



## **Terms of Reference for Consultancy Service to Conduct a Baseline Survey on Persons with Autism Spectrum Disorders (ASDs)<sup>1</sup> in the Kingdom of Eswatini**

### **I. Background**

Centers for Disease Control and Prevention (CDC) of the United States Department of Health and Human Services define Autism Spectrum Disorder (ASD) as a development disability that can cause significant social, communication and behavioral challenges. It is a lifelong development disability that affects the functioning of the brain, characterized by impairments in social interaction, problems with verbal and non-verbal communication and restricted, repetitive behavior, interests and activities.

A range of physical and mental-health conditions frequently accompany autism. They include, but are not limited to: epilepsy, depression, anxiety, schizophrenia, bipolar disorder, attention-deficit/hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), disrupted sleep, etc. The World Health Organization (WHO) indicates that 1 in 160 children has an autism spectrum disorder. Although the similar international statistics are non-existent for adults, the WHO indicates that ASDs begin in childhood and tend to persist into adolescence and adulthood. While some people with ASD can live independently, others have severe disabilities and require life-long care and support.

The early diagnosis, appropriate research and effective interventions are vital to the growth and development of people with ASD. Early intervention is crucial for addressing their needs, thus improving their opportunities to live a quality life with the ability to participate in the greater community and increasing the likelihood that they will need lower levels of support later in life. A cure for ASDs is not available. Evidence-Based psychosocial interventions, however, such as behavioral treatment and skills training programmes for parents and other caregivers, can reduce difficulties in communication and social behavior, with a positive impact on the person's well-being and quality of life.

According to WHO, available scientific evidence suggests that there are probably many factors that make a child more likely to have an ASD, including environmental and genetic factors. However, epidemiological data is conclusive that there is no evidence of causal association between measles, mumps, rubella or any other children vaccine, and ASD.

People with ASDs, as well as other disabilities, are significantly more vulnerable to the risk of HIV infection. A lack of education, of awareness of their rights, and of the possibility of seeking protection (due to social stigma, isolation and lack of access to communications, information and services) makes them more susceptible to deceit, while making it easier for those who abuse them to go unpunished. Communication barriers, affecting people with developmental disabilities, make it difficult to ask for and receive help, to make themselves understood or to be even taken seriously, in addition to professionals (law-enforcement and medical staff) seldom being adequately trained to deal with such individuals.

### **II. Need for Baseline Survey in the Kingdom of Eswatini**

In the Kingdom of Eswatini, very little research has been undertaken to fully understand the prevalence of ASDs and/or prevalence of violence experienced by people with ASDs. Many of these people live in relative isolation and are invisible to society, often kept indoors and out of sight. Their access to education and other basic services is

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<sup>1</sup> Including common comorbid conditions - a range of physical and mental-health conditions which frequently accompany autism. They include, but are not limited to: epilepsy, depression, anxiety, schizophrenia, bipolar disorder, attention-deficit/hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), disrupted sleep, intellectual disability, etc.

limited. But as much as the acute lack of access to basic services (education, medical, psychological, legal and other services) is an issue in the country, attitude and stigma are the significant barriers preventing them from enjoying their fundamental rights. This leaves these people in an extremely vulnerable position.

There is no statistical data available on people with ASDs in the Kingdom of Eswatini as well as no research studies undertaken in this area. Most of health professionals have challenges of diagnosing the children ASDs. There are health facilities coordinated by the Ministry of Health that provide ASD related interventions. However, facilities are not child friendly and lack vital equipment needed for family-centered services based on each child's unique needs. There is inadequate number of human resources to provide appropriate multi-disciplinary intervention. Children with ASDs are denied access to education. Classes are not designed to allow a combination of one-on-one, small group and regular classroom instruction for children with mild symptoms of ASDs. Integration of such children in mainstream schools is possible but only with proper interventions. Furthermore, there are no community-based programmes tailored to people with ASDs.

