

# RESEARCH PROPOSAL

The Holistic Stimulation of the Integral Development of Children in Emergency Situations: A Study on Children with Disabilities in Dzaleka Refugee Camp

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## Title

The Holistic Stimulation of the Integral Development of Children in Emergency Situations: A Study on Children with Disabilities in Dzaleka Refugee Camp

## Summary

This umbrella research project explores the impact of holistic approaches to child development within emergency settings, focusing on children with disabilities in Dzaleka Refugee Camp, Malawi. Refugee children, particularly those with disabilities, face barriers such as exclusion, stigma, and limited access to essential services. The study is organised in two phases: the first is an exploratory mixed-methods component using the structured tool *Child's Record* (Appendix 1), and the second adopts a qualitative design.

The *Child's Record* (Appendix 1) is a questionnaire co-developed by a multidisciplinary team—including clinical psychologists, educators, medical professionals, social workers, and public health experts—alongside local stakeholders, community leaders, and grassroots practitioners embedded in the camp. It aims to map each child's developmental, physical, emotional, and behavioural profile. Administered by trained English-speaking interviewers, the tool will be supported by interpreters in local languages (e.g., Chichewa, Swahili, or Kinyarwanda), ensuring culturally appropriate communication.

The second phase of the study uses semi-structured interviews to assess the relevance and perceived impact of the intervention. Participants include informal caregivers of children with disabilities and staff members from the Refugee Camp Coordinating Committee (RCC). The research will guide service improvements, support inclusive practices in emergencies.

# 1. Background / Introduction

This research explores the impact of holistic approaches to child development in emergency contexts, specifically focusing on children with disabilities in Dzaleka Refugee Camp, Malawi. Refugee camps, by nature, are complex environments where crisis, instability, and poverty intersect, exacerbating the vulnerabilities of populations, particularly children with disabilities (UNHCR, 2023; WHO & World Bank, 2011). In these settings—where resources are scarce and systems are stretched thin—children with disabilities are at heightened risk of poor developmental outcomes (UNICEF, 2021; Zuurmond et al., 2019).

Established in 1994, Dzaleka currently houses over 55,000 refugees, including more than 15,000 school-aged children (UNHCR, 2023; Jesuit Refugee Service Malawi, 2022). Many of these children, especially those with disabilities, face significant barriers to accessing education, healthcare, and essential services. These services are crucial for their development, yet they are often fragmented or inaccessible. Children with disabilities endure multiple layers of exclusion—not only from formal systems but also from social participation—leading to compounded stigma, isolation, and restricted cognitive, emotional, and social growth (UNICEF, 2021; WHO & World Bank, 2011).

Providing holistic care is critical in emergency settings, especially for children with disabilities. A holistic approach integrates various forms of support—educational, healthcare, nutritional, and psychosocial—into a comprehensive framework (Britto et al., 2017; UNICEF, 2017). Research indicates that children in vulnerable situations, such as those in refugee camps, show the most progress when these needs are addressed in tandem, as fragmented approaches fail to respond to their complex challenges (Blanchet et al., 2017; Marfo et al., 2011).

Ubuntu Nation School, operated by the Brazilian NGO *Fraternidade Sem Fronteiras*, and the Respite Care Centre (RCC), also managed by the same organisation, represent critical community-driven interventions in this context. Ubuntu Nation provides formal education opportunities tailored to children with disabilities, while RCC offers therapeutic, medical, and social care. These interventions are shaped by a multidisciplinary team and supported by local community leaders and families (Fraternidade Sem Fronteiras, 2023; Silva & Hakimi,

2024). Despite these efforts, gaps persist in accessibility, quality, and continuity of care—particularly for children with disabilities who require sustained and coordinated support.

This research aims to assess the effectiveness of integrated, holistic interventions in improving developmental outcomes for children with disabilities in Dzaleka. It will examine the services delivered through Ubuntu Nation and RCC and identify enablers and barriers to positive outcomes. Additionally, the research explores the role of community engagement by evaluating how families, caregivers, and volunteers contribute to the development and inclusion of children in this low-resource setting (Marfo et al., 2011; Britto et al., 2017).

Ultimately, this study seeks to generate meaningful evidence on how contextually relevant, integrated approaches can enhance developmental trajectories for children with disabilities living in protracted emergency contexts, contributing to the global literature on inclusive, community-based responses in humanitarian settings (UNICEF, 2021; Zuurmond et al., 2019; Blanchet et al., 2017).

## **2. Context and Rationale for the Study**

As mentioned before, Dzaleka Refugee Camp is home to over 55,000 refugees, with more than 15,000 children of school age. However, many of these children—especially those with disabilities—are unable to attend school due to limited access to education, healthcare, and social services. The camp's infrastructure struggles to meet the complex needs of its residents, and children with disabilities face compounded challenges, such as social exclusion, stigma, and a lack of specialized services. These barriers severely hinder their full participation in educational, social, and health-related activities, leaving them vulnerable to long-term developmental setbacks (Easterly, 2006; Santos, 2016).

Ubuntu Nation School, an initiative by *Fraternidade Sem Fronteiras*, aims to provide inclusive education and psychosocial support tailored to the needs of children with disabilities. Additionally, the Respite Care Centre (RCC), also under the management of *Fraternidade Sem Fronteiras*, delivers specialized care to address

the children's medical, therapeutic, and social needs. These efforts are vital, but they face significant constraints, including service gaps, limited availability of trained professionals, and issues around sustaining continuity in care (Dagnino, 2004; Bourdieu, 1990).

The integration of education, healthcare, and psychosocial support is widely recognised as essential to improving developmental outcomes in emergency settings. Holistic models not only respond to children's individual needs but also work to dismantle structural barriers through coordinated, person-centred strategies. This research seeks to investigate how these integrated interventions—particularly those led by Ubuntu Nation School and the RCC—support the holistic development of children with disabilities in Dzaleka. Moreover, the study will explore the role of community engagement, including the participation of local families, volunteers, and peer caregivers, in helping overcome the persistent challenges posed by resource limitations and systemic fragmentation (Cornwall, 2011; Sachs, 2005).

