



Autism Awareness and Understanding in St. Kitts and Nevis: Perspectives from the Public and Professionals

1. Introduction

Autism Spectrum Disorder (ASD), a complex neurodevelopmental condition, presents unique challenges for individuals living with it and their families. In recent years, there has been a growing recognition of the need for heightened awareness, understanding, and support for ASD globally. This recognition is particularly crucial in regions with limited information and resources, such as the Small Island Developing States (SIDS) like St. Kitts and Nevis.

ASD is characterised by a wide range of symptoms, but it primarily affects an individual's behaviour and how they learn and communicate. It is a lifelong condition, and while there is no known cure, early intervention and appropriate support can significantly enhance the quality of life for individuals with autism.

In St. Kitts and Nevis, we have observed that individuals with autism and their families confront significant challenges. Scarce access to information and resources intersects with societal stigma, leading to isolation and exclusion.

A lack of awareness and knowledge about autism exacerbates the difficulties faced by those with autism. This leads to delayed diagnoses, inadequate access to specialised therapies and interventions, and a shortage of educational opportunities tailored to the needs of individuals with autism. The scarcity of information and educational opportunities can also fuel societal stigma, causing misconceptions about autism to persist, leading to discrimination and a lack of inclusion in community life.

While we have made the above anecdotal observations of these issues, we are committed to conducting systematic research to characterise these challenges quantitatively and qualitatively. We aim to provide key stakeholders, such as the St. Kitts Spectrum Services Centre, the Ministry of Education and the Ministry of Health, with data and evidence. This data we hope will empower decision-makers to develop effective solutions and advocate for policies that safeguard and support individuals with autism.

To initiate this work, we launched two distinct autism awareness surveys: one tailored for professionals and another for the public. These surveys will inform our future mixed-method in-depth autism research project.

This work is important because, beyond the immediate impact on individuals and families, a compelling ethical imperative exists to direct more attention to autism. The principles of justice, equity, and inclusivity demand that societies address the unique needs of all their members. Neglecting to prioritise autism represents a failure to uphold these principles. Moreover, as a society, we must recognise that the potential of individuals with autism is vast and diverse, and by investing in the support and wellbeing of those with autism, we can tap into their unique talents and contributions. Ignoring autism not only deprives individuals of opportunities but also deprives society of their potential contributions.

This report summarises the findings from both our public and professional surveys and provides recommendations that policymakers, the private sector, civil society and the public can consider to ensure a more inclusive society for people with autism.

2. Objectives

The Professional Autism Survey was designed for professionals whose roles may involve interacting with, supporting, or providing services to individuals with autism. Our objective was to gather general insights into professionals' experiences when engaging with individuals on the autism spectrum. We sought to explore their perspectives on the current state of autism care, support and knowledge, pinpointing training needs for professionals, and evaluate the demand for increased support and awareness initiatives concerning autism.

The Public Survey, on the other hand, aimed to gauge the level of awareness among the public regarding autism. By garnering insights from the broader community, we hoped to achieve a good basic understanding of the prevailing perceptions and knowledge gaps related to autism in our society.

3. Methodology

A combination of purposive and convenience sampling methods was used to recruit participants for the public and professional surveys. Purposive sampling involves the selection of individuals based on specific criteria. In this study, the criteria used were:

- For the public survey, adults aged 18 or older residing in St. Kitts and Nevis.
- For the professional survey, adults aged 18 or older working in St. Kitts and Nevis in fields where they are likely to encounter individuals living with autism.

Convenience sampling, on the other hand, selects individuals based on their willingness and availability to participate.

This combined approach aimed to include adults from diverse backgrounds and age groups to provide a comprehensive representation of the population of St. Kitts and Nevis.

A sample size of 382 participants was calculated for the public survey to achieve a 95% confidence level with a 5% margin of error. However, due to recruitment challenges, the survey was completed by 108 respondents. For our professional survey, 103 people completed the survey.

The data were collected between January and September 2024 and analysed using Excel, Kobo Toolbox, and NVivo, enabling both quantitative and qualitative insights to be extracted

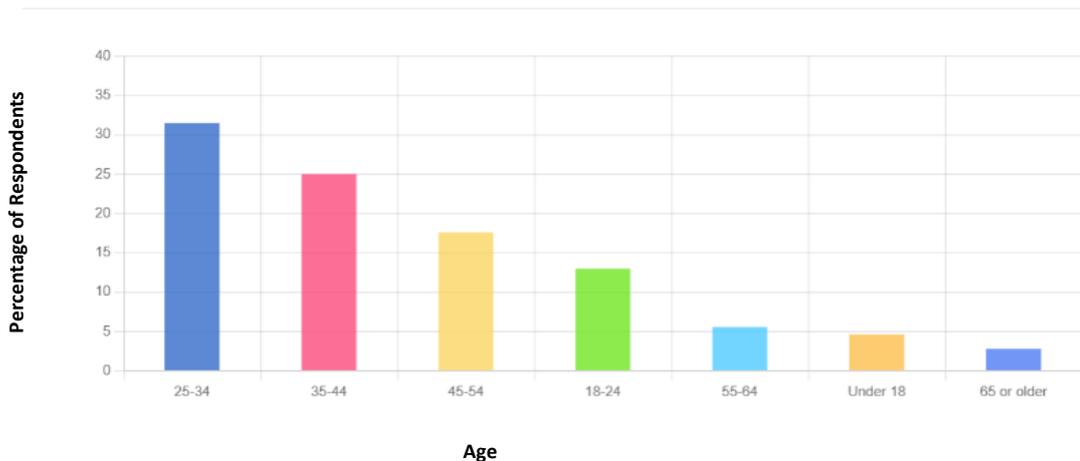
Data collection only commenced once ethical approval was obtained from the Ministry of Health’s Interim Ethics Review Committee. This was granted on 29th November 2023 (IERC-2023-11-065).

4. Results and Discussion

4.1. Public Survey

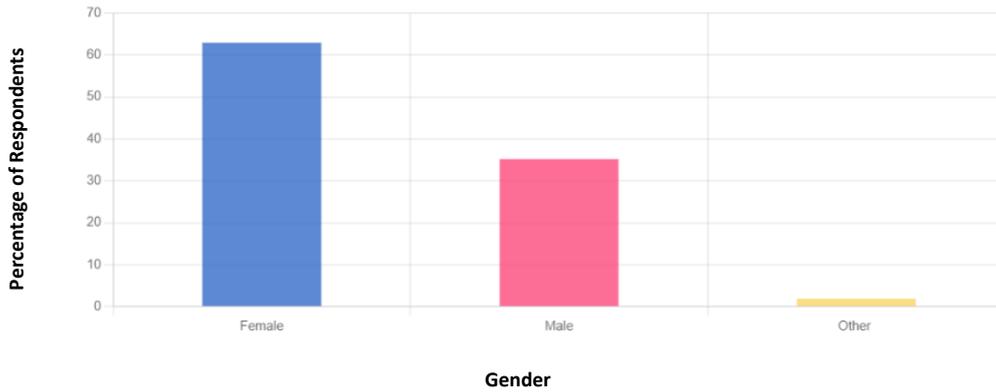
4.1.1. Survey Population

The survey population consisted of a diverse group of 108 respondents. In terms of age distribution, the majority fell within the 25-34 and 35-44 age ranges. Specifically, 31% were aged 25-34, and 25% were aged 35-44. The 45-54 age group also has a substantial representation at 17%, while the 18-24 age group constitutes about 13% of the respondents. Smaller percentages are observed in the 55-64 (6%) and 65 or older (3%) age brackets, with the under-18 category representing approximately 5%.



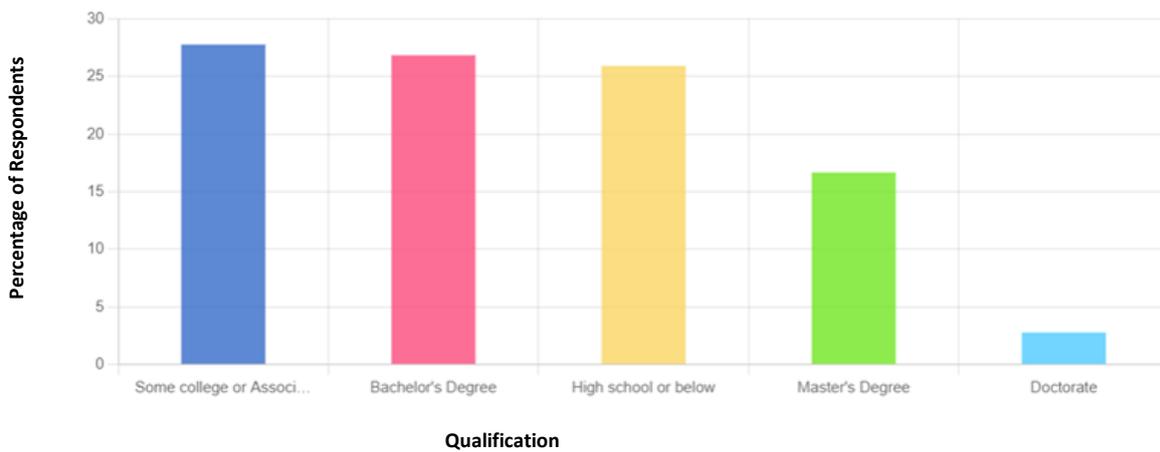
Graph 1: Age Distribution of Survey Respondents

Gender distribution shows that females were the predominant gender in our sample, making up about 62% of the respondents. Males did have a significant representation at around 35%. A small fraction, approximately 2%, identified as 'Other'.