According to the Article 31 of the CRPD, States are required to collect statistics and data to enable them to formulate and implement policies to give effect to the rights of people with disabilities. Furthermore, data disaggregation by disability, sex, and age is indispensable for understanding the situation of women and girls with disabilities and informing policies to ensure their social inclusion and human rights protection. However, such data remains scarce, which is a major obstacle impeding greater progress in policies and programmes for women and girls with disabilities.

To assist the Kingdom of Eswatini to fulfil its commitments under the CRPD as well as inform and support the monitoring of Sustainable Development Goals (SDGs) focused on people with disabilities, until such time that the Kingdom of Eswatini operationalizes both the adopted legislation and the National Disability Policy and, as per the Eswatini National Disability Plan of Action, commits funds to the objectives highlighted in these documents, this proposal aims at undertaking a baseline survey on the people with ASDs.

### **III. Purpose**

The baseline survey is intended to obtain reliable and relevant data on the prevalence of ASDs in the selected region, their access to basic services and prevalence of violence against people with ASDs. The information obtained from the study will be used to inform programmatic interventions focused on ASDs and protection of their human rights. This will further enhance capacities of Government institutions to identify, diagnose and treat people with ASDs; Improve information related to ASDs and challenges faced by these individuals; and promote active advocacy and monitoring on issues related to people with ASDs.

### **IV. Specific Objectives**

#### Prevalence of ASDs in Eswatini

- Identify the number of people with ASDs disaggregated by sex and age
- Identify the number of people with ASDs exposed to or infected by HIV
- Determine where possible the number of people with ASDs in contact with services

#### Prevalence of Violence Perpetrated against People with ASDs

- Identify the prevalence of violence (physical, psychological and sexual) perpetrated against people with ASDs disaggregated by sex and age and by types of violence
- Identify the needs that arise as a result of the aforementioned forms of violence experienced by people with ASDs
- Identify frequency, nature and drivers of sexual violence perpetrated against women and girls with ASDs
- Identify perpetrators of violence
- Identify existing preventative mechanisms established to prevent violence against people with ASDs

#### Access to Basic Services

- Identify the access to basic services of people with ASDs

- Identify gaps in services and unmet needs of people with ASDs
- Identify their access to education and employment
- Identify availability of health services for people with ASDs
- Evaluate the referral networks, linkages and services for people with ASDs
- Assess the current state of ASD detection, diagnosis and treatment in Eswatini
- Assess the access to justice of people with ASDs
- Identify existing supportive services available to people with ASDs
- Identify unmet needs of caregivers of people with ASDs
- Assess the level of ASD competency among the health personnel
- Assess availability of supporting groups for families with people with ASDs
- Assess the level of awareness of medical professions, police, court officers, and traditional leaders on ASDs

**V. Research questions that will be answered by the assessment:**

- What is the extent of people with ASD?
- What is the general level of knowledge of the symptoms of people with ASDs among families and the community?
- Do they access basic services (health (including SRH and HIV), education and social security)?
- What are gaps in services and unmet needs of people with ASD?
- What are experiences of families of caregivers of people with ASD?
- How does ASD affect the individual and their families including issues of GBV?
- What professional support is there for people with ASD and their families?
- What coping strategies do People with ASD and family members use?
- What sources do the families and caregivers use to acquire knowledge about the condition?

**VI. Survey Design and methodology**

The baseline survey will gather information using a combination of quantitative and qualitative data collection methods and tools. Four techniques will be used to collect data, namely the desk review, questionnaires, interviews with key informants and focus group discussions. Wide range of sites, including communities, Government officials and partners will be interviewed.

The consultant/company selected to undertake the assignment will present a detailed inception report indicating how it will undertake the baseline survey before the actual data collection process. The inception report, among other things, will cover the sampling framework for the different data collection sources, data collection methodologies and specific tools to be used. It will also envisage the model of site selection, including covering both rural and urban areas that will be randomly selected and included in the study. The inception will also provide a geographical map of data collection.

Following the submission of the inception report, the consultant/company in coordination with Autism Eswatini will prepare the questionnaires to be used during the individual interviews and group discussions.