By exploring the perceived effectiveness and contextual relevance of these integrated interventions, the study aims to inform the development of inclusive service delivery models in humanitarian contexts. The findings will contribute to global discussions on advancing equitable child development policies and practices in displacement settings.

## **Research Questions**

1. What are the developmental, physical, social, emotional, and behavioural profiles of children with disabilities enrolled in the Ubuntu programme at Dzaleka Refugee Camp?
2. What are the primary caregivers' concerns and needs?
3. How does the Child's Record (Appendix 1) tool function as a culturally adaptable instrument for mapping children's holistic development in an emergency context?
4. How do informal caregivers of children with disabilities perceive the relevance and impact of the Ubuntu intervention on their children's development and well-being?

5. What are the views of RCC staff involved in disability and child protection roles regarding the implementation, cultural fit, and challenges of the intervention?
6. What factors are seen as enablers or barriers to the effective delivery of holistic child development programmes in the context of displacement and cultural diversity?

### **3. Objectives of the Study**

- To establish a comprehensive baseline profile of children with disabilities attending the Ubuntu Nation School and Respite Care Centre at Dzaleka Refugee Camp and of their primary care concerns and needs
- To Assess the Impact of Holistic Interventions: Evaluate the effectiveness of the RCC and the Ubuntu Nation School's educational, medical, and psychosocial interventions on the overall development of children in the camp (Bamberger, 2012; Patton, 2002).
- To Understand the Role of Social Support Systems: Investigate how the involvement of the local community, including parents and volunteers, influences the care and development of children with disabilities (Pretty, 1995; Kolb, 1984).
- To Explore the Challenges and Gaps in Service Delivery: Identify the main challenges faced by caregivers, educators, and children in the delivery of services, especially in terms of infrastructure, resources, and continuity of care (Chambers, 1997; Gohn, 2013).
- To Develop Recommendations for Improving Support Systems: Propose improvements to existing support structures and interventions for children with disabilities in Dzaleka (Morse & Richards, 2013).

## **4. Methods**

### **Summary**

The research will employ a mixed-methods approach combining qualitative and quantitative data collection techniques. The study will involve two phases and

will be conducted over a 24-month period and will focus on children with disabilities attending the Respite Care Centre and the Ubuntu Nation School (Merryfield, 2002; Jones, 2013).

## **Design and Data Analysis**

This research employs a sequential mixed-methods design to explore the holistic development of children with disabilities in Dzaleka Refugee Camp. The design combines quantitative and qualitative approaches to capture both structured developmental indicators and rich, contextualised lived experiences of caregivers and stakeholders.

### **Quantitative Component**

The first phase of the study involves administering a structured tool titled the Child's Record (Appendix 1) with informal caregivers. The questionnaire captures key domains of child development, such as physical health, cognitive functioning, emotional regulation, social skills, educational engagement, behaviour, and home environment.

Data collected through the Child's Record (Appendix 1) will be analysed using descriptive statistics to identify general patterns, frequencies, and trends in children's developmental challenges and their access to services. This statistical summary will enable the identification of service gaps and areas of need across the population. The quantitative data will also serve as a baseline for planning and targeting individualised interventions and for informing future stages of the research (Almeida Filho, 2013; Sabatier & Weible, 2014).

### **Qualitative Component**

The second phase of the study adopts a qualitative approach to gain deeper insight into the social and experiential dimensions of caregiving and service provision in the camp. Data will be gathered through:

- **Semi-structured interviews** with caregivers, RCC staff, and community leaders;
- **Focus groups** with volunteers and stakeholders involved in the Ubuntu Nation School and Respite Care Centre;

- **Field observations** of daily routines, care practices, and learning environments;
- **Case studies** of selected children to follow developmental progress across multiple dimensions.

These qualitative sources will be analysed using thematic analysis, allowing for the identification of key themes, patterns, and meanings within the data (Patton, 2002; Morse & Richards, 2013). This approach will provide a comprehensive understanding of how caregivers perceive the relevance and effectiveness of services, the barriers they encounter, and the cultural and systemic factors shaping their experiences.

By integrating both quantitative and qualitative data, this mixed-methods design offers a robust and nuanced understanding of the effectiveness and limitations of holistic child development interventions in humanitarian settings.

## **Data Collection**

This study will be conducted in two interconnected phases, each designed to gather a comprehensive picture of the developmental experiences of children with disabilities in Dzaleka Refugee Camp.

### **Phase 1: Exploratory Mixed-Methods Using the Child's Record**

The initial phase involves administering the *Child's Record* (Appendix 1) a structured tool developed through collaborative efforts by professionals from psychology, medicine, education, social work, and public health, alongside local stakeholders and community leaders. The tool captures key aspects of each child's health, behaviour, emotional wellbeing, education, and daily routine, as well as information on family and caregiving context.



Data collection will be carried out by trained English-speaking interviewers. To accommodate the multilingual and multicultural nature of Dzaleka, interpreters will be available to assist participants in their preferred language or dialect—including French, Chichewa, Swahili, or Kinyarwanda—ensuring that communication remains inclusive and culturally respectful. This phase will generate structured data that informs both initial profiles and future support planning for the participating children and families.

## **Phase 2: Qualitative Fieldwork**

Building on the structured data, the second phase will involve qualitative methods to explore participants' lived experiences and contextualise service delivery dynamics. In-depth interviews will be conducted with caregivers, educators, and community leaders to understand their perceptions of the holistic care provided and the daily challenges they face (Freire, 1979; Geertz, 1983).

Focus groups will be convened at the RCC and Ubuntu Nation School with staff, volunteers, and caregivers to explore group perspectives, shared concerns, and community-level support mechanisms (Cohen, 2010).

