents the developmental work underway in the Kingdom of Eswatini to raise awareness and to build capacity in autism spectrum disorder. It focuses on (1) increased understanding and recognition of the need and direction for capacity-building, (2) collective learning for proactive change, (3) policy and practice advancement, and (4) disciplinary development in social work in the service of this advancement. Recommendations for ongoing advancement are offered.

**Keywords:** autism spectrum disorder, Eswatini, empowerment, capacity-building, Africa, social work

## Introduction

In the Kingdom of Eswatini, which is located in the southern African region, there is a need to build capacity in autism spectrum disorder (ASD) among social services, health and educational personnel, the government and society-at-large. Persons living with ASD and their families face multiple challenges and vulnerabilities owing to a lack of

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knowledge and an insufficiently responsive system of support. At the family level, ASD has been misunderstood as "kuloywa" (the use of witchcraft on someone), whereas at the community level, it has been labelled as a "bad omen".

This article presents developmental work underway in Eswatini to raise awareness about ASD, including capacity-building efforts. In seeking to strengthen the welfare of children in the country, the government of the Kingdom of Eswatini identified the aim of strengthening care for persons with ASD. Challenges were noted in assessment, diagnosis and interventional access. Coupled with insufficient public education on ASD, children and adults were noted as having difficulty when accessing the necessary interdisciplinary care. To redress these challenges, notable steps have been advanced. This article therefore focuses on these action-oriented capacity-building steps and present recommendations for moving forward to advance understanding of and capacity in ASD in the Kingdom of Eswatini.

## Background

Definitions of ASD have shifted over time (Maich and Hall 2016). According to the American Psychiatric Association (2013), ASD involves differences in an individual's social communication and interaction and restricted and repetitive behaviours and/or interests, with symptoms being present across numerous contexts. The American Psychiatric Association (2013) further denotes various severity levels of ASD. It describes that the symptoms of ASD and support needed by those with ASD vary from individual to individual.

In their review, Elsabbagh et al. (2012) identified a worldwide prevalence of ASD at 62 in 10 000. The World Health Organization (2013) estimated that globally, one in every 160 persons is living with autism. There are no universal estimates of the prevalence of ASD in Africa; however, varying studies indicate a range of estimates. A Nigerian study estimated that 2.3 per cent of children had ASD based on a sample of 2 320 children seen in the paediatric neurology and child psychiatry clinic of a University College Hospital (Lagunju, Bella-Awusah, and Omigbodun 2014). Furthermore, a Ugandan study found a prevalence rate of 6.8 per cent of children with ASD (Kakooza-Mwesige et al. 2014). In a study conducted by Bakare and Munir (2011), the authors noted that the prevalence of ASD among children with developmental disorders in Egypt and Tunisia were 33.6 per cent and 11.5 per cent, respectively.

Autism, according to Bakare and Munir (2011), was seen in previous decades as a Western occurrence, and although recent decades have brought increased research in other parts of the world, many aspects of ASD in Africa are still unclear. Zeliadt (2017) noted that when professional help is absent and families are unaware of ASD, individuals on the spectrum may remain ostracised, with reports of disappearances and potential exposure to danger. Zeliadt (2017) described a scenario by presenting the case of a mother in Ethiopia, stating that the "[mother] is afraid that [the child] would wander

off and drown in the river behind the houses and . . . [has] no choice but to tie [the child] up" (Zeliadt 2017, 1). African families with autistic children often seek assistance from religious houses and traditional healers. Indirect pathways to care and help-seeking behaviour remain major challenges, highlighting the need for family and community support by social workers and other helping professionals including psychiatric nurses, developmental-oriented doctors, therapists, counsellors and clinical psychologists.

## Theoretical Framework

In this reflection article, our aim is to examine the macro–micro connection among different stakeholders (government, schools, family, community services, etc.) in their work of advancing the understanding of, and proactively responding to, ASD in the Kingdom of Eswatini. To that end, we have situated this work in Bronfenbrenner's ecological systems theory, which serves to guide and inform this review of ASD capacity and capacity-building, in the context of sub-Saharan Africa and more specifically, Eswatini. Furthermore, we have sought to better understand the role of social workers in this context.