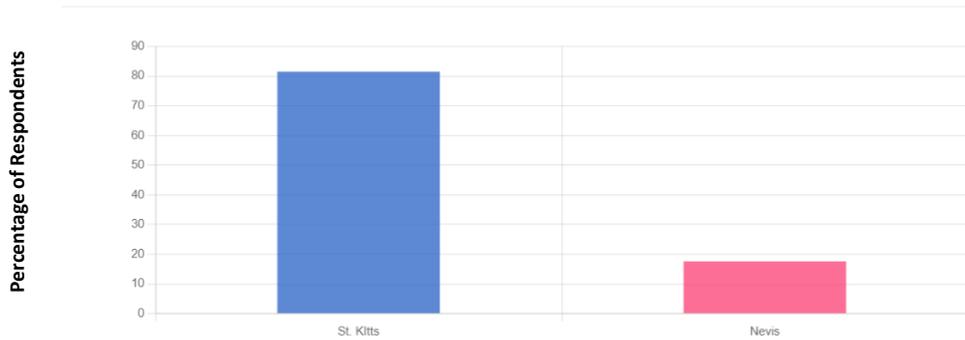
Graph 2: Gender of Survey Respondents

Regarding educational attainment, about 28% reported completing some college or holding an associate’s degree, while those with a bachelor’s degree represent around 27%. Respondents with a high school education or below constitute approximately 26%, those with a master’s degree account for about 17% and those with a doctorate, about 3%



Graph 3: Educational Attainment of Survey Respondents

Geographically, most respondents, around 81%, reside in St. Kitts. This percentage is reflective of the population distribution of St Kitts and Nevis – census data indicates that 80% of residents live on St Kitts and 20% on Nevis.

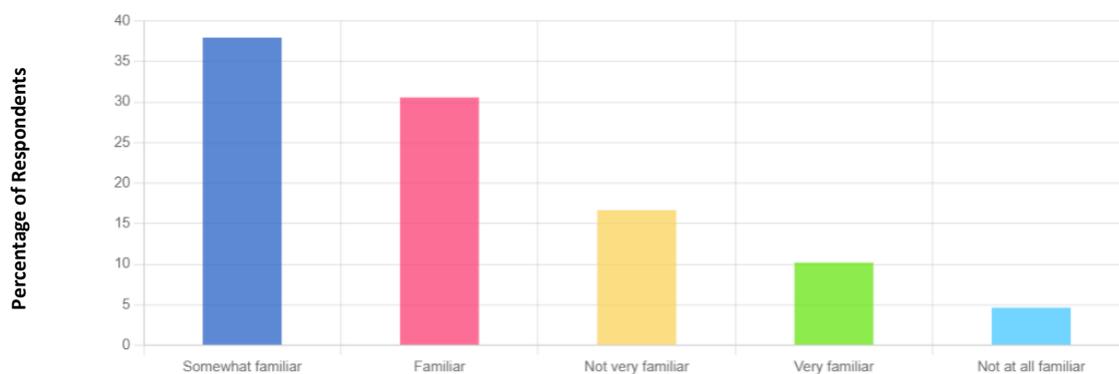


Graph 4: Island of Residence of Survey Respondents

This demographic breakdown highlights a varied and educated survey population of predominantly young adults.

4.1.2. Awareness of Autism

- **General Awareness of Autism:** 93.52% of respondents had heard of autism before the survey, indicating high awareness levels.
- **Gender Breakdown of Awareness:** 95.59% of females and 89.47% of males had heard of autism before this survey
- **Age Demographics of Awareness:** 100% awareness was observed in the age groups 18-24, 55-64, and 65 or older. The lowest awareness was in the age group under 18, with 80% having heard of autism.
- **Familiarity with autism characteristics and symptoms:** Most respondents are either familiar or somewhat familiar with the characteristics and symptoms of autism.



Graph 5: Familiarity With the Symptoms of Autism

As part of the survey, respondents were asked to provide their definition of autism to allow people to use their language and phraseology to describe autism so that we can pick up any beliefs, the level of accuracy and potential nuances around people's ideas of what autism is. When analysing the data, three themes around definitions emerged. These were:

1. Medical and Scientific Descriptions:
 - Neurological Condition
 - Developmental Disorder
 - Spectrum Disorder
2. Symptom Descriptions:
 - Communication Issues
 - Learning Challenges
 - Functional Impairments
3. Uncertain or non-responses

Summary of Respondents' Definition

- **Medical and Scientific Descriptions:** Most definitions include accurate medical and scientific terms, describing autism as a neurological, developmental, or spectrum condition and seem to have a good general understanding of what autism is.
- **Symptom Descriptions:** Many respondents correctly identify communication and learning challenges, although these are only part of the broader autism spectrum. Also, describing behaviours solely as one behaviour, for example: "difficulty coping with changes" and "repetitive behaviours" without context, can perpetuate misconceptions about the nature of these behaviours and how common they are.
- **Uncertain or Non-Responses:** A notable number of respondents are unsure or did not provide an answer (16%), indicating gaps in awareness or understanding.

Assessing Accuracy and Stigma

Accuracy:

- Definitions mentioning "neurological condition," "developmental disorder," and "spectrum disorder" align well with scientific understanding.
- The language used is mostly clinical, though there are variations that suggest different levels of familiarity with autism.
- References to just "communication issues" and "learning disability" are partially accurate but may oversimplify the range of symptoms and behaviours associated with autism.

Stigma:

- There is some evidence of stigma in the sampled responses. The use of terms like "mental deficit" and later in the survey "disgusting", and "can't deal with them as a

normal child” might reflect some underlying negative societal attitudes towards autism.

To continue the assessment of their level of awareness of autism we asked respondents to identify whether certain statements about autism were true or false. These were statements that anecdotally are thought to be common misconceptions locally. The results are as follows:

- **Autism caused by bad parenting or neglect:** 94.44% false, 5.56% true
- **Autism is a lifelong condition:** 77.78% true, 20.37% false
- **Autism affects only children:** 91.67% false, 8.33% true
- **Autism can be cured:** 74.07% false, 25.93% true

The majority correctly identified that autism is not caused by bad parenting or neglect and that it affects adults too, not just children. However, there are some misconceptions, particularly regarding whether autism can be cured, with a significant percentage of respondents (26%) believing that autism can be cured and a significant proportion of respondents (20%) disagreeing that it is a lifelong condition.

Overall, the responses in this section indicate a good level of awareness and understanding of autism, but some areas reflect common misconceptions or incomplete knowledge. To address this, efforts to improve public understanding could focus on the diverse experiences of individuals with autism and the range of abilities they may possess, as well as clearing up any of the identified misconceptions.

4.1.3. Perception of Individuals with Autism

Common perceptions include viewing individuals with autism as unique (71%), in need of special care (61%), capable (51%) and highly intelligent (49%). The perceptions were captured in multiple categories, with many respondents selecting multiple options.

Other perceptions:

- “They are lovely”
- “Withdrawn, not very friendly, very fixated on one thing”
- “Not understood.”
- “Disgusting, time-consuming, need a lot of patience, can't deal with them as a normal child. Need more kindness”
- “No connection between 12 pairs of cardinal nerves in the brain”
- “Every person with Autism is different”

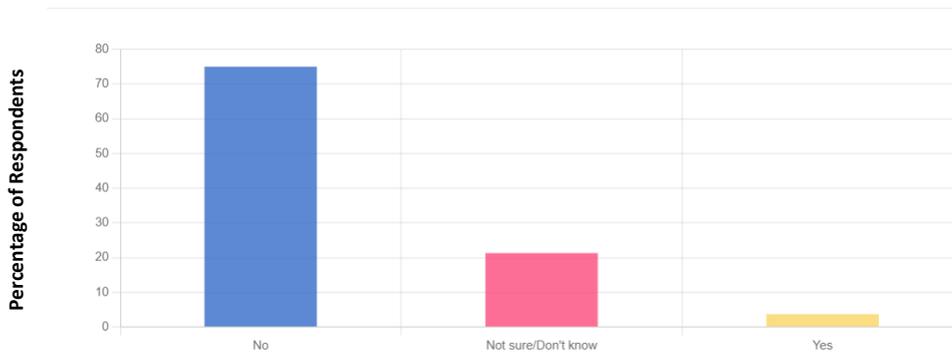
From this information, we can see that overall, respondents' perceptions of people living with autism varied, with the recognition that special care is required. The use of some negative language and the misconceptions identified in previous questions to define autism demonstrate the need for educational work to provide a more rounded and complete picture of autism so that the wider public has a more accurate view. Focus should be placed

on teaching the public to use more inclusive and sensitive language to create a more supportive and informed community. The need to raise public awareness and improve knowledge was highlighted in the next question. In this question, respondents were asked if they were aware of any local initiatives raising awareness of autism, and 74% of respondents said no.

