

Report of the Study Visit on Children Affected With Nodding Syndrome In Maridi County

Commission by Light for the World Light

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Executive Summary

Light for the World Commissioned a study on children affected by nodding syndrome in Maridi County, Western Equatoria State from the 12th -14th December 2023. The study is intended to deliver a brief short report about the visit — which focus on recommendations for further interventions. The study was carried out by three experts from the Ministry of Gender, Child and Social Welfare, Ministry General Education and Instruction and Light for the world. The study aims to: first get better understanding of the nodding syndrome in the area and how it affects the education of children. Secondly, to have an interaction with Sudan Evangelical Mission staffs in Maridi, County Education department staffs, County health department — Teachers and Other implementing partners like AMREF, CAUM on the ground and the families/parents of the affected children. Thirdly, visit to livelihood program being executed by the parents of children with nodding. Fourthly, see some intervention strategies that can be recommended to donors for further support in the region and make a one-day presentation to the Education cluster. The study employed qualitative method in its approach through the use of Key Informant interviews with government officials in the departments of health, education and gender in Maridi County. Focus group discussions were conducted with the Faith based Women Saving and loan Association, Teachers, CBR officers of Sudan Evangelical Mission and the parents of the children affected with nodding syndrome. County health department through the support of AMREF, LIGHT for the World, CAUM and Sudan Evangelical Mission registered a number of achievements in their consortium project which ended last year. These include: health and education outreach that created awareness among the community and were able to refer children to the mental health clinic for medical attention through diagnosis and provision of anti-epileptic drugs that reduced the seizures and contributed to better health outcomes of the children affected with the nodding syndrome. This signifies the critical role played by the Community based Rehabilitation workers in identifying children within communities, making referral to the clinics and ensuring survivors take drugs timely. Secondly, Inclusive approaches were employed in training teachers, school management and pupils on sign language, braille and child safeguarding principles in schools. Despite all these achievements, nodding syndrome is being seen in signs of discrimination in the community and in schools-fear of unknown/uncertainty and multiple theories of causation exist and families of the affected children are grieving not only their children illness but a loss of social value and lineage. The lost and suffering should be seen within the context of wider suffering of the society. The nexus between Sociological-disability-Public Health need to be investigated in order to holistically address the etiology and know the underlying cause which could lead to cure of the disease and reduction of the viral load of the. Finally, there is need to help clinicians, scientists, educationists, and policy- makers develop guidelines for prioritizing the severe conditions of the NS and take this as a national concern for redress.

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LIST OF ABBREVIATION AND ACRONYMS

AMEREF	:	:Africa Medical and Research Foundation
CUUAM:	:	Italian name for organization
CBR	:	Community Based Rehabilitation
CHD	:	County Health Department
DI	:	Disability Inclusion
EC	:	Education Cluster
FGDs	:	Focus Group Discussions
KII	:	Key Informant Interview
LFWT	:	Light for the World
MGCSW	:	Ministry of Gender, Child and Social Welfare
MOGEI:	:	Ministry of General Education and Instruction
MOH	:	Ministry of Health
NS	:	Nodding Syndrome
OV:	:	Onchocerca volvulus
OAE	:	<i>Onchocerciasis-associated epilepsy</i> (
SEM	:	Sudan Evangelical Mission
VSLA:	:	Village Saving and Loan Scheme

PROPOSED INTERVENTIONS FOR FURTHER ACTIONS ON THE NS IN MARIDI

GOVERNMENT

- To address discrimination at schools, there is need to intensify health education and awareness raising among teachers, school management and the pupils/students
- Robust awareness creation on the Nodding Syndrome to all Bomas and Payams and the need for more outreach programs and campaigns
- Recommend the engaging traditional leaders to help refer affected children for medical attention
- Dissemination of school-based policy on Inclusive Education to the schools
- There is need for the affected children to study in the nearby schools,
- Robust capacity building initiatives in all schools and ensure that IBBA and Modibai schools to be inclusive in this programme,
- Extension of the work of CAUM to Kazana payam where most children are affected with nodding syndrome
- Provision of free education to children affected with NS by issuing local orders to exempt all children with Nodding Syndrome
- Call for inclusion and consideration of children with nodding syndrome in the nutrition policy for the special needs and category as it supplements drugs intake and motivate them to access medical treatment.
- Call for the National Ministry of health to prioritize provision of anti-epileptic drugs to Maridi County in order to reduce the seizures of the cases
- Need for rehabilitation services and programs for children /young people affected by NS
- Provision of incentives to teachers handling children affected in Schools.

