

# **Neurxtend Foundation Initiatives in Psychosocial Training and Support for Families Affected by Nodding Syndrome and Other Neurological Diseases in Northern Uganda and Uganda**

## **1. Background**

Northern Uganda remains one of the regions most affected by **nodding syndrome, epilepsy, stroke, and other neurological disorders**. These conditions have had devastating impacts not only on the affected children but also on their **families and caregivers**, who endure prolonged emotional, social, and economic stress.

Families caring for children with nodding syndrome often experience:

- **Psychological trauma and hopelessness** due to the chronic and disabling nature of the disease.
- **Stigmatization and social isolation** within their communities.
- **Economic strain** from the inability to work while providing full-time care.
- **Limited access to mental health and psychosocial support services.**

To address these challenges, **Neurxtend Foundation** has established a specialized **Psychosocial Training and Support Initiative** to restore hope, resilience, and emotional wellbeing among affected families and communities across **Northern Uganda and Uganda**.

## **2. Goal**

To improve the **psychosocial wellbeing and mental health resilience** of families and communities affected by **nodding syndrome and other neurological conditions**, enabling them to live with dignity, hope, and social inclusion.

## **3. Specific Objectives**

1. To train **caregivers, community health workers, and teachers in basic psychosocial care and trauma-informed support.**
2. To provide **individual and group counseling** to families affected by neurological diseases.
3. To establish **community-based psychosocial support networks** that promote emotional healing, mutual support, and stigma reduction.
4. To integrate **mental health and psychosocial services** into **Neurxtend Foundation's Telemedicine and Neurological Care Programs.**
5. To strengthen **community awareness and acceptance** of individuals living with neurological conditions.

## 4. Core Activities and Initiatives

### A. Psychosocial Training for Caregivers and Community Volunteers

- Conduct structured **training workshops** for caregivers and community volunteers on topics such as:
  - Psychological First Aid
  - Stress and Trauma Management
  - Counseling Skills
  - Coping and Self-care Techniques
- Develop a **network of community psychosocial workers (CPSWs)** who can provide ongoing emotional support and referral services at the grassroots level.

### B. Family Counseling and Emotional Support

- Offer **individual and family counseling sessions** to parents and caregivers of children with nodding syndrome.
- Conduct **home visits** and follow-up sessions to assess mental wellbeing and provide ongoing support.
- Empower families to **understand and manage stress**, rebuild hope, and develop coping strategies for long-term caregiving.

### C. Community Psychosocial Support Groups

- Form **peer support groups** for parents and caregivers in affected sub-counties such as **Angagura, Atanga, Awere, and Lamwo**.
- Facilitate **sharing circles** and group therapy sessions that encourage dialogue, empathy, and shared healing.
- Build community solidarity to reduce **stigma and discrimination** toward affected families.

### D. Child-Focused Psychosocial Interventions

- Organize **play therapy, art therapy, and recreational programs** to help affected children express emotions and improve their social interaction.
- Train teachers and caregivers to identify **psychological distress in children** and respond appropriately.
- Establish **safe spaces** for children to learn, play, and rebuild confidence.

### E. Integration with Telepsychology and Neurological Care

- Link psychosocial services with **Neurxtend Foundation's Telemedicine Centers** to provide **online mental health consultations** and continuous follow-up.
- Enable caregivers to access remote counseling through mobile platforms and community hubs.

- Train telemedicine staff in **psychological first aid and crisis response** for neurological emergencies.

## F. Awareness and Advocacy Campaigns

- Conduct **community dialogues, radio talk shows, and sensitization campaigns** to raise awareness about mental health and neurological care.
- Advocate for the inclusion of **psychosocial support and mental health services** in national and district health programs.
- Promote acceptance and integration of affected children into schools and communities.

## 5. Implementation Partners

- **Lead Organization:** Neurxtend Foundation (program coordination, funding, technical guidance).
- **Key Partners:** Ministry of Health, Uganda Red Cross Society, local governments, faith-based organizations, and community-based organizations.
- **Target Beneficiaries:**
  - Families and caregivers of children with nodding syndrome and epilepsy
  - Children living with neurological disorders
  - Community health volunteers and psychosocial workers

## 6. Expected Outcomes

- Over **1,500 caregivers and community volunteers trained** in psychosocial care and trauma management.
- Improved **mental wellbeing, emotional stability, and coping skills** among affected families.
- Established **community psychosocial support networks** across Northern Uganda.
- Reduced **stigma and isolation** of families affected by neurological diseases.
- Integration of **mental health and psychosocial support (MHPSS)** into Neurxtend's broader health initiatives.

## 7. Sustainability Plan

- Continuous mentorship for trained community psychosocial workers.
- Integration of psychosocial care into **Neurxtend's nutrition, telemedicine, and neurological rehabilitation programs**.
- Partnership with **district health and education offices** to embed psychosocial support in community and school programs.

- Development of **digital counseling and awareness platforms** for long-term engagement.

## **8. Conclusion**

The **Neurxtend Foundation Psychosocial Training and Support Initiative** offers a lifeline to families devastated by **nodding syndrome and other neurological diseases**.

By combining **training, counseling, community support, and digital mental health solutions**, Neurxtend Foundation is helping to rebuild hope, resilience, and social inclusion for some of Uganda's most vulnerable communities.

This initiative stands as a model of **compassionate, holistic, and community-centered care**, ensuring that no family is left behind in the fight against neurological and mental health challenges.