4.1.4. Support and Information

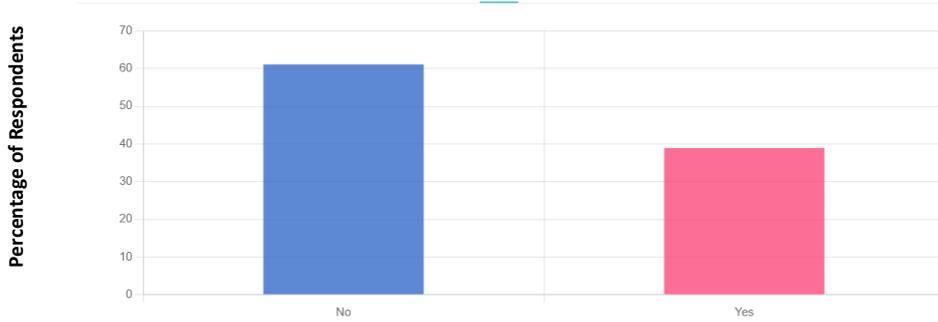
Support

- Only 3.70% of respondents believe there is enough support available for individuals with autism in St. Kitts and Nevis. 75.00% believe there is not enough support, 21.30% are unsure.



Graph 6: Perceptions of if there is enough support in St. Kitts and Nevis

Respondents were then asked if they were aware of any organisations in St. Kitts and Nevis that provide support and information as it relates to autism, 61% said no, and 38% said yes. Of those who were aware of local organisations providing information and support, the most commonly identified organisations were the St. Kitts Spectrum Services Centre and Cotton Thomas Comprehensive School. Additionally, Ade’s Place, Cecele Brown Integrated School and the Child Protection Service were identified. The fact that a majority (61%) were unaware of what organisations provide information and support suggests a significant gap in public knowledge that needs to be addressed. Efforts should be made to improve awareness of the available support and information resources for autism.



Graph 7: Respondents who were aware of organisations providing support in St. Kitts and Nevis

Having recognised, from respondents, that people living with autism do not have enough support in St Kitts and Nevis, to confirm if there is a need for support, we explored whether respondents believed individuals with autism face challenges in their daily lives. A significant number, 94.44%, believe that individuals with autism face challenges in their daily lives, highlighting a significant perceived need for support, while 0.93% do not believe this to be the case. Additionally, 4.63% were unsure.

Percentage of Respondents

Graph 8: Respondents belief that people living with autism face challenges in their daily lives

Those persons who identified that persons living with autism face challenges in their daily lives, were asked to reflect on what they thought those challenges were. A thematic analysis of their responses revealed the following themes:

- Communication and Social Challenges
 - *"Difficulty understanding and being understood, challenges associated with interpersonal relationships."*
 - *"Challenge communicating their needs, challenge socializing with others."*

- Sensory and Behavioural Challenges
 - *"Some individuals suffer with sensory issues, problems with loud noises, and bright lights."*
 - *'Sensitivity to touch and noise.'*
- Daily Life and Functional Challenges
 - *"Functioning normally in society. Ability to perform everyday tasks independently."*
- Stigma and Discrimination
 - *"Being misunderstood by others and facing stigma in social settings."*

"People often see them as less capable or burdensome."

"Access to jobs and education opportunities."

Some responses indicate an awareness of the stigma faced by individuals with autism, but others may inadvertently reinforce ideas that may lead to stigma and discrimination. For example:

- *"Disgusting"*
- *"Time-consuming"*
- *"Need a lot of patience"*
- *"Can't deal with them as a normal child"*

Summary of the Public's View of the Challenges that People Living with Autism Face

The public recognises the communication, social interaction, sensory and behavioural challenges faced by individuals with autism. Respondents understand the practical difficulties in daily life, including employment and education. Acknowledgement of stigma and discrimination highlights awareness of societal challenges but also reveals the need for public education that could reduce misconceptions and promote inclusion.

While many challenges are accurately identified, some language and descriptions could perpetuate misconceptions or fail to capture the full spectrum of autism. Overall, the public appears to have a fairly accurate and possibly empathetic understanding of the challenges faced by individuals with autism.

When we combine this information about the challenges with the fact that respondents also felt that there is not enough support for people living with autism and there was a lack of awareness of existing support services, we can conclude that there is a need for expanded, continued and enhanced support to address these challenges and improve the quality of life for individuals with autism. Furthermore, an emphasis needs to be placed on raising

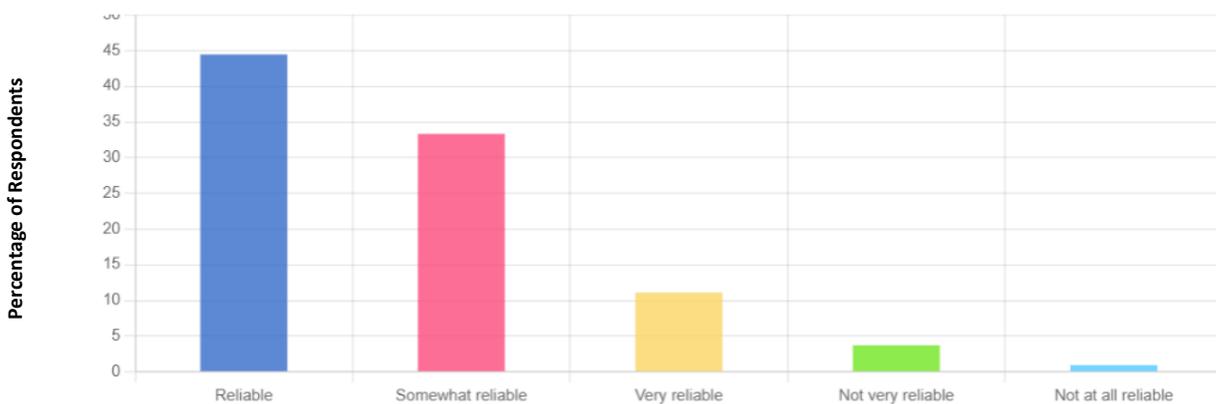
of
that
exist



awareness
the services
currently
so that
those
affected by
autism can
access
these
services
now.

Sources of Information about Autism

The majority of respondents obtain information about autism from internet resources (64%). It appears that people are not obtaining information from official local sources like healthcare professionals (only 22%) and through the educational system (32%). Other ways that people are accessing information are from conversations with family and friends (41%) and the media (32%). This indicates that there is significant scope for the healthcare and educational communities to intervene and provide authoritative, trusted, and accurate information on autism as when asked to assess the reliability of the information they received from these sources, 44% of respondents stated that they thought the information was reliable, 33% believed it was somewhat reliable, and only 11% considered it very reliable. This suggests that there may be a need to improve the quality of the information the public is accessing about autism.



Graph 9: Respondents Perception of the Reliability of the Information They Access

4.1.5. Additional Comments and Insights

Finally, we asked respondents if they had any additional information and insights that they would like to share about autism. The answers they provided could be divided into the following categories:

Awareness and Education

- Some respondents noted the need for increased awareness and education about autism. Specific suggestions on how the education could be delivered included creating workshops, having more conversations and informational sessions, and educating society through TV and social media.
- There was recognition of the need for the enhancement of the social media presence of organisations working on autism, so the public is aware of the presence of these organisations

Support and Integration

- Respondents highlighted the need for better integration of individuals with autism into workspaces and community activities
- There is a need for more programs, activities, resources and information tailored to support people living with autism to help them thrive

Government and Institutional Support

- Several comments called for increased government action and support, including financial assistance and the creation of more autism projects
- It was highlighted that training of teachers was needed so that teachers can better understand and support their students
- It was suggested that school children needed some sensitisation, so they know how to interact with those children who are living with autism
- It was suggested that school programs be developed that empower children living with autism

Parental Support

- There was recognition that parents of children living with autism need support, resources, and training to help them better manage and understand their children's needs.