DONORS

- First call for more partners on disability inclusion to ensure coverage of the area and the schools;
- Need for more funding for supporting parents support groups to advocate and reach more families and communities on the NS and take future responsibilities in providing food, soaps, mosquito nets and other basic requirements
- *There is little funding for research on the disease, consequently, few studies have been conducted to date.* we also need to explore reasons why funding for research on nodding syndrome has been so scarce and compare it to other similarly neglected diseases.

PARTNERS/NGOs

- She recommended material support for the affected children inform of soaps, Nutritional support to those who take medication and continual provision of medicines to the vulnerable families
- More capacity building initiatives on VSLA for the interested families of children affected and eventual formation of more VSLAs
- Inclusive Education is the best way to ensure the children affected are in schools and this cannot be achieved without the support of all development partners.

COMMUNITIES

- The need for communities to know that NS is a communicable disease and take adequate measures to protect other children within their families and in the communities
- Communities should be provided with best practices of the reduction of seizures in children who take medical drugs and have improved with period of time so as to motivate their children to go to the mental health clinics
- Community level role in addressing the correlate factor in the cause of the Nodding Syndrome by cleaning the Maridi dam area every three months in order to clear the breeds of the blackflies and reduce the likelihood of blackflies becoming infected with microfilariae and therefore transmitting a pathogen.

ACADEMIC INSTITUTIONS/INSTITUTIONS OF HIGHER LEARNING

- Nodding syndrome (NS) is a debilitating yet often neglected neurological disease affecting thousands of children in several parts of Western Equatoria state (Maridi, Mundri, Mvolo and Lui). The cause of NS remains unknown, and effective treatment options are lacking. Moreover, knowledge regarding NS is scarce and is based on a limited number

of publications, with no comprehensive overview published to date.’ Hence further research into the cause is highly needed.

INTRODUCTION

OBJECTIVES OF THE STUDY

The study aims to: first get better understanding of the nodding syndrome in the area and how it affects the education of children. Secondly, to have an interaction with Sudan Evangelical Mission staffs in Maridi, County Education department staffs, County health department — Teachers and Other implementing partners like AMREF, CAUM on the ground and the families/parents of the affected children. Thirdly, visit to livelihood program being executed by the parents of children with nodding. Fourthly, see some intervention strategies that can be recommended to donors for further support in the region and make a one-day presentation to the Education cluster.

METHODOLOGICAL ISSUES

The study employed qualitative method in its approach through the use of Key Informant interviews with government officials in the departments of health, education and gender in Maridi County. Three focus group discussions were conducted with the Faith based Women Saving and loan Association, Teachers, CBR officers of Sudan Evangelical Mission and the parents of the children affected with nodding syndrome. County health department through the support of AMREF, LIGHT for the World, CAUM and Sudan Evangelical Mission. Focus group discussions (FGDs) were organized among the community concerning knowledge and perceptions about onchocerciasis and epilepsy. This method is supplemented by participant observation as one of the best methods in such study. Historical data regarding various activities at the Maridi dam were obtained from the administrative authorities.

ON-GOING INTERVENTIONS/ACHIEVEMENTS

- AMREF Health Africa in South Sudan, in partnership with Ministry of Health, and the Nodding Syndrome Alliance (NSA), has been conducting mass treatments to control and eliminate Onchocerciasis, Epilepsy, and Nodding Syndrome, through the annual distribution of Ivermectin Treatment. The organization also conducts bi-annual distribution to prevent more children from developing Onchocerciasis, Epilepsy, and the Nodding Syndrome. The bi-annual distributions started in 2021.
- Amref established a Community vector Control Intervention in 2019 to get rid of the black flies that transmit Onchocerciasis by removing their breeding sites.
- We also provide care for those who have been affected by the condition through the provision of anti-epilepsy and anti-seizure medicines.
- Clinics have been established in Mundri, Maridi, and Lui to provide treatment for the affected children. There are also follow-ups to monitor their progress through the Nodding Syndrome Alliance
 - Lastly, consortium members addresses the problem of exclusion and stigma by creating awareness in those communities through community epilepsy awareness programmes, radios, and community meeting
- Established disability clubs in school, supplemented with health and garden clubs to engage the children
- Training of teachers on sign language, child safeguard and braille
- Provision of school adaptation facilities (Toilets, ramps, boreholes and water tanks)
- Integration of sign language within the lesson plans of the schools
- Provision of school uniforms to the children with NS and other vulnerable children
- Provision of porridge/meals for the affected children with Nodding Syndrome