To enrich the understanding of real-world practices, observational studies will be conducted within both institutions, capturing daily routines and interactions, particularly focusing on how children engage with educational and rehabilitative activities (Bourdieu, 1977; Katz & Anheier, 2002).

Additionally, detailed case studies will be developed for a subset of children to track their experiences and developmental changes over time across multiple domains, including education, medical care, and psychosocial support (Drucker, 1993; Giddens, 2010).

Together, these phases are designed to ensure a holistic and context-sensitive collection of data that reflects the voices of multiple stakeholders involved in the care and development of children with disabilities in emergency settings.

## **Sample Size and Sampling Method**

This study will adopt a purposive sampling strategy, selecting participants who are most relevant to the research aims and who can offer rich, context-specific insights into the holistic development of children with disabilities in Dzaleka Refugee Camp. This method is particularly appropriate for qualitative and exploratory designs where depth and relevance of information are prioritised over generalisability (Patton, 2002; Guest, Bunce, & Johnson, 2006). The sample will include key stakeholders such as parents and caregivers of children enrolled in the Ubuntu Nation School and Respite Care Centre (RCC), as well as teachers, community leaders, volunteers, and RCC staff involved in disability-related care and education.

### **Phase 1 – Quantitative Component (Child's Record Tool)**

A minimum of 30 to 40 caregiver-child dyads will be recruited to complete the Child's Record (Appendix 1), providing a baseline mapping of the children's developmental, social, educational, and health-related profiles. This sample size is considered sufficient for exploratory descriptive statistical analysis, which aims to identify patterns, frequencies, and variations across functioning and support needs (Almeida-Filho, 2013; Sabatier & Weible, 2014).

### **Phase 2 – Qualitative Component**

For the in-depth interviews, focus groups, and case studies, an estimated sample of 20–25 participants will be included:

- 10–12 semi-structured interviews with informal caregivers of children with disabilities.
- 4–6 RCC staff and community leaders involved in child protection or disability-related services.
- 2–3 focus groups with 5–8 participants each (caregivers, teachers, volunteers).
- 3–5 in-depth case studies of children receiving comprehensive support at Ubuntu Nation School and/or RCC.

This qualitative sample allows for thematic saturation, while ensuring diversity across participant roles and lived experiences (Morse & Richards, 2013; Braun & Clarke, 2013). Recruitment will aim for variation in age, gender, type of disability, duration of displacement, and level of engagement with services to provide a nuanced understanding of experiences.

Efforts will be made to ensure inclusion and representativeness, especially considering linguistic and cultural diversity. Trained local interviewers and interpreters will support interviews conducted in preferred languages or dialects, such as Chichewa, Swahili, Kinyarwanda, or French. Interviews may also be conducted in locations preferred by participants to ensure safety, privacy, and comfort (Hennink, Hutter, & Bailey, 2020).

### **Participants**

This study will involve key stakeholders engaged in the care and development of children with disabilities in the Dzaleka Refugee Camp, Malawi. Participants will be selected using a purposive sampling method, ensuring relevance to the study aims and representation of diverse experiences and roles.

### **Target Participant Groups**

1. Caregivers and Parents of children with disabilities enrolled in either the Ubuntu Nation School or the Respite Care Centre (RCC).
2. RCC Staff Members engaged in child protection, disability services, or rehabilitation work.
3. Teachers, Volunteers, and Community Leaders involved with disability-related educational and social support within the camp.
4. Children with disabilities (via caregiver-report using the Child's Record tool).

These groups will contribute to both quantitative (Phase 1) and qualitative (Phase 2) components of the study.

### **Inclusion Criteria**

Participants will be included if they meet the following criteria:

- For Caregivers/Parents:

- Must be the primary caregiver of a child with a disability currently enrolled in the Ubuntu Nation School or receiving services from the RCC.
  - Must be over 18 years old.
  - Must provide informed consent.
  - Willing to participate in the study in either English or with interpreter support in their preferred local language (e.g., Chichewa, Kinyarwanda, Swahili, or French).
- **For RCC Staff, Teachers, Volunteers, and Community Leaders:**
    - Must be actively involved in education, social work, health care, or disability-related services within Dzaleka Refugee Camp.
    - Must be over 18 years old.
    - Must provide informed consent.

### **Exclusion Criteria**

Participants will be excluded if:

- They are under 18 years of age.
- They do not currently hold a caregiving or professional role related to children with disabilities in the context of this project.
- They are unable to provide informed consent or do not wish to participate.
- They present acute mental health challenges or cognitive difficulties that would compromise their ability to engage with the study safely and meaningfully, as assessed by the research team or partner organisations.

### **Recruitment and Safeguarding**

Recruitment will be facilitated through the Ubuntu Nation School and RCC networks, with the support of community liaison workers such as Mama Fatuma and Tresor, who are trusted figures within the camp. Participants will receive clear

information in their preferred language and will be assured that their participation is entirely voluntary, with no impact on the services they receive.

The study is designed to protect vulnerable groups. While the project involves children with disabilities, data collection will occur through caregivers only. Informed consent will be obtained prior to participation. Participants may withdraw at any stage without consequence.

## **Ethical Issues**

This study involves working with vulnerable populations, specifically children with disabilities and their caregivers in a refugee camp setting. Ethical considerations are paramount and have been embedded into all stages of the research design, in accordance with international and institutional standards.

### **1. Informed Consent**

All participants will be provided with a clear and accessible Participant Information Sheet (Appendix 2) and Consent Form (Appendix 3), which explain the study's objectives, methods, potential risks and benefits, and the voluntary nature of participation. Informed consent will be obtained before participation begins. For non-literate participants, verbal consent procedures with the support of trained interpreters will ensure understanding and ethical compliance (Israel & Hay, 2006; British Psychological Society [BPS], 2021).

### **2. Protection of Vulnerable Participants**

The project takes a protective approach by collecting data only from adult caregivers, and not directly from children, including those with disabilities. This design minimises risks of psychological distress or coercion. Ethical inclusion will be based on mental capacity and willingness to participate (UNESCO, 2005; BPS, 2021).