Misconceptions and Stigma

- Respondents noted that misconceptions and a lack of conversation about autism lead to stigma.
- Respondents also highlighted the need to use more compassionate language and for society to be more understanding

4.1.6. Recommendations

Based on our findings, we offer the following recommendations

Awareness and Education

- An autism awareness and education programme is necessary to provide the public with a more rounded and comprehensive picture of autism. Such a programme should focus on teaching the public about the diverse experiences of individuals with autism and the range of abilities they may possess. A campaign or programme that effectively communicates an empowering message about people living with autism with the realities and challenges they face is recommended. The programme should also educate the public on using more inclusive and sensitive language to create a more supportive and informed community.

Addressing Support Gaps

- There is a need for expanded, continued and enhanced support to address the challenges that people living with autism face and to improve their quality of life.
- In the short term, emphasis should be placed on raising awareness of the services that currently exist so that those affected by autism can easily access these services now.
- Support needs to be holistic, and multiple sectors need to be engaged to ensure that they can adequately support people living with autism. This includes working with employers and schools to build the capacity of their staff and teachers so that people with autism can thrive both in the workplace and school environment.
- Support should be developed for parents of children living with autism in the form of emotional support, resources, and training to help them better manage and understand their children's needs.

Information

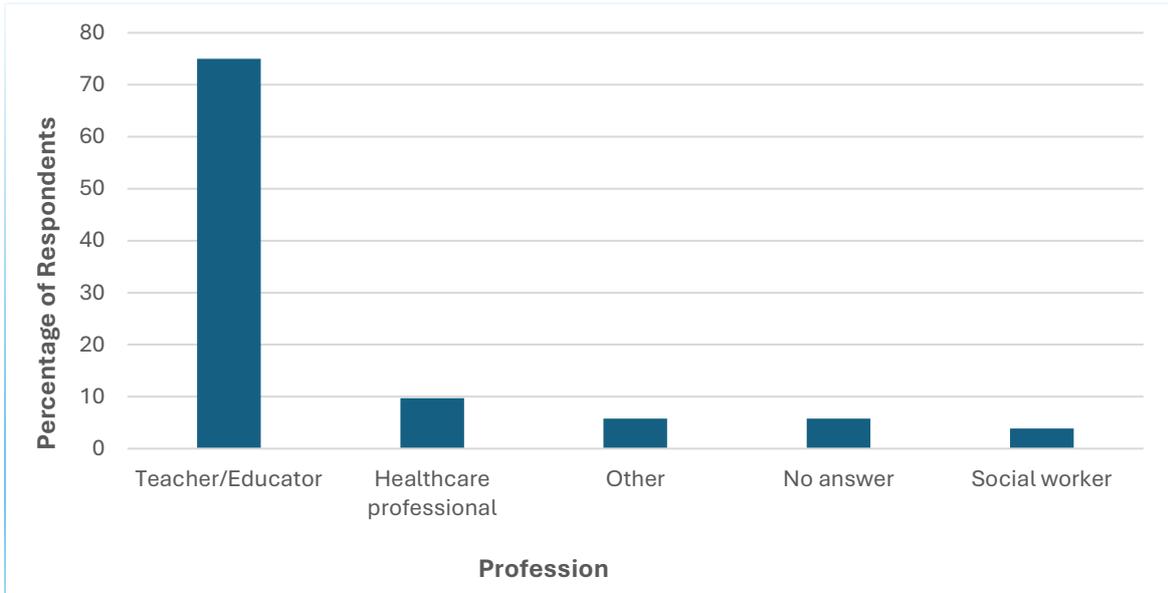
- High-quality, accurate, easy-to-understand, culturally relevant information about autism should be developed
- Local healthcare professionals and the education sector should play a prominent role in providing authoritative, trusted, and accurate information on autism

4.2. Professional Survey

4.2.1. About the Respondents

Profession

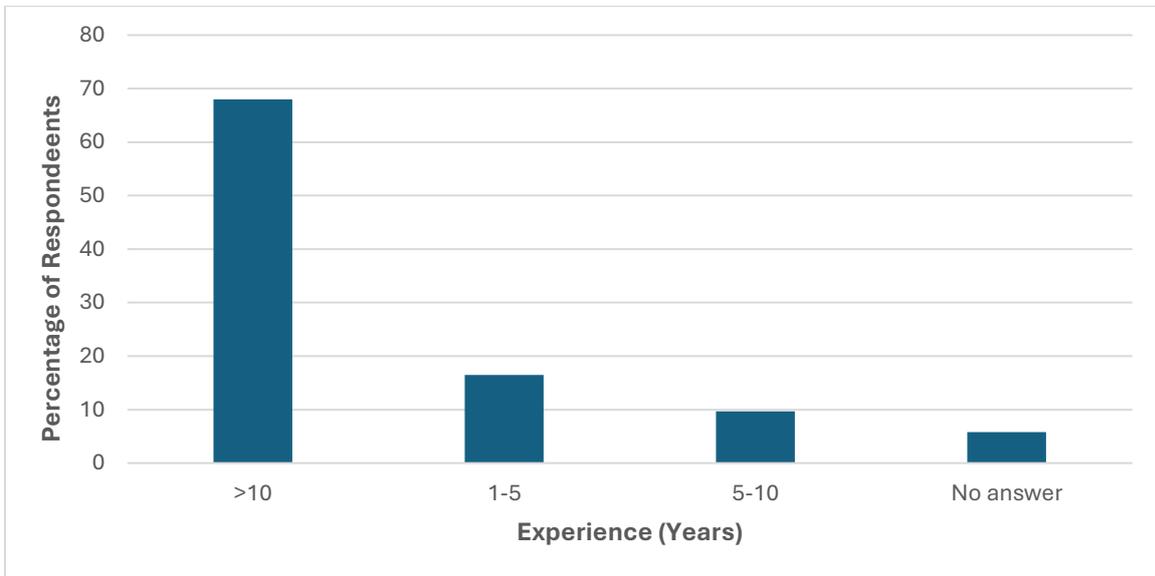
103 individuals completed the professional questionnaire. Among them, 75% were teachers, 9.7% were healthcare professionals, 4% were social workers, 5.8% selected 'other,' and 5.8% did not respond to this question. The significant representation of teachers reflects good engagement and support from the Ministry of Education.



Graph 10: Profession of Survey Respondents

Experience

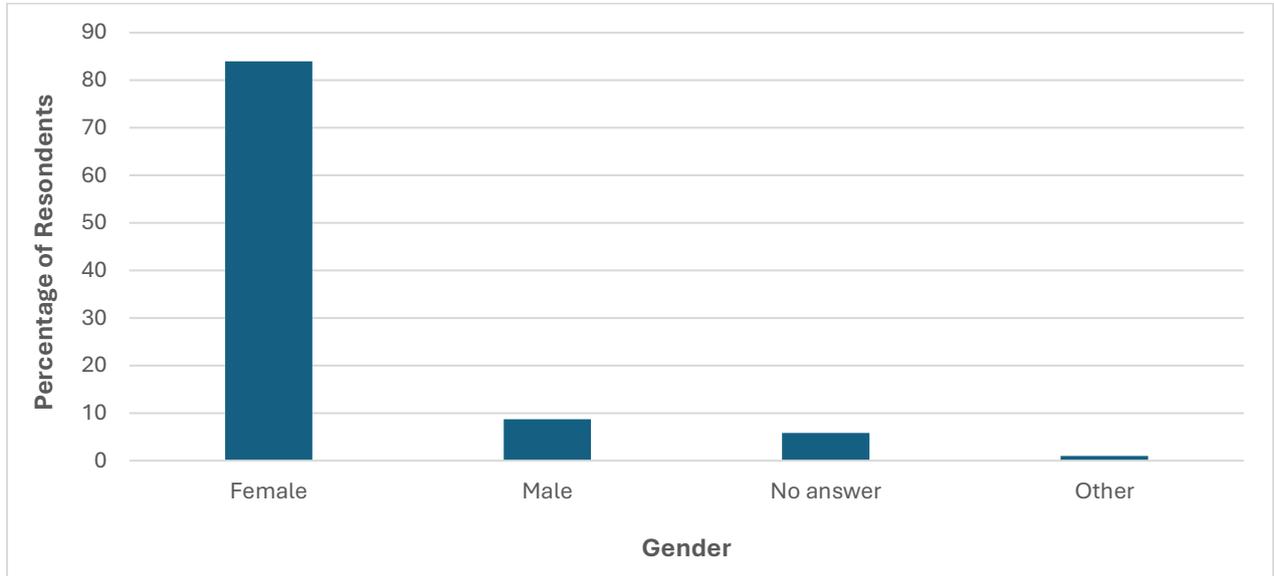
The professionals who completed the survey were highly experienced in their respective fields, with 68% having over 10 years of experience and 9.7% having 5–10 years of experience. Additionally, 16% were relatively early in their careers with 1–5 years of experience, while 5.8% did not respond to this question.