The ecological systems theory highlights the varying roles that systems (micro, meso, exo or chrono and macro) play in understanding and shaping human behaviour and interaction. According to Bronfenbrenner, in order to understand the development and perceptions of individuals, one needs to examine their multiple interactions within the range of settings and systems in which they exist (Butt 2017). In this case of examining ASD in this context, systemically examining the related roles and responses of different actors (such as family members, social workers, community service personnel, school personnel, and government employees) seems instructive. As an example, the micro system is where individuals diagnosed with ASD and their families are located, and in which they experience life in the context of home and community. At the meso-system level, individuals and families connect and interact with service providers, such as social workers and therapists. At the exo- or chrono-system level, children and their families interact with the communities and schools; therefore systems interact in the integration of community level practice. Finally, the macro-system level entails the larger structures or systems such as legislation, policies and programmes that affect the well-being of individuals with ASD and their families. To advance the understanding of ASD and the specific roles that social workers and others can play in support and building quality of life, we offer a reflective and critical review of systems as they pertain to ASD-based practice and experience in Eswatini.

## ASD Capacity in Africa

Knowledge about ASD in Africa is very limited. In a review of the literature, Abubakar, Ssewanyana, and Newton (2016) found that most African studies were conducted in South Africa and Nigeria, with fewer in East Africa and North Africa. A lack of regional

expertise is cited by the authors as a potential reason for the lack of ASD research, as is the lack of resources and interest to conduct regionally based research on ASD. The number of studies dealing with the prevalence, diagnosis, and treatment of ASD are as follows: South Africa 28; Nigeria 15; Kenya 3; Tanzania 2; and Ghana, Uganda, Zambia, Zimbabwe, and Seychelles each having one study (Abubakar, Ssewanyana, and Newton 2016; Bakare and Munir 2011; Franz et al. 2017; Wannenburg and Van Niekerk 2018; Zeliadt 2017). The gap in knowledge about ASD in African countries (excluding South Africa and Nigeria) is largely attributed to, yet also contributes to, a lack of expertise among health professionals, psychosocial service providers, and behavioural therapists.

There are, however, capacity-building initiatives taking place in sub-Saharan African countries at government and community levels. Many countries are enthusiastic to include issues related to autism support as a component of their disability inclusion policies. A review of the capacity-building initiatives demonstrates that some sub-Saharan African countries have initiated capacity-building activities at policy and programme intervention levels. A sample of five countries' capacity-building initiatives are presented in Table 1.

**Table 1:** Example of sub-Saharan Africa countries where capacity initiatives exist

| **Country** | **Capacity-building initiative at government level** | **Capacity-building initiative at community level** | **Source** |
|---|---|---|---|
| South Africa | Inclusive education policy; autism specific schools; national public health system | Equine assisted learning; small grant-assisted family care | Butt 2017; Erasmus 2018; Franz and De Vries 2019; Dalton, McKenzie, and Kahonde 2012 |
| Ethiopia | National mental health strategy; health sector transformation plan; education sector development programmes | Specialised NGOs exist to provide services to children with autism and their parents | Legesse 2018; Tekola et al. 2016 |
| Kenya | National special needs education policy framework; special needs units in public schools and inclusive education model | Special education professionals; private treatment centres; NGOs established to create community awareness | Autism Society of Kenya 2017; Riccio 2011 |

| Country | Capacity-building initiative at government level | Capacity-building initiative at community level | Source |
|---|---|---|---|
| Cameroon | Inclusive education policy | Consideration of the role of teachers and parents in inclusive education | Cockburn et al. 2017; Ivan 2017; Tukov 2008 |
| Ghana | Inclusive education policy | Community-based speech and language therapy services | Abbey 2018; Ghana, Ministry of Education 2013 |

NGO: non-governmental organisation

## ASD Capacity in Eswatini

The challenges associated with ASD specifically in Eswatini are noted to be substantial. Currently, ASD is the most prevalent undiagnosed disability in the country (Dlamini 2012), with many people misguided in believing that people with ASD are bewitched. Many children are therefore left without services or treatment, including a discursive orientation that dissuades consideration of treatment or support needs. The most serious challenge is thought to include widespread misunderstanding, with deleterious effects on persons with ASD and their families. According to Mvubu (2018), founder of Autism Eswatini, such misunderstanding results in delays in accessing treatment, which leads to little or no attempt to seek help by parents and inadequate schooling options for children with ASD. Incapacities like these yield other negative effects such as heightened stress, risk of family poverty, alienation from community interaction, lowered status of children with ASD, and increased exposure to various forms of abuse including sexual abuse (Mvubu 2018).