DISABILITY INCLUSION INTERVENTIONS IN MARIDI COUNTY

- Training of teachers on sign language, child safeguard and braille
- Provision of school adaptation facilities (Toilets, ramps, boreholes and water tanks)
- Integration of sign language within the lesson plans of the schools
- Provision of school uniforms to the children with NS and other vulnerable children
- Provision of porridge/meals for the affected children with NS
- Community based Rehabilitation officers play a role in identification, referral and management of the affected children
- Parents outreach support programmes for awareness creation
- Establishment of disability clubs in all schools
 - lack of braille for children with visual impairments

CHALLENGES

- Many of the affected children are not at schools due to the long distance, lack of school fees and nutritional support from the families
- People become fearful and for the children to go to school is a stigma issue, discrimination both at home, in the community and at school
- Parents prefer traditional medication than the clinical medicine and hence referral pathway to the mental health clinic is highly affected
- Early and unintended pregnancy affects many girls in the County with NS (Unable to take care of their babies and hence, circle of poverty)
- The fear of nodding syndrome has brought changes to school admission procedures, with signs of discrimination
- AMEREF is not providing everything due to the project limit of funding and hence, survivors need food, soap, blankets and mosquito nets. 11 patients among the children were found malnourished
- Most of the teachers trained on sign language, child safeguard and braille were transferred from one school to another which impacted negatively in management of children with NS in schools
- Lack of Braille materials for practice

PROCEEDINGS OF THE ASSESSMENT VISIT ON THE NODDING SYNDROME IN MARIDI COUNTY, WES

12th /12/2023

S/N	NAMES	POSITION/ORGA NIZATION	ISSUES DISCUSSED
1.	Mr. Elia Zacharia	Director General/MOGEI	<ul style="list-style-type: none"> ➤ NS is prevalent but the causes is unknown ➤ Kazana payam is the most affected area in Maridi ➤ Total number of children affected is 89(33 girls &56 boys) ➤ Children affected are in different schools and many are not at schools due to the long distance, lack of school fees and nutritional support from the families ➤ On-going interventions include teachers trained on how to handle and manage NS in schools, and there was progress on the health of children who received medication from CAUM ➤ He proposed the following recommendations-1. There is need for the affected children to study in the nearby schools, 2.-Robust capacity building initiatives in all schools and 3. IBBA and Mordibai schools to be inclusive in this programme, 4. Extension of the work of CAUM to Kazana Payam
2.	Emmanuel Lodo	Sudan Evangelical Mission	<ul style="list-style-type: none"> ➤ Support VSLA to families/ parents of children with NS (5 groups) <p>The highest grade for children with NS in schools is primary level (cases of P.7 and P. 8, who drop out)</p> <ul style="list-style-type: none"> ➤ Children who take drugs have improved with no seizures ➤ Early and unintended pregnancy affects many girls in the County with NS

6. Glob. Res. J. Publ. Health Epidemiol.

- Established disability clubs in school, supplemented with health and garden clubs to engage the children
- Teachers trained on inclusive education when schools closed
- Children with NS are supported with school uniforms
- Key recommendations include, first call for more partners on disability inclusion to ensure coverage of the area and the schools; Second, dissemination of school-based policy on Inclusive Education to the schools

**ELI ALFRED
MAKIRIOJ**

Director for Gender, child & Social Welfare

- He said NS is a big threat to the community in Maridi County and people don't know how it can be handled, It is communicable disease and transmitted through saliva
- Some people came two years back to investigate the issue but up to now no results
- People become fearful and for the children to go to school is a stigma issue, discrimination both at home and in the community
- No new cases but those affected remained with the disease,
- Cultural beliefs, bewitched, misfortune, curse might have contributed to the infection
- Ongoing medical intervention is provision of medication to subside the effect of the disease but no cure
- AMEREF and CAUM aid but the cases remain stagnant
- One challenge is parents prefer traditional medication than the clinical medicine
- Recommend the engaging traditional leaders to help refer affected children for medical attention and more funding for supporting parents support groups to advocate and reach more families and communities on the NS
- He received the delegation and expressed Mr. John Ezekiel Paul Mr. John

**MR. JOHN
EZEKIEL PAUL**

Executive Director/Maridi County

GRACE MICHAEL

Parent/family of the Affected children

Ezekiel Paul appreciation for looking into the issue of NS.

- Children with NS do not go to school due to the parents
- Expressed need to support the delegation in acquiring information in the county

- They have 9 cases in the family and one died and expressed the financial burden of medication before AMEREF and CAUM came in Maridi.