### **3. Cultural Sensitivity and Language Inclusion**

To ensure equity and respect for participants' identities and experiences, interpreters will support data collection in preferred local languages and dialects (e.g., Chichewa, Swahili, French, Kinyarwanda). The involvement of respected community leaders (e.g., Mama Fatuma and Tresor) in the recruitment process will

help ensure cultural appropriateness and trust (Mertens & Ginsberg, 2008; Mackenzie et al., 2007).

#### **4. Confidentiality and Data Protection**

All data will be managed in compliance with the General Data Protection Regulation (GDPR) and the University of Essex's Research Data Management Policy. Personal data will be stored securely in encrypted formats and uploaded only to institutional Box folders accessible by the research team. Data will be anonymised for reporting and academic dissemination (Bryman, 2012; University of Essex, 2023).

#### **5. Risk and Distress Management**

While minimal, the potential for emotional discomfort exists, particularly when discussing caregiving burdens, trauma, or exclusion. Interviewers will be trained in trauma-informed approaches and active listening techniques. Participants may pause or discontinue at any time and will be signposted to local psychosocial support where necessary (Liamputtong, 2007; WHO, 2016).

#### **6. Compensation and Avoidance of Coercion**

Participants will not receive monetary incentives. A previous draft mentioned non-monetary gifts (e.g., maize flour), which has been removed to avoid potential coercion. The flyer and information sheet emphasise voluntary participation and explicitly state that participation (or non-participation) will not impact any services they receive (Alderson & Morrow, 2011; BPS, 2021).

#### **7. Ethical Oversight and Accountability**

This study follows the ethical frameworks established by the British Psychological Society (BPS), Economic and Social Research Council (ESRC), and relevant guidance on research in humanitarian settings. Ethical approval will be sought through the University of Essex ERAMS system, and gatekeeper permissions will be obtained from relevant community and institutional authorities (e.g., Respite Care Centre, RCC) (ESRC, 2023; UNOCHA, 2021).

### Timetable of Work

Phase	Activity	Responsible	Timeline
1. Planning & Preparation	Finalise tools (Child's Record (Appendix 1)), design consent forms and PIS	PI, Co-Is, Collaborators	July – August 2025
	Translate and culturally adapt materials (if needed)	Co-Is, Interpreters, Local Leaders	August 2025
	Train interviewers/interpreters (ethics, confidentiality, use of tools)	PI, Co-Is	August – September 2025
	Obtain ethical approval and gatekeeper permissions (RCC, Ubuntu, Local Authorities)	PI, Co-Is	August – September 2025
	Participant recruitment and engagement	RCC staff (Mama Fatuma, Tresor), Ubuntu staff	September – October 2025
2. Data Collection – Phase 1	Administer Child's Record (Appendix 1) to caregiver-child dyads	Trained Interviewers, Interpreters	October 2025 – January 2026
	Monitor administration process and ensure quality control	Co-Is, Research Assistants	November 2025 – February 2026
	Data entry, anonymisation, and storage in secure Box folder	Research Team	November 2025 – February 2026
3. Midpoint Evaluation	Review preliminary findings from Child's Record (Appendix 1)	PI, Co-Is	March 2026
	Adjust study design or tools if needed based on findings	PI, Co-Is, Collaborators	March – April 2026
	Prepare for Phase 2 (materials, ethics amendments if needed)	PI, Ethics Team	May – June 2026
4. Data Collection – Phase 2	Conduct interviews with caregivers, teachers, community leaders	Co-Is, Local Researchers	August – October 2026

	Facilitate focus groups with RCC and Ubuntu staff and caregivers	Co-Is	September – October 2026
	Perform non-intrusive observational studies at RCC and Ubuntu Nation School	Co-Is, Field Researchers	September – November 2026
	Conduct in-depth case studies	Co-Is	October – December 2026
5. Analysis & Interpretation	Quantitative analysis (Child's Record (Appendix 1) – descriptive stats)	PI, Co-Is, Statistician	January – March 2027
	Thematic analysis of qualitative data (NVivo/manual)	Co-Is, Assistants	February – April 2027
	Integrate findings across datasets	PI, Co-Is	April – May 2027
6. Reporting & Dissemination	Share preliminary findings with RCC, Ubuntu, caregivers	PI, Co-Is, Local Leads	June 2027
	Host community feedback event	RCC, Ubuntu, Research Team	July 2027
	Draft final reports, publications, and conference submissions	PI, Co-Is	July – August 2027
	Conclude data archiving and close-out	PI	August 2027

### Dissemination Plan

The dissemination strategy for this research project is designed to ensure that findings are shared with relevant stakeholders at local, national, and international levels. Dissemination will be participatory, culturally appropriate, and tailored to the audiences involved, with a strong focus on social impact and practical application.

#### 1. Local Community Dissemination

- **Community Presentation in Dzaleka:** A participatory dissemination event will be held within the Dzaleka Refugee Camp. Key findings will be presented to participants, caregivers, RCC staff, Ubuntu Nation School educators, and community leaders in an accessible format (e.g., posters, infographics, and oral presentations in local languages).



- **Feedback and Dialogue:** The event will allow space for feedback from the community, discussion of implications, and joint reflection on how findings can support service improvements.
- **Use of Visual Materials:** Infographics, summary leaflets, and bilingual posters will be created to summarise key results for community distribution.

## 2. Organisational Dissemination

- **Fraternidade Sem Fronteiras (FSF):** A tailored report will be provided to the Brazilian NGO leading Ubuntu Nation School and RCC to support programme planning, fundraising, and advocacy.
- **RCC and Ubuntu Leadership:** Detailed summaries and strategic recommendations will be shared with managerial teams to inform practice and sustainability planning.
- **University of Essex & Partner Institutions:** Internal presentations and written briefings will be prepared for dissemination within the University of Essex, Bangor University, and the University of Lilongwe.