The provision of ASD-based person and family-centred care is a pressing concern in Eswatini, with increasing attention in recent years noted by the print media. For instance, Dlamini (2012) reported, “in Swaziland, it is believed that autism affects four times as many boys as girls.” Khoza (2018), a journalist for the Eswatini Observer, further reported on the opinions of experts that more children in Eswatini are annually diagnosed with ASD than juvenile diabetes, AIDS or cancer combined. Khoza (2018) quoted experts stating, “We need to stand up as families and as a nation to find all the knowledge we need about autism, arm ourselves for it and then we will be in a position to face it successfully for a bright future.” Interventions currently offered to individuals with ASD include speech and language therapy by the Mbabane Government Hospital for SZL2.00 (approximately USD0.15) per session, occupational therapy by the National Psychiatric Referral Hospital without fees, and a range of services offered by private practitioners for a fee (Dlamini 2012). Several steps have been taken to constructively redress these issues in Eswatini: commitment to building national ASD capacity, collective learning for change, and social work development for advocacy and

practice advancement. These steps are outlined next, with a focus on the way in which they apply and the micro-, meso-, and exo-level advances are illustrated.

## Micro-, Meso- and Exo-level Considerations: Recognising and Responding to the Need for ASD Capacity-Building

Families tend to be the primary care providers for persons with ASD, especially children. Prelock and Hutchins (2008) noted that family support for children with ASD includes developing social communication skills and guiding children on societal and cultural norms. Yet in the provision of this care, parental competence and the well-being of families may be challenged by extraordinary care requirements. Autistic individuals experience a range of challenges in their daily functioning such as eating, toileting, personal care issues and social behaviours. There are often additional stressors for a family, which can include financial strain, limited access to formal and informal support, and family adjustment to ASD (Preece and Almond 2008). Supporting the micro system by empowering parents, caregivers and family members is an essential component in the care of individuals diagnosed with ASD and in alleviating the challenges parents experience in rendering care to their child with ASD. Webster, Cumming and Rowland (2017) documented that many countries recognise the importance of involving parents in the decision-making process for their child's school enrolment and attendance. They further noted that "most countries and schools agree that parents play a critical part in creating educational plans and programs for their children with disabilities" (88).

At meso- and exo-system levels, home- and school-based interventions are important to support and enhance the confidence of parents when attending to the care needs of their child with ASD. Key stressors on families may also include financial concerns, coping and adjusting to the presence of autism in the family, and the inadequate availability of formal and informal support (Preece and Almond 2008). Home-based interventions necessary to supporting families entail the provision of updated information about ASD, supportive resources, meaningful linkage with the school system, training of caretakers on the way in which to manage the physical, social and emotional needs of individuals with ASD, and sharing information with and seeking support from extended family and community members (Timmons, Breitenbach, and MacIsaac 2004). Home-based interventions may further improve child functioning, including knowledge and understanding, communication, play skills, means to deal with stress and depression, and support to recognise and nurture parental satisfaction with the child's outcome gains (Cincinnati Children's Hospital Medical Center 2013).

Parent education to understand and navigate ASD has been noted as integrally important for supporting individuals with ASD. In offering knowledge and skills to parents and other family members, education reportedly results in "reductions in stress and anxiety, improved coping, improved parent-child interaction and communication, improved understanding of ASD, efficacy and confidence and improved parental quality of life" (Preece and Trajkovski 2017, 122). School-based interventions contribute to dealing

with children's developmental needs (Webster, Cumming, and Rowland 2017). Specific school-based interventions may include, but are not limited to: teaching communication to replace challenging behaviour; socialisation training; nurturing self-management skills; enhancing peer relationships; building teacher effectiveness in ASD; and promoting school–parent collaboration or partnership (Koegel et al. 2011). In recognising and responding to the need for ASD capacity-building at the micro level, the next section will discuss meso-, exo- and macro-level responses to foster change in the context of Eswatini.