Graph 11: Professional Experience of Survey Respondents

Gender

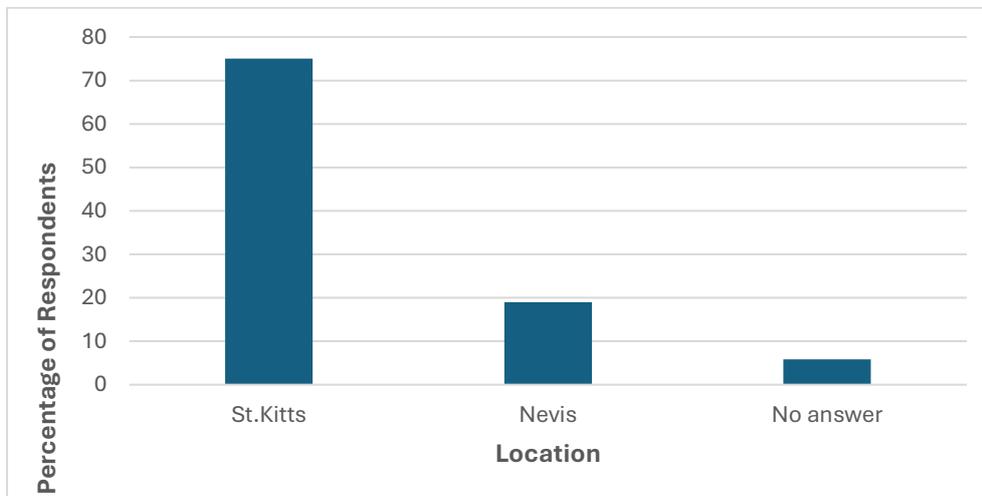
Examining the gender breakdown of respondents, the majority were female, reflecting the predominantly female composition of the teaching profession, which formed the largest group of respondents. In total, 84% of respondents were female, 9% were male, 1% identified as 'other,' and 5.8% did not respond to this question.



Graph 12: Gender of Survey Respondents

Location

Regarding geographic location, 74% of respondents were based in St. Kitts, while 19% were in Nevis, and 5.8% did not respond. This distribution aligns with the National Census, which indicates that 80% of the population of St. Kitts and Nevis resides on St. Kitts, and 20% on Nevis.



Graph 13: Location of Survey Respondents

4.2.2. Knowledge of Autism

As with the public survey, we asked professionals completing the survey how they would define autism. Most respondents described autism as a developmental or neurological condition affecting behaviour, cognition, learning, communication, social interaction, emotional wellbeing and sensory processing. Some also described autism as a spectrum condition, highlighting that it affects individuals differently and can range from mild to severe.

Below are examples of how professionals define autism:

“Autism is a brain development condition that impacts how a person perceives and socializes with others, causing problems in social interaction and communication.”

“Autism is a complex neurodevelopmental condition that affects an individual's social interaction, communication, behaviour, and sensory processing.”

While the majority of respondents referred to autism as a condition, illness or disorder, some described it as a disability. These respondents used terms such as *“mental disability”*, *“differently abled”*, and *“developmental disability.”*

Some went on to note that autism is a condition that individuals are born with, cannot be cured and leads to those affected seeing and perceive the world differently.

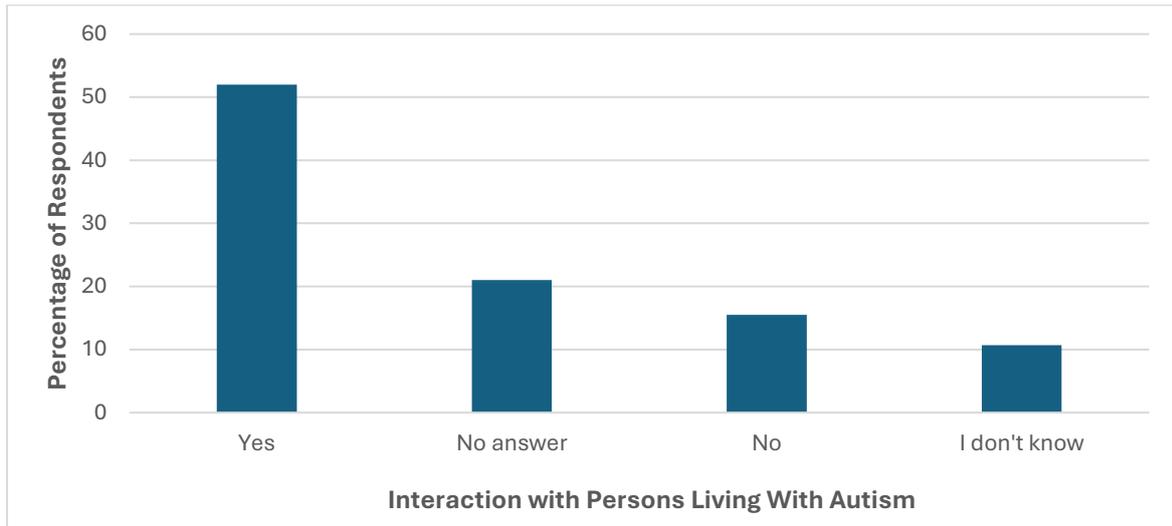
When assessing their confidence in their knowledge of the characteristics and symptoms of autism, respondents reported varying levels of confidence. Among them, 32% felt somewhat confident, 31% were not confident at all, 20% felt confident, 14% did not respond, and 4% reported feeling very confident.



Graph 14: Respondents' Confidence in their Knowledge of the Symptoms of Autism

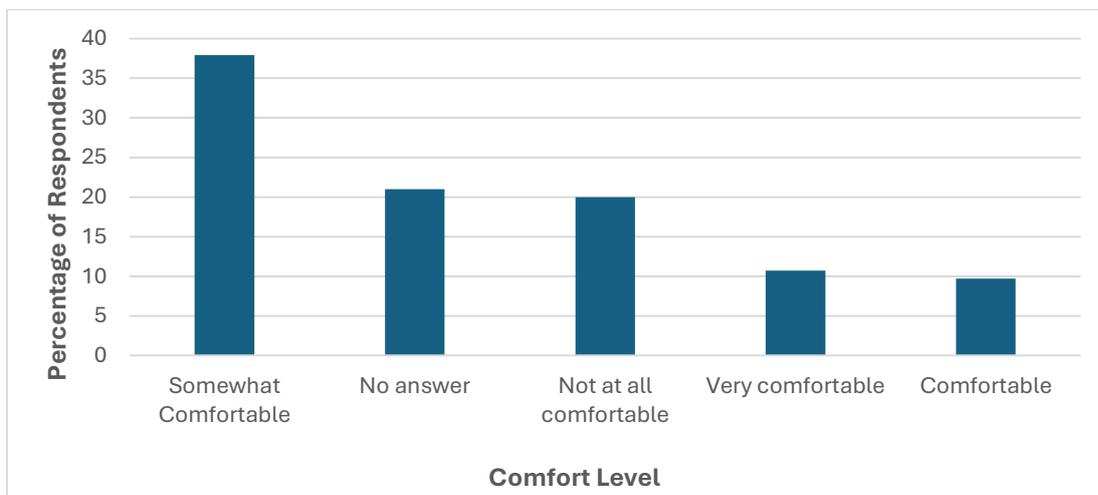
4.2.3. Experience with People Living With Autism

When asked whether they had interacted with individuals diagnosed with autism as part of their professional role, the majority of respondents (52%) said yes. Meanwhile, 16% said no, 11% were unsure, and 21% did not respond to this question.