## 3. Academic Dissemination

- **Conference Presentations:** Findings will be submitted for presentation at relevant international conferences focusing on refugee studies, inclusive education, disability, and global mental health (e.g., International Association for the Scientific Study of Intellectual and Developmental Disabilities, Refugee Research Network, and Global Mental Health conferences).
- **Peer-reviewed Publications:** The research team will aim to publish in open-access academic journals relevant to global health, education in emergencies, and disability studies to ensure accessibility of knowledge (e.g., *Disability & Society*, *Global Health Action*, *International Journal of Inclusive Education*).

## 4. Policy and Practitioner Dissemination

- **Policy Briefs:** A concise, action-oriented policy brief will be developed and disseminated to NGOs, government agencies, and international organisations working in the humanitarian and disability sectors in Sub-Saharan Africa.
- **Workshops with Practitioners:** Workshops and reflective sessions will be offered to RCC, Ubuntu Nation School staff, and other field professionals to explore the practical implications of the research.

## Budget and Funding

This study will be implemented with careful financial planning to ensure ethical and effective use of resources. The budget is being prepared in alignment with both field-based operational needs and institutional expectations. The project will be submitted to funding calls, including research development funds, humanitarian research grants, and disability-inclusive development funding schemes.

### 1. Funding Strategy

The project team intends to apply for external funding from a range of national and international organisations that support research in global health, humanitarian response, disability inclusion, and education in emergencies. Potential funding sources include:

- UKRI – GCRF (Global Challenges Research Fund)
- Elrha – Research for Health in Humanitarian Crises (R2HC)
- Wellcome Trust – Health and Social Science Stream
- NIHR Global Health Research Programme
- British Academy
- UNICEF or UNHCR special education and inclusion funds

Applications will also be explored through internal university research development funds and collaboration with partners such as Bangor University, University of Essex, and University of Lilongwe.

### 2. Projected Budget Overview (Indicative)

Category	Estimated Cost (GBP)	Details
Personnel	£12,000	Research assistants (local and UK-based), translators, data entry clerks
Training & Capacity Building	£2,500	Training local fieldworkers and interpreters on ethics, data collection

Category	Estimated Cost (GBP)	Details
Data Collection Tools	£1,200	Printing questionnaires, notebooks, software subscriptions (e.g. NVivo)
Travel and Accommodation	£6,000	Field travel, accommodation, and per diems for UK-based researchers
Community Engagement Activities	£2,000	Dissemination workshops, community meetings, bilingual materials
Translation & Interpretation	£1,500	For interviews and community materials (Swahili, Chichewa, French, etc.)
Ethical Compliance & Oversight	£500	Consent forms, insurance, gatekeeper letters, safeguarding provisions
Monitoring & Evaluation	£800	Field coordination, remote support, regular evaluation of field activities
Dissemination	£2,500	Conference fees, policy brief production, publications, community feedback
Contingency (10%)	£2,500	Unforeseen costs (currency shifts, travel disruptions, additional materials)
Total Estimated Budget: £31,500		

### 3. In-Kind Contributions

- University of Essex will provide academic supervision, office resources, and ethics oversight.
- Bangor University and University of Lilongwe will offer research advice, access to literature, and contribute to capacity-building components.
- Fraternidade Sem Fronteiras (FSF) will support local infrastructure, coordination with RCC and Ubuntu Nation School, and facilitate community access.

#### 4. Financial Management

Should funding be secured, all financial procedures will adhere to the University of Essex's financial governance regulations. The Principal Investigator and Co-Investigator will jointly oversee budget allocation, ensure transparent documentation, and coordinate reporting to funders.

### 5. Study Setting and Areas

The study will be conducted in three key settings: the Ubuntu Nation School, which provides inclusive education to children with and without disabilities; the Respite Care Centre (RCC), which offers therapeutic care and respite for families; and the homes of participants, where interviews may be conducted if preferred for privacy or accessibility.

The research will focus on four main thematic areas. First, the domain of education will examine the quality and accessibility of educational opportunities provided at both the Ubuntu Nation School and the RCC, and how these contribute to the developmental outcomes of children with disabilities (Cornwall, 2011). Second, the healthcare and nutrition component will explore the availability and effectiveness of medical and nutritional services, with attention to issues such as the supply of neuropsychiatric medications and the presence of specialized care (Santos, 2007; Sen, 1999). Third, social integration and psychosocial support will be assessed by looking into how children with disabilities engage with their community, and the extent to which support networks help reduce stigma and social isolation (Diniz, 2001; Brown, 2012). Lastly, the study will investigate infrastructure and resources, including the adequacy of facilities like seating, educational materials, and therapeutic tools, and how these factors influence service delivery and participation in developmental interventions (Freire, 1987; Giddens, 2010).

## **6. Expected Outcomes**

This research is expected to generate several key outcomes that will contribute to both academic knowledge and practical service improvements in humanitarian settings:

### **Improved Developmental Outcomes for Children**

It is anticipated that the study will reveal positive developmental progress among children with disabilities who are receiving support through the holistic interventions offered by the Respite Care Centre (RCC) and the Ubuntu Nation School. These interventions, which integrate education, health, and psychosocial care, are expected to demonstrate measurable benefits in areas such as emotional regulation, social participation, and learning engagement (Bourdieu, 1990; Dagnino, 2004).

### **Recommendations for Improved Service Delivery**

The findings will offer practical, evidence-based recommendations aimed at enhancing the quality and continuity of care provided to children with disabilities in emergency contexts. Specifically, the study will suggest models for better integration across educational, medical, and psychosocial domains, supporting the development of child-centred, context-sensitive programming (Bamberger, 2012; Patton, 2002).

### **Increased Community Engagement**

The research will also emphasise the importance of community involvement, demonstrating how caregivers, volunteers, local leaders, and staff can play a pivotal role in strengthening inclusive practices and sustainability. It will explore community-

led strategies that contribute to resilience, ownership, and collective care for vulnerable children (Morse & Richards, 2013; Tapscott & Williams, 2010).