## Meso-, Exo- and Macro-Level Response: Collective Learning for Change via National Strategic Capacity-Building in ASD

To advance ASD capacity on a national level, the inaugural ASD national conference was convened at the Royal Swazi Spa Convention Centre in Eswatini in August 2018. The event brought together the Royal Family of the Kingdom of Eswatini, United Nations representatives, European Union (EU) representatives, government ministers, senior government officials, civic organisations, academics, schoolteachers, parents, caregivers, and individuals (including children) with ASD (Ndlela 2018). The conference identified current challenges and opportunities to proactively deal with ASD in Eswatini. Her Royal Highness Inkhosikati LaMatsebula challenged stakeholders and declared that support for ASD is of high priority in Eswatini. She indicated that "people addressing issues of autism should be empowered with necessary tools – government should empower officials with knowledge" (LaMatsebula 2018). The Deputy Prime Minister, Senator Paul Dlamini, offered a strong call to proactively deal with ASD, stating that "there has to be increased communication with a wider audience on autism, support from families and communities has to be available (for) children with ASD. And [the] government commits to ensuring that strong partnerships will be in place" (Dlamini 2018).

## Macro-Level Response: Policy and Practice Advancement

Various national legislative frameworks and policies in Eswatini serve children with special needs, including the Eswatini Constitution Act of 2005, the National Children's Policy, the Children's Protection and Welfare Act of 2012, and the National Disability Policy and Persons with Disability Act of 2018. The Education and Training Policy of the Eswatini government's Ministry of Education and Training has been under review to seek greater inclusivity for persons with disabilities (Mtshali 2018). This Ministry emphasised training for professionals related to special and inclusive education, and school leadership and management. The Ministry offers in-service training to deal with the special needs population, including persons with ASD. This training targets preschool, primary and high school teachers, school inspectors, nurses, health workers, community leaders and parents. Key challenges impeding broad-based consideration and advancement reportedly include limited access to assessment, inadequate family support, incomplete national data on special needs including ASD, and lack of research to inform policy and practice. Dealing with these areas, building capacity offers steps

forward at regional and societal levels (Mtshali 2018). Applying this at a community level, Mwanjali (2018) noted the need to train teachers and religious leaders who could assist with referrals for potential diagnosis and support.

Practice and policy advancement efforts are also observed in neighbouring countries in the southern African region. For instance, Franz et al. (2018) noted that in South Africa's Western Cape province, a child suspected of having ASD is evaluated and referred to a neuro-developmental clinic. Following diagnosis, the child may be referred for therapy, and registered on the Western Cape Education Department's waiting list for school placement.

The South African Constitution (RSA 1996) abolished educational inequalities, and the country adopted an inclusive education policy that facilitated opening autism-specific schools or units for special needs classes within public and private schools (Erasmus, Kritzinger, and Van der Linde 2019). There are also many associations and professional groups collaborating to advance policy and practice in ASD in South Africa. A few of these entities include Autism South Africa, the South African Disability Alliance, Parents for Children with Special Needs, the National Coalition of Social Services, and the South African Association for Learners with Educational Difficulties (Autism South Africa n.d.).

In Zimbabwe, the Inclusion Education Policy adopted in 1994 enhanced the enrolment of children with special needs including autism (Majoko 2017). Several government policy legislations – including the Zimbabwe Education Act of 1996, the Disabled Persons Act of 1996, and the Education Secretary's Circular No. P36 of 1990 – are consistent with the intent of inclusive education (Mutepfa and Mpofu 2007). A practical advancement of ASD support in Zimbabwe indicates that

> students with special needs are educated using the inclusive education model where in addition to educating some students with disabilities in the general classroom, a continuum of placements (e.g., resource room, self-contained special education classrooms in regular schools, and special schools) are retained for students who may need such placements. (Chitiyo et al. 2019, 31)

In Botswana, Abosi (2000) reported that in 1994, "the Botswana National Assembly approved the Revised National Policy on Education, which in part stated that the government is committed to the education of all children, including those with disabilities" (48). This policy outlined the development of a special education programme and guided the integration of the special education with the mainstream education system. As the result of this policy, there are seven schools in Botswana that serve children with learning impairments. However, despite these policies and practices, there are some challenges in Botswana in relation to inclusive education, with reports of teachers who state that the "inclusion of students with disabilities into mainstream settings is difficult and stressful" (Chhabra, Srivastava, and Srivastava 2010, 221).