Graph 15: Percentage of Respondents Who Have Interacted with a Person Living With Autism

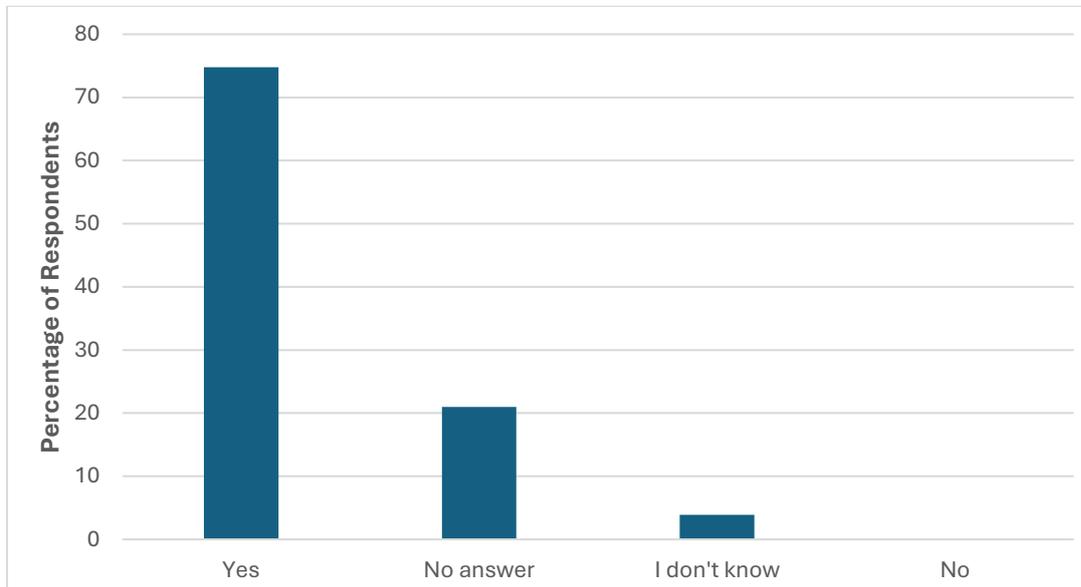
Respondents were asked how comfortable they felt supporting individuals with autism in their professional role. The majority (38%) indicated they felt somewhat comfortable, while 20% reported not feeling comfortable at all. Additionally, 11% felt very comfortable, 10% felt comfortable, and 21% did not respond to this question.



Graph 16: Respondents' Level of Comfort When Supporting Individuals Living With Autism

4.2.4. Views on Support Available for People Living With Autism

When asked whether they believed individuals living with autism require unique support strategies compared to those without autism, 75% of respondents said yes, none said no, 4% said they didn't know, and 21% did not respond to the question.



Graph 17: Respondents' Perception of Whether People With Autism Require Unique Support

Type of Support Required

We then explored what types of support professionals felt were necessary for people living with autism. The responses from participants fell into three main categories:

- Exposure to trained professionals
- Personalised support
- A change in societal attitudes and behaviour

Access to Trained Professionals

Firstly, it was recognised that for people living with autism to thrive, they need support and guidance from trained professionals and there needs to be adequate human resources to enable organisations to address autism effectively. Specifically, respondents emphasised the importance of general training for professionals to enhance their understanding of autism and to develop the skills to manage, teach, guide and support individuals on the spectrum. It was felt that training should empower professionals to help individuals with autism to function effectively in society, so they are not excluded and isolated. Furthermore, it was felt that professionals should exhibit sensitivity, compassion, patience, understanding and the willingness to dedicate the time required to support people in their organisations who are living with autism.

Given that most respondents were teachers, many responses focused on educators. It was felt that all teachers should receive training on how best to teach children who are living with autism so that children can reach their full potential. It was also felt that some educators should become certified autism educators to provide more targeted and specialised support for students who require it. Respondents also stressed the importance of integrating students with autism into the formal education system to prevent exclusion and segregation.

Here are some quotes illustrating these points:

“All teachers to be trained and equipped to support their formal education within the regular school system, so they are not segregated and made to feel different all their lives”

“Provide effective training on how to teach students.”

“Educators who are certified to cater to them.”

“Teacher trained in dealing with or assisting the students who are on the spectrum”

Finally, a sentiment that was expressed was that certain educators might be better suited to supporting students with autism due to their temperament and natural affinity for the role. Based on this, it may be worth identifying such individuals and building their capacity to become specialised autism educators because, as one respondent put it:

“If your heart and mind is not into helping such individuals, then whatever support you're thinking about might cause more damage than help.”

[Personalised Support](#)

Respondents emphasised the importance of educators and professionals developing a comprehensive understanding of the needs of each individual with autism under their care. They believed that this understanding should guide the tailoring of support and learning strategies to address the specific needs of individuals living with autism. Achieving this, respondents noted, may require some one-on-one support to ensure adequate time is dedicated to understanding the type of environment that will be optimal for their learning and functioning. Furthermore, one-to-one attention offers the opportunity to deliver personalised interventions such as speech, occupational, and psychological therapy, as well as training in social, communication, and other interpersonal skills.

Examples of the perspectives shared by respondents are below:

“First, you have to fully understand how a person with autism reacts before you can support them.”

“Different forms of therapy such as speech, occupational and social.”

“One-on-one interaction.”

“One on one tutors.”

Additionally, respondents highlighted the need for practical day-to-day support for individuals living with autism. Suggestions included:

- Providing additional resources and learning aides, including technology-based solutions and visual aids
- Offering prompts to assist with completing tasks
- The development of a structured routine
- Allowing extra time to complete tasks
- Teaching coping skills
- Creating quiet spaces and quiet times to recover from overstimulation
- Ensuring an inclusive curriculum or work environment

This combination of personalised and practical support was seen as vital in helping individuals with autism navigate their daily lives and achieve their full potential.

[A Change in Societal Attitudes and Behaviour](#)

For people living with autism to succeed and apply what they learn from trained professionals and personalised support, it was recognised that society has a part to play by changing its attitudes and behaviour towards people living with autism. Respondents stated this requires campaigns to raise the public’s awareness of autism, the creation of a more inclusive society that embraces neurodiversity and addressing stigma. As one respondent stated, we need:

“General awareness of the nation especially those people who work in public service areas.”

[Level of Support in St. Kitts and Nevis](#)

Respondents were also asked if they thought there was sufficient support in St. Kitts and Nevis for people living with autism. The majority (55%) said no, 18% were unsure, 1% said yes, and 26% did not provide an answer.

4.2.5. Challenges When Working With People Living with Autism

We explored the challenges respondents have encountered when working with individuals living with autism. The challenges fell into two categories.

1. The challenges they observed in people living with autism
2. The challenges they faced when providing support.

Challenges Observed in People Living With Autism

The challenges observed in individuals living with autism can be further categorised into:

- Behavioural
- Academic
- Environmental
- Emotional

Behavioural Challenges

Regarding behavioural challenges, whilst some respondents did not specify the behaviours they observed, others highlighted issues such as tantrums, outbursts, aggressive behaviour, self-harming actions (e.g. hitting their head against a wall), mood swings, harming other children, disrupting classes, fixations (e.g. persistent need to stay clean). Respondents also mentioned difficulties in managing responses to certain triggers (noise, lights, etc) and the distress individuals experienced when they lacked the resources and tools to function and cope effectively.

Examples of some of their observations are provided below:

“Interrupts class, fidgets, outbursts.”

“Sudden mood swings.”

“Tantrums/outbursts, loss of self-control, dangerous coping mechanism such as hitting head against a wall”

“They hurt the other children without caring or even stopping when that child cries.”

Communication and Social Challenges

Related to behavioural challenges, respondents highlighted issues with communication and social skills. For example, professionals observed that those living with autism often struggle to communicate with both their peers and authority figures. Challenges included understanding and responding to instructions, as well as communication styles that could be misinterpreted. For instance, their tone of voice may be interpreted as being rude, though this is understood to be unintentional and a characteristic of their clipped or terse communication style. Additionally, some individuals on the spectrum are non-verbal, making meaningful communication and understanding between all parties more difficult.

“One of the primary challenges I have encountered is difficulty communicating with peers and teachers.”

Learning and Academic Challenges

Another significant challenge was related to learning and academic achievement. Respondents explained that students living with autism experienced challenges with writing, understanding key concepts, maintaining attention, focusing on tasks, and may be easily distracted. Due to these challenges, some students with autism perform poorly on written tests.

Emotional Challenges

Respondents also observed emotional challenges among students with autism. These included difficulties in managing their emotions, being easily upset and experiencing sudden mood swings. There was also an observation that some people living with autism sometimes lacked empathy, which could negatively affect their interactions with their peers.

“They have no empathy. They hurt the other children without caring or even stopping when that child cries.”

Environmental Challenges

Finally, respondents highlighted that some of these challenges stemmed from the environments individuals with autism are exposed to. Environments that are overwhelming and overstimulating, such as those with flashing lights, shiny materials, a high level of noise and excessive information, can make it difficult for individuals with autism to cope and function effectively.