The team of data collectors selected by Autism Eswatini will be trained by the consultant/company to ensure that the data collected is carefully managed (handled, transported and stored) throughout the study period. Furthermore, careful and detailed records of all interviews will be maintained for each community surveyed. The training of data collectors by the consultant/company before sending them to the field will ensure that good quality data is obtained. The data collection instruments will meet international standards. The training will also ensure that team members, researchers and data collectors are aware of the key areas to be covered including their sensitive nature. Role playing will provide further assurance that high quality will be maintained.

All interviews, with appropriate consent, will be recorded. The data collectors will take notes during the group discussions and individual interviews carried out with respondents. The number of teams for each community/district will be identified by the consultant/company and included in the inception report. Each data collection team will be comprised of a supervisor and data collectors. The team supervisor will be directly reporting to the consultant/company and getting guidance on the data collection issues as well as soliciting guidance from Autism Eswatini on the issues related to ASDs.

The baseline study proposal will be submitted for review and approval at the Ethics Committee of Eswatini for approval. All members of the research team and data collectors will be provided guidance in research ethics to meet the highest ethical standards of data collection and analysis throughout the study. A process of obtaining informed consent will be put in place using the standard information sheets and consent forms provided by the Ethics Committee of Eswatini. In addition, permission to conduct the survey will be obtained from the relevant Government institutions. Given the sensitive nature of the survey, efforts will be made to ensure that respondents are fully aware of the risks and benefits of participating and that the confidentiality and anonymity will be maintained.

#### **VII. Management of the Baseline Survey**

The baseline survey will be conducted under the overall supervision of UNFPA Eswatini Country Office. A steering committee (comprising of representatives of UNFPA, UNDP, UNICEF, and Deputy Prime Minister's office: Department of Gender and Family issues and Department of Social Welfare (disability, National Population Unit and Autism Swaziland) will be set up to closely monitor the implementation of the baseline survey, provide feedback on each stage of the exercise and provide required support to ensure smooth undertaking of the survey.

The consultant/company selected to undertake the survey will be responsible for designing a survey and data collection tools, training the data collectors, analyzing the collected data and preparing a baseline report. Autism Eswatini as a technical partner will be responsible for sensitizing communities sampled for the survey in the respective region and support the data collection process, together with the identified team, interview key informants and facilitating focus group discussions, collecting and storing the data. The Department of Social Welfare (as lead in issues of disability) together with the Department of Gender and family issues (as accountable contract holders) will be overseeing the review of the baseline report and leading the validation process.

#### **VIII. Duration and Scope of Assignment**

The baseline survey is expected to be completed within a total of five months' duration. The inception report to be submitted by the consultant/company to be considered for the assignment should consist of a detailed work plan, including major tasks, deliverables and time frame. The survey will be undertaken in the Lubombo region and will cover both rural and urban areas.

#### **IX. Expected Deliverables**

The consultant/company will submit the following:

- Inception report containing a detailed work plan for the entire duration of the consultancy
- Weekly progress reports (verbal) should be made by the consultant/company to the UNFPA Eswatini CO
- Data collection methodology and tools utilized for collecting information in the field
- Complete list of sampled districts/areas with accompanying maps
- Draft report with inputs from all stakeholders, including UN agencies and the DPM's office (not exceeding 50 pages)
- All working files and final dataset including the raw data gathered during the research from different sources
- Final Baseline Survey report

**X. Required Expertise and qualifications**

The consultant/company to be considered for the assignment is expected to have the following experience and qualifications:

- Postgraduate degree in public health, statistics, epidemiology, applied research and related technical fields
- Minimum seven years of experience in quantitative and qualitative methods and/or monitoring and evaluation
- Demonstrated experience in:
  - organizing and undertaking both quantitative and qualitative data collection
  - performing data analysis and management. Demonstrated ability to transform large amounts of data into theory by reducing the volume of raw information and creating a conceptual framework
  - using statistical software for quantitative analysis
- knowledge of areas: Autism Spectrum Disorders, developmental disabilities, disabilities and HIV, sexual and reproductive health and disabilities, violence against persons with disabilities is a strong asset
- Excellent command of spoken and written English.