## 7. Conclusion

This research aims to contribute meaningfully to the understanding and advancement of holistic, community-based interventions for children with disabilities living in emergency settings, specifically within the Dzaleka Refugee Camp in Malawi. By combining an exploratory mixed-methods approach with deep community engagement, the study seeks to provide a comprehensive picture of how integrated education, health, and psychosocial services can enhance developmental outcomes (Almeida Filho, 2013; Cornwall, 2011). Grounded in participatory ethics and cultural sensitivity (Freire, 1979; Santos, 2007), the project not only addresses critical service gaps but also elevates the voices of caregivers, practitioners, and local leaders (Morse & Richards, 2013). The findings are expected to inform future service design, influence humanitarian policy, and support the ongoing development of all investigators and collaborators academic work (Patton, 2002; Tapscott & Williams, 2010).

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**Child's Record Form**

1. **Full Name:** \_\_\_\_\_
2. **Date of Birth:** \_\_\_\_/\_\_\_\_/\_\_\_\_
3. **Gender:**
  - ☐ Male
  - ☐ Female
  - ☐ Other: \_\_\_\_\_
4. **Parent/Guardian Contact Information:**
  - ☐ Name(s): \_\_\_\_\_
  - ☐ Relation to child: \_\_\_\_\_
  - ☐ Phone: \_\_\_\_\_
  - ☐ Address: \_\_\_\_\_
  - ☐ Email: \_\_\_\_\_
  
5. **English speaker informer's Contact Information: (any person that is part of or close to the family and helped the family to provide reliable information):**  
  
Name(s): \_\_\_\_\_  
  
Relation to child: \_\_\_\_\_  
  
Phone: \_\_\_\_\_  
  
Address: \_\_\_\_\_  
  
Email: \_\_\_\_\_
  
6. **Family Background:**
  - ☐ Refugee (specify nationality: \_\_\_\_\_)
  - ☐ Malawian
  - ☐ Other: \_\_\_\_\_
  
7. **Primary Language Spoken at Home:**
  - ☐ Kiswahili
  - ☐ Kirundi
  - ☐ Kinyarwanda
  - ☐ Chichewa
  - ☐ French
  - ☐ Other: \_\_\_\_\_

# Appendix 1

## Medical and Health Information

7. **Does the child have a diagnosed condition (stated in the Health Passport)?**

- ☐ Yes
- ☐ No

8. If yes, specify the condition(s): \_\_\_\_\_

9. Description provided by the Health Passport:

---

---

---

---

10. No specific/official condition(s), but observed symptoms by the guardian:

---

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---

11. **Does the child take medication regularly?**

- ☐ Yes
- ☐ No

If YES, complete questions 12 and 13 below:

12. List the name or de description of medication(s):

---

---

---

13. Who is responsible providing the child with the repetitive prescription?

- ☐ Health Centre in Dzaleka
- ☐ Other Health Organization in Malawi (eg. Hospital St. John of God or others)
- ☐ Family or relatives buy the medicine
- ☐ International Health Volunteer Professionals through Fraternity Without Borders
- ☐ Others: \_\_\_\_\_

14. **Does the child have any allergies?**

## Appendix 1

- ☐ No
- ☐ Food
- ☐ Medication
- ☐ Environmental
- Specify: \_\_\_\_\_

### 15. Does the child use any special equipment?

- ☐ No
- ☐ Wheelchair
- ☐ Hearing aids
- ☐ Feeding tube
- ☐ Adaptations at home (eg. bars for walking training at home, prosthetics, ...)
- ☐ Other: \_\_\_\_\_

### 16. Does the child follow a special diet?

- ☐ No
- ☐ Vegetarian
- ☐ Gluten-free
- ☐ Other: \_\_\_\_\_

---

## Prenatal and Birth Information

### 14. Prenatal Period:

- ☐ Normal pregnancy
- ☐ Complications (please specify – accidents, hemorrhages, threats of miscarriage, diseases):  
\_\_\_\_\_
- ☐ Exposure to substances (alcohol, drugs, etc.)
- ☐ High-stress environment
- ☐ Prenatal care

### 15. Birth Information:

- Duration of pregnancy: ☐ Full-term ☐ Preterm ☐ Post-term
- Place of birth: ☐ Home birth ☐ Hospital Birth ☐ Health Centre Birth
- Type of delivery: ☐ Vaginal ☐ Cesarean
- Birth weight: ☐ Normal ☐ Low - too small ☐ High - too big

## Appendix 1

### 16. Complications at birth:

☐ Yes (please specify): \_\_\_\_\_

☐ No

### 17. Neonatal period:

☐ Normal

☐ Required NICU care (please specify duration and reason eg. light shower, intensive care, others): \_\_\_\_\_

☐ Feeding difficulties

☐ Respiratory issues (eg. baby didn't cry, others...)

☐ Other health concerns (please specify): \_\_\_\_\_

---

## Behavioral and Emotional Needs

### 18. How does the child react to new environments?

<input type="checkbox"/> Calm <input type="checkbox"/> Anxious <input type="checkbox"/> Excited <input type="checkbox"/> Other: _____	<b>Comments:</b>
--	------------------

### 19. Does the child experience behavioral challenges?

- ☐ ☐ No
- ☐ ☐ Tantrums or meltdowns
- ☐ ☐ Aggression
- ☐ ☐ Withdrawal
- ☐ ☐ Other: \_\_\_\_\_

### 20. Does the child prefer:

☐ Group activities

☐ One-on-one interaction

☐ Solitary play

## Appendix 1

### 21. What helps calm the child during distress?

- ☐ ☐ Quiet space
  - ☐ ☐ Favorite toy
  - ☐ ☐ Physical comfort (hug, holding hands)
  - ☐ ☐ Other: \_\_\_\_\_
- 