## Disciplinary Advancement across System Levels: Pro-ASD Social Work Capacity and Training

*The Contributing Role that Social Workers Can Play when Dealing with ASD Challenges in Eswatini*

To further deal with the challenges at micro, meso, exo and macro levels, disciplinary advancement can be facilitated for proactive change. Social workers can serve as key actors to raise awareness and to provide support at individual, family, community, and societal levels. As the profession of social work develops in Eswatini, it is anticipated that there will be new opportunities to initiate community-based programmes. Personal communication with Moses Dlamini, Director for Social Welfare (in August 2018), informed that there are, however, only four school social workers (one per region) in the entire nation who are expected to serve over 40 000 students each; further social work staffing capacity is warranted. Several studies similarly convey the role and importance of school social workers. For example, Borling and Mumm (2009) discussed the way in which a school social worker can play the role of a "clinician, consultant, educator and advocate" (1). Given these multifaceted roles, it is recommended that school social workers be "knowledgeable about all facets of ASD, including the diagnostic process, the assessment process, and the range of evidence-based intervention efforts" (Borling and Mumm 2009, 1).

In contributing to the lives of families affected by ASD, social workers are well-positioned to advance change and capacity-building owing to their disciplinary focus, location and role in school and community, and family situatedness (for example, context, role). School social workers support children with ASD and their families in both direct and indirect ways. Direct roles include their involvement in assessment processes, supporting and engaging family members, and providing support to school staff. Indirect roles include collaboration with multidisciplinary teams and advocating policy change (Foster 2015). Together, these roles and their impacts extend over micro-, meso-, exo- and macro-system advancement.

To effect change and in concert with other change agents, the role of social work professionals is increasingly recognised as integral, particularly given the complexity and multiple intersections of ASD (individual, family, community, health, mental health, education, disability services) (Autism Ontario[1] 2011; Morris, Muskat, and Greenblatt 2018). According to Morris, Muskat, and Greenblatt (2018), "social workers who work in health care settings can play a key role in enhancing family-centred care through crises intervention, counselling, collaboration, advocacy, and resource gathering for patients and their families" (484). Given the important role of social

1 Autism Ontario is based in Toronto, Canada.

workers in dealing with ASD challenges, the next section will consider the state of social work education in building capacity for social work responses.

*Current Capacity of Social Workers in Eswatini*

In Eswatini, social work education is a recent initiative (2014), with the first cohort of students graduating in October 2018. This newly established social work education programme was recently revised (as approved by University Senate in 2018) to ensure the programme includes courses on vulnerable groups including persons with disabilities such as ASD. In the revised programme, specific courses provide social work students with the required knowledge and skills to support individuals with special needs including those with ASD. These courses include: Counselling in Social Work, School Social Work, Healthcare Social Work, Social Work with Vulnerable Groups, Case Management, and Social Work with Families, Children and Adolescents. As social work students graduate and become competent practitioners with the knowledge, skills and values to effectively work in numerous systems, the capacity of social work to deal with ASD will be advanced. Future training and professional development opportunities can be advanced by the University of Eswatini (UNESWA) in agencies such as the Ministry of Education and Training, the Department of Social Welfare (DSW), the National Children Services Department, the Ministry of Health and other governmental organisations, NGOs and civil society organisations.

Although other disciplines are recognised as integral to widespread capacity-building in ASD-based knowledge, advocacy and support, social work in Eswatini has been a catalyst and connector for the advancement of ASD capacity at national, community and family support levels. As part of the interdisciplinary team, social workers identify core areas of concern and strength, and develop recommendations and strategies. The role of social workers, as leaders in case management and community change, is increasingly identified to ensure that interdisciplinary teams are: (1) supported in effectively communicating with each other; (2) assisted in amplifying individual and family strengths and needs; and (3) nurtured in developing and implementing collaborative plans to support the individual, family and community (Global Social Service Workforce Alliance Case Management Interest Group 2018).

