

HOPE CENTRE UGANDA

Concept Note

Project Name: Special Needs Intervention for Livelihoods
improvement and protection of the
Rights of
& Families Children living with Nodding Syndrome,
Affected By Nodding Syndrome.

Project Goal The primary goals of the project are to strengthen livelihoods, improve on menstrual health education, and to scale up special needs intervention, particularly through music therapy at the rehabilitation Centre, whilst also increasing the amount of children living within the Centre, for children living with Nodding Syndrome and their affected families.

Project Target: Children affected by Nodding Syndrome

Project Area: Gulu, Kitgum, Pader and Omoro District

Project Duration: 36 months (3 years) starting from November 2018

To November 2021

Introduction and Problem Statement

After two decades of Civil War in Northern Uganda between the LRA and the Government; the region has seen relative stability and silence of guns since 2006. A significant majority of communities have returned back to their home villages after years of living in IDP (Internal Displacement Persons) camps. There was considerable pressure on communities as they moved back to their place of origin, clearly seen in the resettlement of the former IDPs. There was little to no preparation as they returned back to their ancestral lands. The Northern Uganda war led to the loss of lives, properties, culture, social settings and socio-economic activities.

As a result of this, there has been a great change in gender roles, single parents in the community and the new era of child headed households. The people of Northern Uganda needed to invest in rebuilding their livelihoods through agro business, life skills, micro-credit, agri-business, and livestock rearing.

After the return of the communities, back to their respective home from the IDP camps, the beginning of 2007 posed new health challenges to children directly affected by the disease known as the Nodding syndrome (NS), a condition which remains with no identified scientific name.

Nodding Syndrome, a neurological condition with unknown etiology, was first documented in the United Republic of Tanzania (URT) in the 1960s, then later in the Republic of South Sudan in the 1990s and in Northern Uganda in 2007-2009. There was push by the Civil Societies, international organizations and many individuals to ensure that the issue of Nodding Syndrome is brought to the knowledge of both the Government and the International community. During this process, little was done for the children suffering from the condition.

Typically, Nodding Syndrome affects children between the ages of 5 and 15 years old, and brings the clinical symptoms of progressive cognitive dysfunction, neurological deterioration, stunted growth and a characteristic nodding of the head. These effects are accompanied by other social and familial problems such as the poor or lack of proper caretaking of children with NS. Within the family NS is often seen as a huge burden, with families now also developing depressive and anxiety disorder as a result.

Despite the various efforts of the Ugandan Government and civil society organizations, particularly in offering support at the Centre in Omoro district, in the way of bio medical interventions and psychosocial support to families affected by NS, it seems to be at a loss. Due to lack of funds the Centre is officially committed to be closed by the central Government. This has led families with children in the Centre to the worsening of ...

At the moment the Centre has only 25 kids and over 200 victims of NS in the community. As per our assessment of families and the

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| Project Goal | The Goal of the project is to strengthen livelihoods, improve on the menstrual health cycle, expand and increase the number of kids with NS and scale up special needs intervention through music therapy at the centre for the children and families affected by nodding syndrome. |
| Specific Object of the Project | <ol style="list-style-type: none">1. Provide psychological and social support that seeks to restore relationships and healing of wounds for families of children affected by Nodding syndrome.2. Provide rehabilitation services with occupational, physio, speech and language therapy to improve and restore some of lost functions and prevent further disability through Music therapy friendly services.3. Build the capacity of office duty bearers / leaders to advocate for better health services delivery for children affected by nodding syndrome. |

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| <p>Justification and Detail Implementation Strategies</p> | <p>1. <u>Strengthening Medical Management of Nodding Syndrome and Improve Emergency Response.</u></p> <p>The Nodding syndrome centre in Odek was set by Hope for Human Organization which unfortunately closed in December 2017 and the Government Took over in July 2018 but have ran short of funding. According to the LCV of Omoro, the Centre has very little fund left that can run up to the End of October 2018. This is the only Government recorgnized Rehabilitation Centre for the Children living with Nodding Syndrome in the entire Northern Uganda. The Centre is with well established facilities and support staffs to administratively manage the centre, however with the current new development of closing the centre due to poor legislations from the office duty bearers had negatively impacted on the centre for example drugs recommended by World Health Organization for life threatening co-morbidities including status epilepticus, severe anaemia, hypoglycaemia and hypothermia especially in severely malnourished children at the centre are not stocked. In addition extreme cases like extensive burns and other severe injuries drugs are not supplied to the centre by the National Drug Authority. several anaemic children that needed haemoglobin with under nutrition and dehydration status are not supported and yet it's a requirement for them to have packed blood cell transfusion that should help in the concurrent congestive cardiac failure which sometime the centre lacks.</p> <p>Hope Centre Uganda therefore will strengthen the Management of the centre by, Advocating for the rights of the children living with Nodding Syndrome, Open the Centre for more Admission of the children living with Nodding Syndrome, and strengthening the families and parents of this children living with Nodding Syndrome in the field of Agro-Business/livestock, Agri-Business, Micro Credit loan program and doing community sensitization and awareness creation on how cope with the Nodding syndrome victims.</p> <p>SUSTAINABLE GOAL</p> <p>Hope Centre Uganda would love to establish a strong Agro Business with much emphasy on animal husbandry that shall in future help to help improve on the Nutritional diet and some finances for supporting in the administrative cost. This shall be a collective responsibility from both the affected community/families and the victims themself.</p> <p>Hope Centre Uganda will train a team of parents to become ambassadors for the rest of the victims living with Nodding Syndrome. This shall ensure that the plights of the victims are discussed in many forums both local, National, Regional and international.</p> <p>These parents shall also be equip with counseling and</p> |
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| 1. <u>Participants, location and target</u> | 2. <u>Participants, location and target</u> Primary Participants The primary direct beneficiaries of the project are children admitted at the Centre. Secondary Participants Members of the family and children of affected by the Nodding syndrome outside the centre Tertiary Participants The tertiary participants of the project include the duty bearers in the political office and community to actively participate in the campaign and advocacy in supporting the children affected by NS. Project location The catchment areas of the operation incorporate Acholi sub region. |
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| s/no | Item | Per unit costs | quantity | total quantity costs | Remarks |
|------|----------------------------------|----------------|-------------------|----------------------|----------|
| 1 | Bed | 200,000 | 38 | 7,600,000 | one time |
| 2 | Feeding | 100,000 | 24 weeks(68 kids) | 2,400,000 | 6 months |
| 3 | Care takers | 200,000 | 8 staff | 9,600,000 | 6 months |
| 4 | security guard | 100,000 | 1 | 600,000 | 6 months |
| 5 | Cook | 150,000 | 2 | 2,400,000 | 6 months |
| 6 | Transport | 200,000 | 6 | 1,200,000 | 6 months |
| 7 | Music system(tv, radios, speaker | 1,500,000 | 1 | 1,500,000 | one time |
| 8 | miscellaneous | 100,000 | 6 | 600,000 | 6 months |
| 10 | Chicken | 5000 by 68 | 68 | 3,400,000 | one time |
| 11 | Goats | 60,000 by 68 | 68 kids | 4,080,000 | one time |
| 12 | Grand Total | | | 33,380,000 | |