### Daily Care Requirements

#### 22. Is the child independent in eating and drinking?

- ☐ ☐ Yes
- ☐ ☐ No

#### 23. Does the child require assistance with toileting?

- ☐ ☐ Yes
- ☐ ☐ No

#### 24. Does the child have a consistent sleep routine?

- ☐ ☐ Yes
- ☐ ☐ No

#### 25. Does the child nap during the day?

- ☐ ☐ Yes
  - ☐ ☐ No
- 

### Communication and Sensory Needs

#### 26. How does the child communicate?

- ☐ ☐ Verbal
- ☐ ☐ Non-verbal
- ☐ ☐ Malawian sign language
- ☐ ☐ Uses a communication device

## Appendix 1

**27. Does the child have sensory sensitivities? (think of different environments eg. at the church, at the school, at home, others). Could you give me any example of it?**

- ☐ No
- ☐ Bright lights
- ☐ Loud noises
- ☐ Textures (clothing, surfaces)
- ☐ Other: \_\_\_\_\_

**28. What is the best way to give instructions to the child?**

- ☐ Short sentences
  - ☐ Visual aids
  - ☐ Demonstration
- 

### Safety Considerations

**29. Does the child have a history of wandering or running away?**

- ☐ Yes
- ☐ No

**30. Does the child experience seizures or other medical emergencies?**

- ☐ Yes - describe the emergency protocol: \_\_\_\_\_
  - ☐ No
- 

### Parent/Guardian Preferences

**31. What is the primary goal for the child in respite care?**

- ☐ Socialization
- ☐ Recreational activities
- ☐ Independent skill development
- ☐ Providing relief for the parents
- ☐ Providing opportunity to work or to search for sustenance
- ☐ Others: \_\_\_\_\_

## Appendix 1

### 32. Are there any activities the child should avoid?

- ☐ Yes (specify): \_\_\_\_\_
- ☐ No

### 33. Would you like updates about the child's activities?

- ☐ Daily
  - ☐ Weekly
  - ☐ Only if issues arise
  - ☐ I don't want or need any update
- 

## Caregiver Feedback (to be completed after care)

### 34. How did the child respond during the session?

- ☐ Positive engagement
- ☐ Some challenges
- ☐ Significant difficulties

### 35. Were there any incidents to report?

- ☐ Yes (describe): \_\_\_\_\_
- ☐ No

### 36. Recommendations for future sessions:

- ☐ Continue as planned
- ☐ Adjust activities (specify): \_\_\_\_\_



## Appendix 2



Dear Participant,

We are a group of researchers at the University of Essex. Together with our trusted community partners at the Respite Care Centre (RCC), me and some research collaborators are carrying out this research to learn more about how to best support children with disabilities and their caregivers living in Dzaleka Refugee Camp. We are committed to listening to your voice and understanding your experiences. We believe that local voices are central to building helpful and respectful services.

### **Participant Information Sheet**

ERAMS number: \_\_\_\_\_

Date: \_\_\_\_\_

#### **What is the purpose of the study?**

This study aims to explore how holistic interventions, such as those implemented at the Ubuntu Nation School and the Respite Care Centre (RCC), can improve the developmental, medical, and social outcomes of children with disabilities in Dzaleka Refugee Camp. It also seeks to understand the role of caregivers, staff, and the wider community in supporting these children in a context of displacement and limited resources.

#### **Why have I been invited to participate?**

You have been invited because you are a parent, caregiver, teacher, community leader, or staff member who is involved in caring for or supporting children with disabilities at the RCC or Ubuntu Nation School. Your experiences and insights will help researchers understand how to improve support systems for these children.

#### **Do I have to take part?**

No. Participation is entirely voluntary. You are free to decide whether or not to take part and may withdraw at any time without giving a reason. Your decision will not affect any services or support you receive.

## **Appendix 2**

### **What will happen to me if I take part?**

If you agree to participate, you may be asked to take part in a one-to-one interview, focus group, or complete a questionnaire (Child's Record). The session will last approximately 40 to 60 minutes and can take place at the RCC, Ubuntu Nation School, or a location of your preference.

### **Will I be recorded and how will the recorded media be used?**

If you participate in an interview or focus group, audio recordings may be made (with your permission) to help the researchers accurately understand your responses. These recordings will only be accessible to the research team and will be securely stored.

### **What information will be collected?**

We will collect information about your experiences, perspectives, and any relevant support you or your child receives. If you are a caregiver, we will gather information about the child's health, behaviour, education, and daily life using a structured tool called the Child's Record.

### **What are the possible benefits of taking part?**

Your input will help improve the services provided to children with disabilities in your community and may influence policies for more inclusive care in refugee settings.

### **What are the possible disadvantages and risks of taking part?**

There are no known risks associated with this study. However, some questions may bring up sensitive memories or feelings. If this happens, support will be available.

### **How will my data be stored and who will have access to it?**

Your data will be stored securely in a password-protected Box folder accessible only to the research team. Data will be anonymised, and your identity will be protected at all times.

## **Appendix 2**

### **How long will my data be stored for?**

Data will be stored securely for up to 10 years in accordance with University of Essex research data policies.

### **Will my participation be kept confidential?**

Yes. All information you provide will be treated in the strictest confidence. Only the research team will have access to identifiable data, and all findings will be anonymised.

### **How will my data be used and in what form will it be shared further?**

Data will be analysed to generate academic papers, reports, and presentations. Any shared data will be fully anonymised to ensure confidentiality.

### **Withdrawing my data**

You can withdraw your data at any point up to two weeks after your participation by contacting the research team. After that time, data may have been anonymised and included in analysis, and cannot be withdrawn.

### **What is the legal basis for using personal data and who is the Data Controller?**

The University of Essex processes personal data under the lawful basis of Article 6(1)(e) of the UK GDPR, for tasks carried out in the public interest. Special Category data is processed under Article 9(2)(j) for research purposes. The Data Controller is the University of Essex. For more information, visit the University's Data Protection webpage or contact [dpo@essex.ac.uk](mailto:dpo@essex.ac.uk).