- Discrimination of the children at school and in the community

- She recommended material support for the affected children inform of soaps

- Nutritional support to the affected children who take medication and continual provision of medicines to the vulnerable families

- Provision of free education to children affected with NS and

- IT is their 3rd saving scheme and the will graduate on the 14th December 2023

- The VSLA is for supporting the families of children affected by the NS

- They advocate for more VSLA and create awareness too. Bu due to lack of support, the activity stopped

SUZAN KEJI,
UMJUMA, EZIKIA,
LILLIAN JOSEPH,
LUCIA WILSON,
RODA EZIKIA ,
ESTHER JOHN,
NADIA JOHN AND
NURA JOHN

Faith Village Saving /Loan Group

KEZIYA JOSEPH
FARABA,
0929809258

Parent/ Families of children affected in kazana 2

- She expressed how it started in her family, 3 cases, one subsided but 2 are not responding to the treatment

- Husband died and all the burden of taking care of the affected children on her with no support, neither part of the VSLA

- Cried of the need for provision of food for the affected children as they have high appetite

-

S/N	NAMES OF PERSONS INTERVIEWED	ORGANIZATION	
1.	Samuel Chador(Mental health officer) , Samuel Aburi(Finance officer) and Taban Stephen Alex(AMEREF team leader)	AMEREF	<ul style="list-style-type: none"> ➤ The cause of the NS not known so far but found to be related to onchocerciasis -OV around Maridi Dam ➤ Interventions of AMEREF include treatment based and research-based interventions and thirdly, mass distribution of drugs twice a year to reduce the parasite load of OV. Fourthly, AMEREF work with community volunteers to identify and refer cases for treatment and ensure affected children take medications on time
2.	Asiki Festo	County Health Department	<ul style="list-style-type: none"> ➤ NS is a neglected disease in Maridi ➤ Until seizures are stopped, those affected cannot go to school. Parents have lost hope and there is need for more health education and community awareness ➤ Community level contribution is required as part of their role in the intervention by cleaning the breeding place for the blackflies around the Maridi Dam (Every three months) ➤ Need for rehabilitation services and programmes for children /young people affected by NS ➤ Provision of incentives to teachers handing children affected in Schools ➤ Government to reconsider all aspects of NS-psychological interaction and ensure adequate social workers area available to provide psychosocial support.

DEBRIEFING

On the 13th December 2023, the delegation completed the required key informant interviews and focus group discussions with stakeholders at Maridi County and held a debriefing session with the Sudan Evangelical Mission at 4:00 pm at Greenland hotel.

Responsible person	Remarks
John Ahculube (<i>Light for the World</i>)	<ul style="list-style-type: none"> ➤ Appreciated the CBR workers, the SEM supervisor and mental health officer for all the logistical support and coordination for achieving the objectives of the mission ➤ Expressed the need for on -going advocacy to reveal more new cases and he finally reiterates the commitment of Light of the World to continue to work with them
Esther Akumu Achire	<ul style="list-style-type: none"> ➤ She appreciated the team from Sudan Evangelical Mission for the hard work and all the support in making the visit successful. She uttered the how the team carryout their work in humanity to support the affected children and build their resilience. She said we don't need to create gaps in the communities and despite all the efforts, we are not yet there. Restoring the education of these children is very important.
Hon. Esther Ikere Eluzai	Expressed the opportunity provided by Light for the world for her to visit Maridi County for the first time. She expressed a concern on the devastating impact of nodding syndrome in Maridi and WES in general. She said, NS is a public health, Disability- and a social welfare issue that needs to be flag at the national level. Finally, she thanked the SEM team on top of them Emmanuel Loda for all the coordination and logistical support in making our visit successful
Emmanuel Loda, Joy Guramu, Isaac Barak and Justin Yassin	All the team of SEM were very grateful for the visit and thank the delegation for choosing to come to Maridi and uncover the hidden vice that affected many children. You have seen by your own eyes and hope you go and advocate on our behalf. One recommendation for you is to support us by mobilizing more partners to assist the children in Maridi.
4:00pm-6:00	End of the Programme/Rest

KEY RECOMMENDATIONS

- Government to reconsider all aspects of NS-psychological interaction and ensure adequate social workers are available to provide psychosocial support.
- Recommend formation of more VSLA for more women and families of Children affected with NS are inclusive (Many women with affected children expressed interest to join the VSLA)
- *There is need to help clinicians, scientists, and policymakers develop guidelines for prioritizing this severe condition.*
- There need to examine global health approach to nodding syndrome via the sustainable development goal by investing in some of the goals concerning health, poverty alleviation and quality education, among others. Thus, individuals suffering from nodding syndrome and their families may derive clear benefits which eventually can lead to an overall reduction in morbidity and mortality