Challenges Faced by Professionals

Respondents also highlighted the challenges they encountered when supporting individuals living with autism. These challenges included:

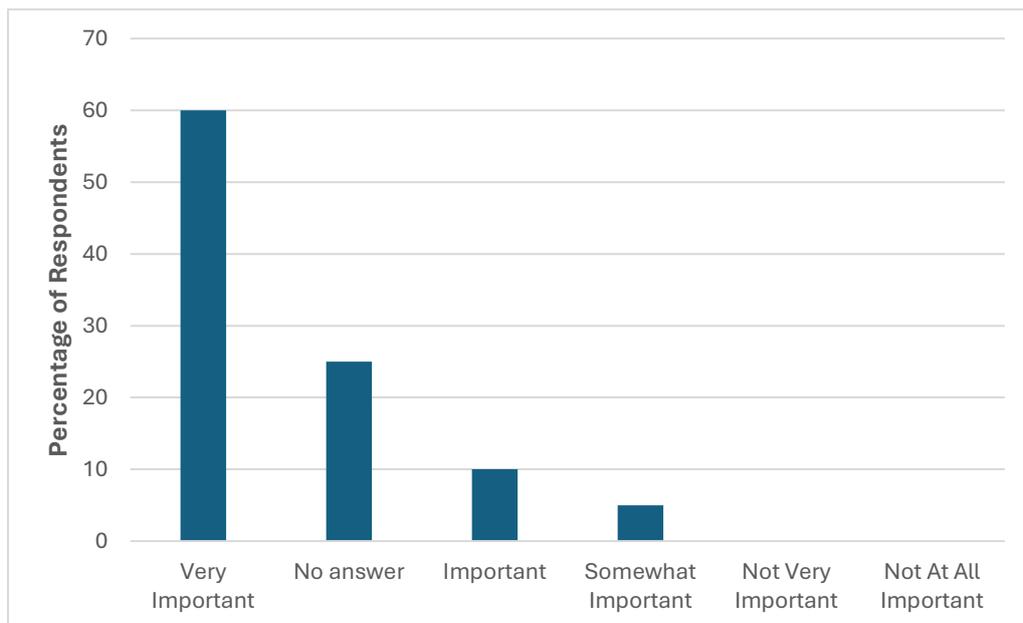
- **Limited knowledge of autism:** Professionals acknowledged gaps in their understanding of autism, which affected their ability to provide appropriate support.
- **Difficulty catering to individual needs:** Respondents highlighted the difficulty of addressing the unique needs of individuals with autism, particularly during challenging moments such as tantrums or mood swings.
- **Lack of resources:** There was a concern about the lack of availability of tools, materials, and other resources necessary to support individuals with autism effectively.

- **Inadequate environment:** Respondents noted that the environments in which they worked were often not conducive to supporting individuals with autism.
- **Attention required:** Supporting individuals with autism was seen as requiring significant time and attention.
- **Insufficient training:** A lack of training on how to effectively engage individuals with autism, especially in getting them to complete assignments, was also raised as a challenge
- **Communication barriers:** Professionals struggled to communicate effectively with individuals with autism.
- **Balancing diverse needs:** Managing children with autism alongside other children in the same setting was described as a challenging task.
- **Lack of funding:** Insufficient financial resources to secure the necessary support and interventions was also a limitation.

“Several teachers who currently work with children with autism struggle with strategies to work with them. Additionally, the classrooms lack the resources to aid teachers in their duties of catering to autistic students.”

4.2.6. Access to Resources and Guidelines

Respondents were asked how important they felt it was to have access to resources and guidelines specific to supporting individuals with autism as part of their professional role. The majority, 60%, stated that this was very important, 10% said it was important, and 5% indicated it was somewhat important. Notably, no respondents considered this to be "not very important" or "not at all important," underscoring the importance of equipping professionals with the necessary guidance and resources to effectively support individuals living with autism.



Graph 18: Respondents' Perception of How Important It Is For Them To Have Resources and Guidelines Related to Autism

Importance of Access to Autism Resources and Guidance

To gain deeper insights, respondents were asked why they felt access to autism resources and guidance was so essential. Their responses fell into four main categories:

1. Improving Awareness and Understanding (Their Own and Others')

Respondents highlighted the importance of access to autism resources for enhancing their own awareness and understanding of autism. This, in turn, would enable them to better understand individuals living with autism and equip them with the tools to educate others, address misconceptions, and reduce stigma.

"Because autistic persons are equally capable but often misunderstood in our society by others."

2. Advocating for People Living with Autism

Having access to resources and guidance was seen as a way to strengthen their ability to advocate effectively on behalf of individuals with autism.

"To advocate for students and initiate programmes for the benefit of them all."

3. Empowering Individuals Living with Autism

Respondents noted that resources and guidelines would empower them to provide better guidance to individuals with autism, build their confidence, and support their journey to becoming productive citizens. For children, this includes preparing them for adulthood and enhancing their ability to navigate their environment and society effectively.

"To enhance their ability to function in their environment."

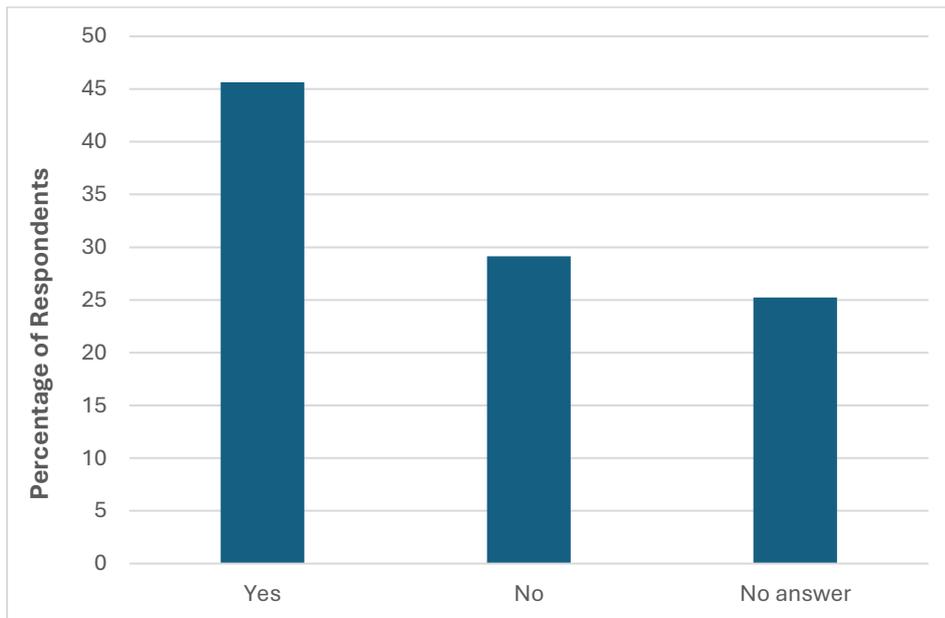
4. Empower Teachers and Parents

Respondents emphasised that access to autism resources and guidance would empower them, particularly teachers, by strengthening their ability to effectively teach and support individuals with autism. This would not only enhance but also transform the entire teaching and learning process, enabling educators to better meet the needs of students on the spectrum. Additionally, respondents felt that having access to such information would help them identify organisations and individuals they could contact for assistance when necessary. Importantly, they noted that these resources would also enable them to empower parents, equipping them with the knowledge and tools needed to support their children effectively.

“Schools are now adapting to mixed disability classes. You’ll never know what cards you are dealt with. Information makes educating a bit easier because now you would have the know-how.”

Awareness of Existing Resources and Support

We asked respondents if they were aware of any local organisations or resources that provide support for people living with autism and their families. Of the respondents, 45% indicated they were aware, 29% said they were unaware, and 25% did not provide an answer. Among those who were aware, the most commonly recognised organisation was the St. Kitts Spectrum Services Centre, with all but one respondent mentioning it. Other organisations identified included the Cotton Thomas Comprehensive School, Ade's Place, the St. Kitts-Nevis Association of Persons with Disabilities, the Special Education Unit, the Ministry of Education's Student Support Department, Student Services Personnel at the Ministry of Education, and the Nevis CBR Advocates. Additionally, respondents highlighted that the internet is a valuable resource, enabling online research on autism.



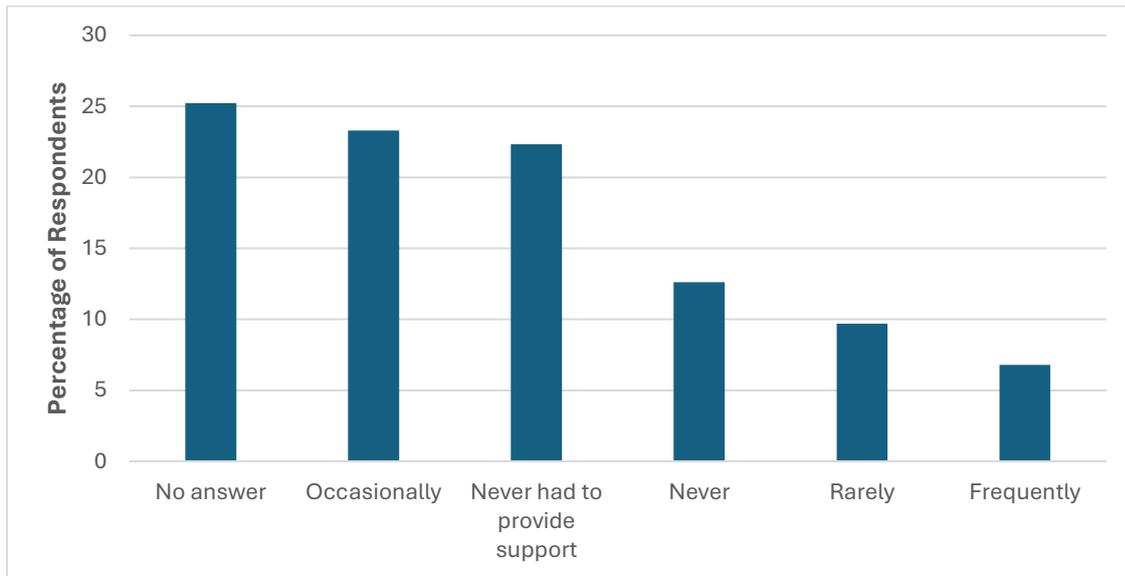
Graph 19: Respondents' Awareness of the Existence of Organisations or Resources That Provide Autism Support

4.2.7. Training

We asked respondents if they had ever received training on autism, and 26% indicated they had, while 49% said they had not. When asked specifically about evidence-based training on autism, 17% reported having received such training, while 58% said they had not.