### **Who has reviewed the study?**

The study has received favourable ethical review from the University of Essex Ethics Committee and Fraternity Without Borders.

### **Concerns and Complaints**

If you have concerns about the study, please contact the principal researcher, Principal Researcher: Dr. Liliane Silva – Email: [Liliane.silva@essex.ac.uk](mailto:Liliane.silva@essex.ac.uk). If unresolved, contact Dr. Kostis Roussos ([k.roussos@essex.ac.uk](mailto:k.roussos@essex.ac.uk)), Director of

## **Appendix 2**

Research, or the Research Integrity Manager (reo-integrity@essex.ac.uk). Please include the ERAMS reference.

### **Contact details**

Principal Researcher: Dr. Liliane Silva – Email: Liliane.silva@essex.ac.uk

Co-Investigator: Dr. Sanjaya Aryal - Email: sa17852@essex.ac.uk

Director of Research: Dr Kostis Rousses - E-mail: k.roussos@essex.ac.uk

Research Integrity Manager - E-mail: reo-integrity@essex.ac.uk

Or speak with Mama Fatuma or Tresor at the RCC and they will contact us directly.

## Appendix 3

### Participant Consent Form

**Project Title:** The Holistic Stimulation of the Integral Development of Children in Emergency Situations

**Researchers:** Dr Liliane Silva, Dr Sanjaya Aryal, Prof. Peter Huxley, Caitlin Phillips, Vafa Hakimi, Lilian Villanova, Gideon Kapalasa

**Institution:** University of Essex, in collaboration with the Respite Care Centre (RCC), Dzaleka Refugee Camp

You are being invited to take part in a research study. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and ask questions if anything is unclear.

Please initial each box if you agree with the following statements:

- ☐ I confirm that I have read and understood the Participant Information Sheet for this study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.
- ☐ I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my rights being affected.
- ☐ I understand that any data collected during the study will be anonymised and kept confidential.
- ☐ I agree for the interview to be audio recorded for research purposes.
- ☐ I understand that anonymised quotes may be used in future publications.
- ☐ I understand the purpose of the study and what is expected of me.
- ☐ I agree to take part in the above study.

Name of Participant: \_\_\_\_\_

Signature of Participant: \_\_\_\_\_

Date: \_\_\_\_\_

Name of Researcher: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 4



School of Health & Social Care  
Colchester Campus  
Wivenhoe Park  
Colchester, Essex  
CO4 3SQ

### Study Debrief

#### Study Title:

The Holistic Stimulation of the Integral Development of Children in Emergency Situations

#### Brief Summary:

This study aimed to explore how integrated services in education, healthcare, and psychosocial support contribute to the development and well-being of children with disabilities living in the Dzaleka Refugee Camp, Malawi. By assessing current interventions delivered by the Ubuntu Nation School and the Respite Care Centre (RCC), the study collected both quantitative and qualitative data to build a comprehensive understanding of the needs, challenges, and outcomes associated with these services.

#### How was the study carried out?

The study was conducted in two phases. Phase 1 employed a structured tool known as the Child's Record to gather baseline data on children's health, behaviour, education, and social context. Phase 2 involved qualitative methods, including in-depth interviews with caregivers, teachers, and community leaders, focus groups with volunteers and staff, observational studies at RCC and Ubuntu Nation School, and individual case studies to assess developmental progress. Trained interviewers and interpreters ensured inclusive communication in the participants' preferred languages.

#### What if I have been affected by the contents of the study?

If any of the topics discussed during your participation caused you distress or discomfort, please know that you are not alone. We encourage you to speak with staff at the RCC or Ubuntu Nation School, who can offer support or refer you to appropriate services. The study team is also available to provide additional resources or support where needed.

#### What are the potential benefits of this study?

The findings from this research will inform service providers and policymakers on how to better meet the needs of children with disabilities in emergency settings. The results may lead to improved practices, increased awareness, and enhanced support for both children and their caregivers, ultimately aiming to promote more inclusive and sustainable interventions.

## Appendix 4

### What if I want to know more?

If you are interested in learning more about the study or would like to receive a summary of the research findings, please feel free to contact the research team. Your contribution has been invaluable, and we would be happy to share what we have learned through this work.

### What if I want to withdraw from the study?

If you decide that you no longer wish to be part of the study, you can withdraw your data at any time before the analysis is complete. To do so, please contact a member of the research team using the details provided below.

### What if I have any concerns or complaints?

If you have any concerns or complaints about any aspect of the study, in the first instance, please contact the principal investigator, Dr Sanjaya Aryal, using the contact details below. If you are still concerned, if you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal researcher, please contact the departmental Director of Research in the department responsible for this project, Dr Kostis Roussos at [k.roussos@essex.ac.uk](mailto:k.roussos@essex.ac.uk). If you are still not satisfied, please contact the University of Essex REO Research Integrity Manager ([reo-integrity@essex.ac.uk](mailto:reo-integrity@essex.ac.uk)). Please include the ERAMS reference, which can be found at the footer of this page, so that the study can be identified, details of the name or description of the study, the researcher(s) involved, and the details of the complaint you wish to make.

**ERAMS number:** \_\_\_\_\_ **Date:** \_\_\_\_\_

### Contact details:

Principal Researcher: Dr. Liliane Silva – Email: [Liliane.silva@essex.ac.uk](mailto:Liliane.silva@essex.ac.uk)

Co-Investigator: Dr. Sanjaya Aryal - Email: [sa17852@essex.ac.uk](mailto:sa17852@essex.ac.uk)

Director of Research: Dr Kostis Rousses - E-mail: [k.roussos@essex.ac.uk](mailto:k.roussos@essex.ac.uk)

Research Integrity Manager - E-mail: [reo-integrity@essex.ac.uk](mailto:reo-integrity@essex.ac.uk)

Or speak with Mama Fatuma or Tresor at the RCC and they will contact us directly.