

## Understanding the Experiences and Support Needs of Young People with Autism in St. Kitts and Nevis

A Short Review by Wendy Spas, MPH Student, St George's School of Medicine, prepared for Lake Health and Wellbeing

Autism spectrum disorder is a lifelong neurodevelopmental condition that affects how individuals communicate, interact socially, process sensory information, and experience the world around them (National Institute of Mental Health, 2024). Globally, autism is now recognised as an important public health and social inclusion issue affecting children, adolescents, and adults across all regions. Recent global estimates suggest that approximately 1 in 100 to 127 people worldwide were on the autism spectrum in 2021, with relatively little regional variation in prevalence (Santomauro et al., 2024; Zeidan et al., 2022). Importantly, autism has also been identified as one of the leading contributors to non-fatal health burden among people younger than 20 years, underscoring the importance of early recognition, appropriate support, and sustained attention to the needs of young people with autism (Santomauro et al., 2024; Lin et al., 2025).

Despite the global relevance of autism, the evidence base remains uneven. Much of what is known about autism prevalence, diagnosis, support needs, and interventions comes from high-income countries, while low-resource, small-island, and culturally diverse settings remain underrepresented in autism research. Durkin et al. (2015) noted that although most autistic individuals live outside North America, Europe, and Japan, these regions have historically contributed the majority of autism epidemiologic research. Elsabbagh et al. (2012) similarly emphasised that the lack of evidence from much of the world creates a critical need for further autism research and capacity-building in underrepresented settings. This imbalance matters because autism-related tools, services, and interventions developed in one cultural or resource context may not fully reflect the realities of another. In small-island settings such as St. Kitts and Nevis, local evidence is therefore essential to understand how autism is recognised, discussed, supported, and experienced within the country's own educational, healthcare, family, and community systems.

Young people with autism commonly face challenges that can affect their education, mental health, social inclusion, family life, and transition into adulthood. International qualitative research has documented experiences of loneliness, bullying, sensory overload, feeling misunderstood by teachers, and distress within mainstream school environments (Goodall, 2018). Broader reviews of inclusive education for students with autism have also identified alienation, unmet needs, limited professional development, and insufficient autism-specific strategies as barriers to meaningful inclusion (Petersson-Bloom & Holmqvist, 2022). Teachers and school staff may support the idea of inclusion but still lack the confidence, training, resources, or environmental supports necessary to effectively meet the needs of students with autism (Cook & Ogden, 2021; Hasson et al., 2022). These educational challenges are especially relevant when considering adolescents and young adults, because school experiences can shape confidence, social development, future employment opportunities, and overall wellbeing.

Mental health and quality of life are also major concerns for young people and adults with autism. Crane et al. (2019) reported that children and adults with autism experience high rates of mental health difficulties, particularly anxiety and depression, and that young adults with autism often describe poor quality of life, low confidence, and difficulty accessing appropriate

support. Mason et al. (2018) found that quality of life among adults with autism is often lower than in the general population and is positively associated with factors such as support, employment, and relationships. These findings suggest that autism support should not be limited to diagnosis or childhood services alone. Instead, support must address the broader social, emotional, educational, and community conditions that influence wellbeing across adolescence and young adulthood.

Barriers to appropriate care and support are especially concerning in settings where autism-related awareness, services, and professional training may be limited. International research has identified stigma, low awareness, lack of or long waiting times for autism-specific support, and services that only respond once individuals are already in crisis as major obstacles to care (Crane et al., 2019; Divan et al., 2021). In low-resource settings, additional barriers may include limited diagnostic capacity, a shortage of trained specialists, lack of adapted screening tools, and systems that are not designed to provide scalable community-based support (Divan et al., 2021; Naithani et al., 2022). Without local research, it is difficult to know how these global patterns appear in St. Kitts and Nevis, what barriers are most urgent, and what types of support young people and families would find acceptable, realistic, and meaningful.

In St. Kitts and Nevis, Phase 1 of Lake Health and Wellbeing's Autism Project found that general autism awareness exists, but misconceptions, stigma, and support gaps remain. In the public survey of 108 respondents, 93.52% had heard of autism, yet 25.93% believed autism can be cured, 20.37% did not agree that autism is a lifelong condition, and some responses used stigmatising or demeaning language. Awareness of local support was also limited: 74% were unaware of local autism awareness initiatives, 61% were unaware of organisations providing autism-related support and information, and only 3.70% believed there was enough support available, while 75.00% believed there was not enough support (Lake Health and Wellbeing, 2025). The professional survey of 103 respondents showed similar capacity gaps: teachers made up 75% of respondents, 31% of professionals were not confident at all in their knowledge of autism characteristics and symptoms, only 26% had received autism training, only 17% had received evidence-based autism training, and 55% believed support was insufficient. These findings indicate that St. Kitts and Nevis faces not only an autism awareness challenge, but also significant gaps in support, training, service access, and coordination (Lake Health and Wellbeing, 2025).

However, Phase 1 did not directly capture the lived experiences of young people with autism themselves. This is a critical gap. Public and professional perceptions are important, but they cannot substitute for hearing directly from young people with autism about their daily experiences, barriers, strengths, priorities, and support needs. Without this local lived-experience evidence, policies, programmes, advocacy campaigns, and future services risk being shaped primarily by outside research or by the assumptions of adults and professionals rather than by the voices of the young people most affected. Research from other settings shows that people with autism and their families often experience stigma, exclusion, unmet support needs, and systems that are not designed around their realities (Botha et al., 2020; Han, Scior, et al., 2021; Han, Tan, et al., 2021). St. Kitts and Nevis now needs locally grounded evidence to understand whether and how these issues are experienced by adolescents and young adults with autism in its own context.

This proposed Phase 2 project responds to that gap by seeking funding to conduct a mixed-methods research project on the experiences of young people aged 13–30 who are living with autism in St. Kitts and Nevis. The project will explore their lived experiences, support needs,

barriers, priorities, and perspectives on inclusion, while also gathering insight from parents, carers, educators, healthcare providers, and other relevant stakeholders. In addition, the proposed autism open-mic night will provide a creative and engaging platform for young people with autism to express themselves, build visibility, and participate in autism awareness in a way that is not limited to formal research interviews or professional discussions.

If this issue is not addressed, St. Kitts and Nevis may continue to rely on limited public awareness, insufficient professional training, and imported assumptions about autism that may not reflect local realities. Young people with autism may remain underserved in schools, healthcare settings, employment preparation, family support systems, and community life. Families may continue to face uncertainty about where to seek help, and professionals may remain without the training and resources needed to provide effective support. By generating local evidence and creating space for expression amongst youth with autism, this project will provide a foundation for more informed advocacy, better-targeted services, future funding proposals, professional training, public awareness, and policy dialogue in St. Kitts and Nevis.

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