

# AJOLI Community Report

Developing culturally-sensitive understanding of autism and community needs in Northern Uganda



# Introduction

**Autism Spectrum Disorder (herein autism) is a neurodevelopmental condition** which affects how individuals **communicate, process information and engage with the world around them.**

The worldwide prevalence of **autism is around one in 100** although estimates suggest this could be as high as **one in 31 among children.**

Globally, the experience and management of autism have improved significantly but in low-resource settings, **autism is often not well understood.** Autism remains **under-researched and under-diagnosed in Uganda leading to significant gaps in care and support for children and their families.**

As part of the AJOLI project, we conducted a comprehensive study on **rates of autism in Northern Uganda** as well as **identifying family and community support needs.**

The project was supported with a grant from the Joy Welch Fund, UK and completed by a multidisciplinary team of experts in public health, community development, education, pediatrics, and psychiatry from **Global Health Uganda, Women and Children Agenda, Lancaster University, Makerere University and Gulu University.**

Our aim is to use these findings to **develop more awareness and understanding about autism** and **influence community leaders and policy-makers** to improve the **support for autistic children, their families and communities.**



# Mapping autism in Northern Uganda

We mapped the **prevalence, distribution and associated factors of autism among 1,139 children aged 2-9 years** across three districts in the Acholi sub-region, Northern Uganda. **Gulu City** represented the urban population while **Amuru** and **Pader** districts represented more rural populations.

We used the **230, a screener for neurodevelopmental conditions** developed specifically for the Ugandan context. If a child screened positive then they underwent **clinical assessment with a Psychiatric Nursing Officer and a medical officer** using DSM5. Where this indicated a possible neurodevelopmental condition, the child was referred for a **full diagnostic assessment completed jointly by a consultant psychiatrist and consultant paediatrician on the study team at Gulu Hospital.**

## 01

### Neurodevelopmental Conditions

**4.8% of children** that we assessed were identified as having a **neurodevelopmental condition**

## 02

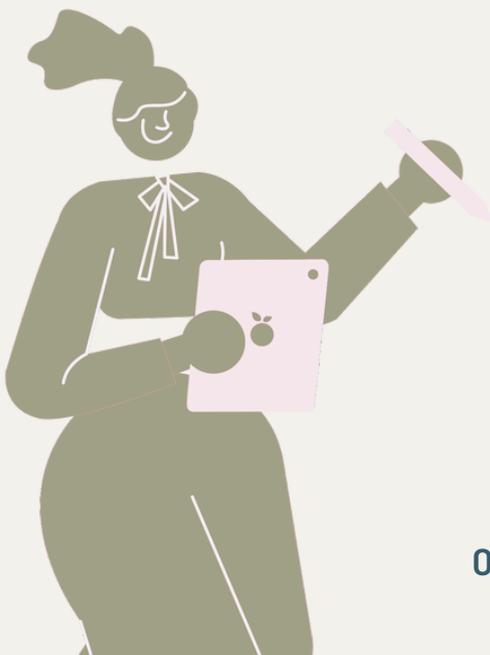
### Autism

**1% of children that we assessed were identified as autistic.** Of these, **81.8% had at least one co-occurring neurodevelopmental condition.**

## 03

### Predictors of autism

Key **predictors of autism** were **genetic and obstetric** factors, including pre-term birth, teenage motherhood, breech labour, and oxygen resuscitation at birth.



# Understanding autism in Northern Uganda



Across the three regions, we conducted **25 interviews and 4 focus groups** with **autistic young people, parents, cultural and community leaders, teachers, medical professionals, and representatives from government.**

**In total we spoke to over 40 people** to find out what people **understood about autism** and what they perceive to be the **most important needs of autistic people in the community.**

Theme	Description	Quotations
Causes of autism	<b>Little consensus</b> about what <b>causes autism</b> and some <b>cultural misconceptions</b> including <b>sin, curses or witchcraft</b>	"We sometimes tend to conclude that it could be <b>spiritual issues</b> and the reason we would say that is because <b>we didn't have these things in the past.</b> " (Parent)
Autism traits	Identified <b>differences with behaviour</b> but also difficulties with <b>social communication</b> and <b>sensory processing</b>	"Children of these categories... <b>show their expression or feelings through different acts.</b> They may be making it <b>verbally using sound like shouting</b> [or] expressing their understanding using some equipment". (Social Worker, Gulu)
Community barriers	<b>Stigma, physical abuse,</b> access to <b>suitable education,</b> <b>little understanding</b> among the community, and a <b>lack of family support</b>	"Many <b>parents feel ashamed</b> of those kind of children." (Teacher) <b>Most people think that you are mad...</b> They think our <b>parents have a curse</b> and <b>they just abuse us.</b> (Autistic young person)
Community solutions	<b>Educating families, communities and health / education professionals,</b> plus expanding <b>educational offer</b> to ensure <b>long-term independence</b>	"So <b>teach [families] what autism is,</b> teach what it takes to have a child, <b>teach them about the options of care.</b> " (Health professional) <b>"By being close to them, showing them love like that.</b> In class <b>you motivate, you encourage...</b> so that he feels he is also part." (Teacher)

# Takeaway message

Our AJOLI study suggests that around **1% of children in Northern Uganda are autistic**. It indicates, however, that there are **likely many more who have not been diagnosed, including many young people and adults**.

Most are not identified by health or educational professionals due to the **stigma that surrounds autism** and other neurodevelopmental conditions. Parents feel **ashamed** and frequently don't possess the **knowledge** or **financial means** to care for their child, which can lead to **isolation, educational exclusion, and a lack care**.

**Autism is not a curse, not the outcome of sin, nor a disease that can be passed on. It is simply a difference in the brain, which leads individuals to communicate and experience the world differently. Autism can include difficulties but also strengths and, with the right support, autistic people can lead long and meaningful lives.**

With **greater knowledge and acceptance** from community members, teachers, and health professionals, as well as parents, many autistic children and young people have the potential to **gain an education**, grow up to be **valued members of the community**, and **live independently**.



Our AJOLI project was only the first step in a long journey together. We are aiming to take what we have learned from this and develop further in order to generate sustainable change for families and communities across Northern Uganda.

## 01

### Increase knowledge about autism

We will connect with families and communities to develop knowledge, understanding and acceptance of autism and reduce stigma.

## 02

### Improve access to education

Education is a human right for all children. We will work with local schools to improve awareness and training for teachers to support autistic learners.

## 03

### Develop capacity among health professionals

We will partner with regional and national universities to develop understanding of autism among clinical health professionals in order to improve identification of needs.



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