*Broadening Strategies to Advance the Capacity of Social Workers in Eswatini*

Specific efforts to increase ASD-focused social work capacity in Eswatini are largely driven by the national government (for example, the Deputy Prime Minister's Office) and UNESWA, based on an ecological systems advancement framework. Capacity-building activities in social work were developed with the support of the EU in the project "Technical Assistance for the Development of Social Protection System in Swaziland" (Pain 2016) that was implemented from May 2016 to October 2019. The primary tasks of this initiative entailed an assessment of the training needs in the existing social work labour force employed by the DSW, and a proactive revision of the Bachelor of Social Work curriculum at UNESWA.

The training needs assessment revealed various social worker capacity gaps, including limited knowledge and skills in relation to case management, professional ethics, child justice, policy implementation, trauma counselling, research, monitoring and evaluation, communication skills, client assessment and report writing (Maonde et al. 2016). Based on these findings, capacity-building in-service training opportunities were designed and implemented for the social work labour force. In order to begin to deal with the gaps, training was offered in 2017 to 2018 on salient topics such as case management, supportive supervision and mentoring at the request of the DSW.

To strengthen the undergraduate social work programme at UNESWA, the EU technical support team provided capacity-building activities which included revising the Bachelor of Social Work curriculum, teaching social work courses, and mentoring social work staff in academic research and field education. UNESWA is positioned to offer research and training to meet stakeholder needs in ASD; indeed, an important step forward. Accordingly, UNESWA is undergoing transformative change in professionalising the social work programme to better meet the needs of individuals, families, communities and Eswatini society. The revised social work programme thus offers courses on children, families, and vulnerable groups in communities. Advances to the social work education programme have the potential to substantially benefit the social service workforce and service delivery relative to individuals with ASD and their families. As noted from group discussions during the National Conference on "Empowering the Nation on ASD" in August 2018, attention was brought to bear on dealing with the need for heightened cooperation among professionals such as nursing, social work, psychology and education when tackling pressing issues associated with ASD. Recognising need and embarking on future steps constitute important initial steps, inviting further work in moving forward and multiple systemic and disciplinary levels, as illustrated within social work.

Other meso and macro level social work capacity-building efforts reflect partnership formation such as establishing a professional association of social workers and forming a national council of social work (Hall and Georgiev 2019). UNESWA initiated a partnership agreement with the University of Pretoria in South Africa, through which the social work programmes of both universities will benefit in terms of staff and student exchanges and research collaborations. A memorandum of understanding was also signed between UNESWA and the University of Calgary in Canada to facilitate academic research and field partnerships (Drolet 2019). The EU project team in Eswatini, in collaboration with UNESWA social work staff, encouraged the Deputy Prime Minister's Office (DPMO) in Eswatini to drive the process of establishing a national council of social work. In this effort, terms of reference were prepared and submitted to the DPMO. These various activities are expected to contribute to building capacity of the profession of social work in Eswatini, and thereby contribute to improving the role of social workers when dealing with the needs of persons affected by ASD.

**Ensuring a Stronger Future Relative to ASD**

The multisystemic approach recognises that care demands on parents of children with ASD call for supportive engagement and assistance. A study in Ghana documented the most commonly reported service needs of parents with children diagnosed with ASD, which included speech therapy, teacher education, parent or family training and behavioural management (Thomas, Badoe, and Owusu 2015). Efforts are being made in Eswatini to accommodate the needs of these parents. For example, Dlamini (2012) and Khoza (2018) noted that consideration of the multifaceted needs associated with ASD is further evidenced by increasing momentum in print media. The commitment in Eswatini to deal with the needs of individuals with ASD is not only internally driven, but is also reflective of the ratification of the 1995 Convention on the Rights of the Child and the signatory of the United Nations Convention on the Rights of Persons with Disabilities of 2012. Moreover, the Persons with Disabilities Act was endorsed by Parliament in 2018. Increasingly, we are recognising that an individual approach is insufficient as pervasive issues associated with a diagnosis of autism constitutes multifaceted and population-level "layers", requiring multisystemic approaches in moving to "real" and sustained change.