4.2.8. Collaboration with Other Professionals

Respondents were asked whether they collaborate or communicate with other professionals when supporting individuals living with autism. The results showed that 23% occasionally collaborate with other professionals, 12% stated they have never collaborated with other professionals, 10% reported they rarely do, and 7% said they frequently collaborate with others.



Graph 20: Respondents' Assessment of How Often They Collaborate or Communicate With Other Professionals When Supporting a Person Living With Autism

4.2.9. Effective Strategies for Autism Management

To gain insights into effective practices, we asked respondents to share the strategies and approaches they found most successful in supporting individuals with autism in their professional roles. They identified the following:

a) Practical Support

- **Activities and Games:** Incorporating kinaesthetic activities, short videos, and games like building blocks into support activities
- **Task Breakdown:** Dividing assignments into smaller, manageable tasks.
- **Routine and Structure:** Establishing to-do lists and schedules to create consistency.
- **Simple Communication:** Using clear, concise language.
- **Quiet Time:** Allowing moments of calm and reflection.
- **Tailored Support:** Customising strategies to meet individual needs.

- **Therapies:** Play therapy, speech development, individual counselling, and calming techniques.
- **Visual Supports:** Using relevant resources like visual aids.
- **Training:** Providing training to people with autism in areas like social skills, behaviour management, and listening skills.

b) Treatment Approach

Respondents emphasised that the way individuals with autism are treated can significantly impact the success of the support provided. Key traits contributing to positive outcomes include:

- Patience
- Understanding
- Compassion
- Empathy
- Inclusivity

4.2.10. Training and Development Priorities

To identify key priorities for professional training and development, we asked respondents what knowledge areas were most important. They highlighted the need for professionals to be aware of:

- **Effective Support Strategies:** Techniques to help individuals with autism thrive, including tailored learning strategies.
- **Identification Skills:** Recognising individuals with autism in their organisations.
- **Empathy and Compassion:** Cultivating understanding and care in interactions.
- **Effective Communication:** Mastering listening and communication skills for engagement.
- **Understanding Autism:** Developing a comprehensive understanding of autism, including triggers, characteristics, challenges, and the unique ways individuals with autism perceive the world.

4.2.11. Enhancing Autism Awareness and Support

Respondents also shared suggestions for improving autism awareness and support within their fields:

- **Enhanced Knowledge:** Regular and extensive training at all levels, including certified courses, hands-on interaction with individuals with autism, awareness campaigns, media engagement (e.g., ads, social media), talk sessions, and outreach programmes.

- **Inclusion and Acceptance:** Promoting equal opportunities and ensuring those with autism are included in all aspects of society.
- **Advocacy:** Calling for policies, legislation, and effective interventions within organisations and society.
- **Collaboration:** Encouraging interdisciplinary collaboration to create an all-of-society approach.

“Encourage collaboration among professionals to provide comprehensive support and services for individuals with autism and their families.”

4.2.12. Additional Insights

Finally, we asked participants if they had any additional information or insights to share. Respondents expressed a desire for greater government action, particularly in creating collaboration among policymakers in the Ministry of Education, school counsellors, and other departments. They suggested that departments should work together more cohesively rather than in isolation, enabling a more integrated and unified approach. Additionally, they called for the development of legislation to enhance autism care and management in St. Kitts and Nevis.

Concerns were raised about the high levels of isolation, stigma, and discrimination faced by people living with autism, including bullying. While some participants felt that creating safe, structured environments might require a degree of separation for individuals with autism, there was an overarching emphasis on inclusion and support.

“They are totally marginalised.”

Participants reiterated the need for increased public and professional awareness of autism and a more robust support system in St. Kitts and Nevis. They stressed the importance of early intervention to help children with autism succeed across all stages of life.

“We need to work in the best interest of the children and provide early intervention so the children can succeed at all levels.”

4.2.13. Recommendations

Based on the results of the professional survey we offer the following recommendations to policymakers.

1. Invest in Regular and Evidence-Based Training

Provide mandatory, ongoing training for professionals, such as teachers, counsellors, and healthcare providers, focusing on evidence-based approaches to autism care.

Training should include effective communication strategies, behavioural management, and tools for inclusive education.

2. Develop and Implement Autism-Specific Legislation and Policies

Create laws and policies that ensure the rights of individuals living with autism and mandate the provision of resources, early intervention programmes, and access to appropriate education and healthcare services.

3. Promote Interdepartmental Collaboration

Promote joined-up working among the Ministry of Education, the Ministry of Health, schools, and other relevant departments and sectors to improve service delivery and eliminate siloed approaches. Interdisciplinary teams should be established to coordinate support for individuals with autism.

4. Improve Access to Resources and Guidelines

Develop and disseminate autism-specific resources and guidelines for professionals. These should include toolkits, visual aids, and strategies to empower both professionals and families.

5. Develop and Implement Autism Awareness Campaigns

Launch public awareness initiatives to reduce stigma, discrimination, and bullying of individuals living with autism. Campaigns should target schools, workplaces, and communities, highlighting empathy, understanding, and the capabilities of those with autism.

6. Allocate Funding for Supportive Infrastructure

Increase funding for resources like sensory-friendly classrooms, therapeutic equipment, and additional staff to provide tailored support for children and adults with autism. Ensure these resources are available in both St. Kitts and Nevis and across villages on both islands.

7. Expand and Invest in Services at the St. Kitts Spectrum Services Centre

Expand existing services at the St. Kitts Spectrum Services Centre to serve so it can become a hub for training, resource distribution, counselling, and family support. This requires investment in both human resources and physical resources.

8. Promote Inclusion and Equal Opportunities

Develop policies that mandate inclusive education and workplace practices, ensuring individuals living with autism have equal opportunities to participate in all aspects of society. Provide incentives for organisations and schools that champion inclusion.

9. Encourage Early Diagnosis and Intervention

Implement programmes to support early screening and diagnosis of autism, followed by timely interventions tailored to individual needs. This should be a key component of the healthcare and education systems.

10. Support Advocacy Efforts

Support and partner with NGOs, community groups, and families to advocate for autism-friendly policies and initiatives. Policymakers should encourage community-based advocacy and ensure that people living with autism and their families have a voice in decision-making processes.

5. Conclusion

Our surveys underscore a need for more focus on autism with increased awareness, education, support and training. We have identified that a basic level of understanding of autism exists for both professionals and the public. What is now needed is a more nuanced and deeper understanding of autism that promotes a more positive and empowering dialogue that tackles stigma, discrimination and exclusion. To achieve this, an all-of-society approach is needed where the government, civil society and private sector come together to provide education and awareness programmes, resources, support, training, and inclusion opportunities.

6. Next Steps

These surveys have provided us with useful information from both the public and professional points of view. Most importantly, we need to understand the perspective of people living with autism. Therefore, the next phase of our project is to gain a comprehensive understanding of the experience of young people aged 13-30 who are living with autism in St. Kitts and Nevis. This will be achieved by conducting qualitative interviews with those living with autism as well as their parents, carers, doctors, teachers and guidance counsellors.

7. Acknowledgements

We are very grateful to all those who took the time to complete the surveys. We would also like to thank our volunteers for their hard work and dedication as they went out into the community to implement this questionnaire.

We would also like to thank the leadership and staff at the St. Kitts Spectrum Services Centre for all their guidance and support, and the Ministry of Education for assisting us with distributing the survey to teachers.

Finally, we would like to thank our donor for their generous contribution, without which this project would not have been possible.

8. Our Use of People-First Language

We recognise that language preferences can vary within the autism community. While some individuals may prefer identity-first language (e.g., “autistic person”), we have chosen people-first language for this report in keeping with guidance from many health and research institutions. We remain open to ongoing dialogue and learning around language use and will continue to listen to and respect the preferences of the communities we work with.