CONCLUSIONS

South Sudan is amongst the highly endemic countries for Onchocerciasis in Africa, with the disease endemic around half (49%) the country. The most highly endemic foci of onchocerciasis in South Sudan are in Western Equatoria, Northern and Western Bahr el Ghazal regions. A very high prevalence and incidence of epilepsy was observed in several villages in Maridi County located close to the Maridi River and the Maridi dam. Urgent action is needed to prevent children in Maridi County from developing OAE by strengthening the onchocerciasis elimination program (Jane, y Careter & Peter Claver, 2018). Therefore awareness of nodding syndrome needs to be raised, so that it will not be forgotten and inclusive approaches to education need to be sustained in schools to ensure the affected children are enrolled and attend school in Maridi County.




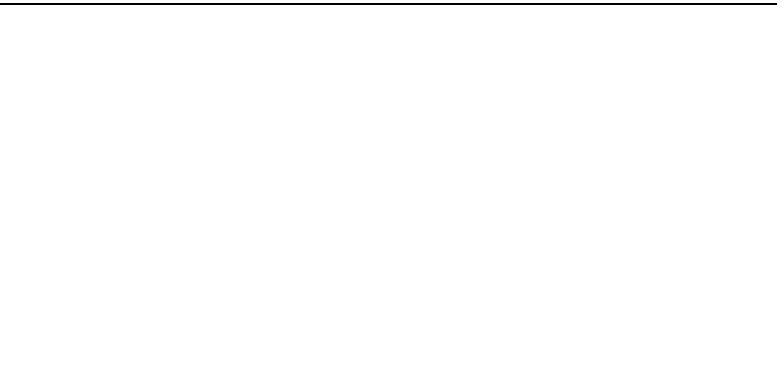
ANNEXES

ANNEX 1: Programme of the consultation with stakeholders in Maridi from the 12th -14th December, 2023

ANNEX 2: List of stakeholders Interviewed

S/N	NAMES	INSTITUTION	CONTACTS
1.	Emmanuel Lodo	CBR, Supervisor, Sudan Evangelical Mission	0928119920, 0921119297 emmanueloda1@gmail.com
2.	Mr. Elia Zacharia	Director, Maridi County Education Department	0923139879
3.	Eli Alfred Makirioj	Director of Gender, Child & social welfare	0922396603 elialfred14@gmail.com
4.	Mr. John Ezekiel Paul	Executive Director, Maridi County	0929378751
5.	Grace Michael	Parent of the Affected children with NS	
6.	Suzan keji,	Faith Women Saving and Loan Association	0929244209
7.	Umjuma, Ezikia	II	
8.	Lillian Joseph,	II	
9.	Lucia Wilson	II	
10.	Roda Ezikia	II	
11.	Esther John,	II	
12.	Nadia John		
13.	Nura John	II	
14.	Keziya Joseph Faraba,	Parent of the affected children	0929809258
15.	Samuel Chador	Mental health officer, AMREF	0920011006
16.	Samuel Aburi	Finance officer, AMREF	0924722046
17.	Taban Stephen Alex	(AMREF team leader)	0923544923 Taban.stephen@gmail.com
18.	Asiki Festo	CHD, Maridi County	0927602403, 0922580026 asikifesto@gmail.com
19.	Levi William Juma	D/H/Tr., Maridi One School	0927369224
20.	Oliver Kaga William	H/teacher, Mudibai School	0921513350
21.	James Baraka Dominic	School officer, Omungasa School	092476223,
22.	Joy Guramu	Mental health officer, SEM	0921637076
23.	Justin yassir	CBR, SEM	0925254893
24.	Isaac Baraka	CBR, SEM	0921643885

Annex 3. Photos

	<p>Photo at the entrance of the Mental Health Clinic at Maridi Hospital</p>
	<p>At the Mental Health clinic at Maridi Hospital With survivors waiting for medicines</p>
	<p>Meeting with the AMREF staff at Maridi Hospital (13th December 2023)</p>
	<p>Staff of health department and AMREF at the Mental Health clinic(13th December, 2023).</p>



Meeting with the Families/Parents of nine(9) children affected with nodding syndrome in one household at Kazana one area(12th December 2023).



Meeting with the parents of the affected children in kazana Otwo(2)



Parent of the children affected with nodding syndrome in kazana 2(12th December 2023)



Pictures of the blackflies, a correlate factor for the cause of the Onchocerca volvulus. OV is the virus which cause NS