In this case, commitment on paper – if not accompanied by "on the ground" implementation across sectors and systems – risks impeded progress. Fortunately, real change has occurred, yet must continue. For instance, relative to earlier times in Eswatini and other world regions, erroneous myths about ASD are increasingly being demystified and debunked, with greater awareness about the causes and challenges of ASD and the needs of autistic people, particularly in schools (Laitila 2018; Mthombeni and Nwoye 2017; Ruparelia et al. 2016). In Eswatini, teachers and parents are becoming more knowledgeable about the needs of children with ASD. A small number of schools have established a special education support strategy for children with ASD. Nationally based education policy is under review to better accommodate the needs of persons with disabilities (Mtshali 2018). The profession of social work has contributed to these important changes and will need to continue to advocate future professional development and training to implement these policies into practices that make a difference in the lives of persons with ASD.

## Discussion

As demonstrated in this review, initiatives for ASD capacity advancement made by government and other stakeholders in Eswatini, reflect a mutual aim to achieve better options and outcomes for individuals with ASD and their families. Figure 1 depicts these steps forward. On the left side of Figure 1, we note increasing recognition of the need for community-based and system-wide capacity development. Towards that aim, as depicted in the centre of Figure 1, specific capacity-building elements have been undertaken to realise sought-after ASD capacity in Eswatini. It appears that vision and

substantial efforts are underway, resulting in strides forward relative to collective advancement.

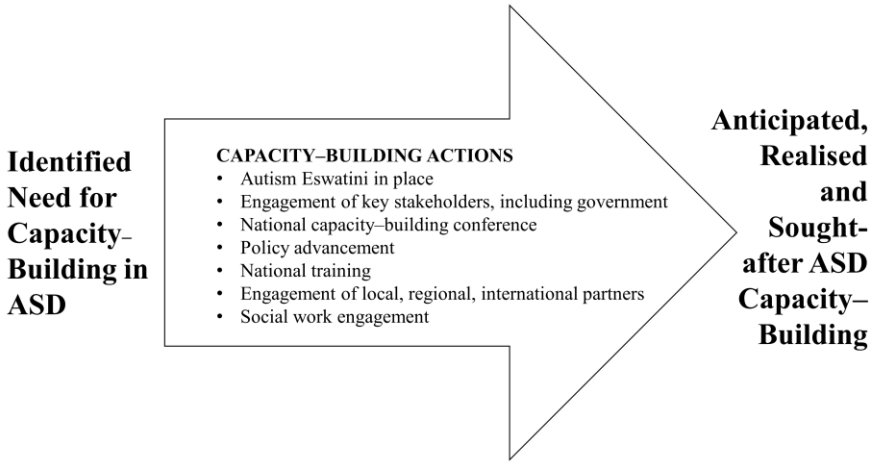


**Figure 1:** Capacity-building efforts underway

Although gains have been realised, challenges remain. Individuals diagnosed with ASD face vulnerability and continue to be at risk, particularly if they lack sufficient opportunity for integration and social protection. Such gaps, vulnerability and a lack of sufficient support heighten concern over potential societal exclusion, risk for abuse and human rights violations, continued family struggles, restricted availability of services, and thus diminished individual and family quality of life.

Policy gaps, which were particularly observed in the Education and Training Policy of Eswatini (Mtshali 2018), identify the need for proactive shifts, including a policy-based framework ensuring holistic and integrated approaches redressing the challenges of individuals with ASD and their families. Such a framework could inform strategies to support persons with ASD and their families, and offer guidance for generating local and regional knowledge and resources. Priority areas of potential action and innovation could include education, employment, housing, health, social care and legal services. Policy and service inclusiveness is critical to improving experiences and outcomes. Accordingly, capacity-building must honour individuals with ASD and their families through upholding their rights, ensuring sufficient resources, and building a societal ethos of acceptance, inclusion and support; thus enacting gains across systems.

## Conclusion

ASD capacity advancement has emerged in Eswatini, yet continues to be needed at micro-, meso-, exo- and macro-system levels. This reflection article invites consideration of steps taken (in looking back) as well as strategy development (in looking forward) in the ultimate aim of advancing national ASD infrastructure and community service capacity. Systemic effort, as presented here, seems integral to the aim of optimal quality of life – a state of well-being that indeed is deserved by individuals affected by ASD and their families.

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