Implementation Manual for Community-Based Groups



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Strategic guidance and implementation recommendations for groups formed by people affected by skin-NTDs

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Disclaimer
The recommendations presented in this publication are based on evidence and learning from the UPLIFT study and may need to be adapted to local contexts, policies and health systems. They do not necessarily represent the official views of all consortium partners or the funding organization.

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FOREWORD

The Implementation Manual for Community-Based Groups (CBGs) represents an important contribution to the growing global efforts to strengthen people-centred approaches for Neglected Tropical Diseases (NTDs), particularly skin-related NTDs that continue to affect some of the world's most marginalized communities. Beyond their physical consequences, these conditions often lead to stigma, social exclusion, mental distress, reduced livelihood opportunities, and long-term disability. Addressing these challenges requires not only access to quality health services, but also stronger community participation, inclusion, and empowerment of persons affected.

This manual provides a practical framework for establishing and strengthening CBGs, often referred as self-support or peer-support groups, as platforms for peer support, self-care, psychosocial support, advocacy, and an opportunity to strengthen existing NTD Programmes. It reflects the growing recognition within the WHO NTD Roadmap 2021–2030 that persons affected by NTDs must play a central role in shaping the responses that affect their lives and communities.

Developed through collaboration between persons affected by NTDs, community leaders, health workers, researchers, NGOs, and technical partners across Bangladesh, Ethiopia, and India, the UPLIFT model demonstrates the value of harmonized and locally adaptable approaches that strengthen both individual and community resilience. Importantly, the manual recognizes that sustainable progress depends on building local ownership, strengthening linkages with health and socio-economic systems, and pursuing multisectoral collaboration beyond disease-specific approaches.

ILEP welcomes initiatives that advance dignity, inclusion, participation, and the meaningful engagement of persons affected by NTDs. We hope this manual, together with its companion tools and facilitation guides, will serve as practical resources for both programme designers and implementers. As countries and partners continue to strengthen integrated skin-NTD approaches, CBGs have the potential to become an important mechanism for promoting self-care, social participation, advocacy, and long-term community resilience.

We thank all partners, technical experts, communities and persons affected who contributed their time, experience, and leadership to the development of this manual and to the broader vision of a more inclusive future for people affected by NTDs.

Geoff Warne



Chief Executive Officer at ILEP (International Federation of Anti-Leprosy Associations)

Abbreviations

BPS-N	Basic Psychosocial Support for Persons Affected by Neglected Tropical Diseases
CBG	Community-based group
DMDI	Disease Management, Disability and Inclusion
GAD-7	Generalised Anxiety Disorder-7
M&E	Monitoring and Evaluation
mhGAP	Mental Health Gap Action Programme
NGO	Non-governmental organization
NTD	Neglected tropical disease
PHC	Primary healthcare centre
PHQ-9	Patient Health Questionnaire-9
PM+	Problem Management Plus
PSS	Psychosocial support
Skin-NTD	Skin-related Neglected Tropical Diseases
UPLIFT	Unlocking the Potential of Leprosy & NTD affected people, to pursue Inclusive, Fulfilling and Transformational lives, through a harmonized Community Based Group model
WASH	Water, Sanitation and Hygiene
WEMWBS	Warwick-Edinburgh Mental Wellbeing Scale
WHO	World Health Organization

Glossary

Community-based Group (CBG): In the context of this manual, CBGs refer to groups of people affected by chronic skin-NTDs or other long-term disabling conditions who gather and meet regularly in their communities to strengthen self-care practices, provide mutual psychosocial support, and address shared challenges such as stigma, disability and access to services. CBGs evolve from externally facilitated support to self-facilitation, while maintaining linkages with health services and community structures. Depending on context and group priorities, CBGs may also engage in social participation, advocacy or sustainability activities.

The term CBG is therefore used here as an umbrella concept for self-care, peer-support and self-help functions that often overlap in practice.

Self-care: Regular practices undertaken by people affected by skin-NTDs to manage their condition, prevent complications, maintain functional ability, and improve wellbeing in daily life. Self-care includes activities such as skin and wound care, hygiene, behaviours, exercises, use of assistive or protective devices such as footwear, and timely health-seeking when warning signs arise.

Self-care is both an individual responsibility and a peer-supported process within CBGs, serving as the primary entry point for CBG formation and a foundation for psychosocial support, trust building, and long-term autonomy.

Psychosocial support (PSS): Support that addresses the interconnected psychological, emotional, physical and social challenges associated with living with chronic and stigmatising conditions. Within this manual, PSS refers to basic, non-clinical support provided primarily through peer interaction in CBGs, including opportunities for emotional expression, mutual encouragement, problem-solving, stigma reduction, confidence building, and strengthening social participation. PSS does not replace professional mental health care but includes recognising signs of severe distress and facilitating referral to appropriate services when needed.

Empowerment: “A process through which people gain greater control over decisions and actions affecting their health and patients or community members are empowered to assume greater responsibility for their own care and well-being.” [1].

Ownership and empowerment reinforce each other. Empowered individuals are likely to take ownership of collective action. Whilst ownership refers to the sense of responsibility, group belonging and control over the group’s activities and decisions, empowerment is a wider concept, encompassing the “process” of enabling CBG members to develop the necessary skills and autonomy needed to take control over decisions and actions affecting their condition.

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Introduction

A family in Madhya Pradesh, India, participating in Sankalp, an initiative led by Effect Hope, Lepra and LEPRA Society, that strengthens communities and health systems to combat leprosy and lymphatic filariasis. Photograph by Tom Bradley

INTRODUCTION

1.1 CBGs as community platforms for integrated skin-NTDs

Skin-related Neglected Tropical Diseases (skin-NTDs) are associated with long-term physical impairment, mental distress, stigma, and other socio-economic factors. While clinical manifestations and treatments vary across conditions, many people affected experience chronic care needs that go beyond the scope of public health services [2].

The World Health Organization (WHO) NTD Roadmap 2030 [3] calls for person-centred and locally owned approaches that address the long-term needs of people affected. In this context, community-based groups (CBGs) provide a practical community platform to address clinical, emotional and social dimensions of skin-NTDs.

Self-care is often the primary entry point for CBG formation [4]. Regular self-care practice responds to immediate health needs of chronic skin-NTDs while creating a space for psychosocial support (PSS). From this entry point, group members progressively strengthen their physical health and mental wellbeing while gradually expanding into wider functions such as collective problem-solving, advocacy and participation in community initiatives.

In settings where health systems face constraints in addressing the long-term needs of people affected, CBGs offer an important community-level platform to complement formal services, support continuity of care, and strengthen accountability [2, 4]. For these reasons, CBGs are increasingly promoted within WHO's strategic framework for the integrated control and management of skin-NTDs [1] to advance both people-centred care and progress towards elimination targets.

1.2 The UPLIFT Study

The UPLIFT[1] study was launched in 2023 to address gaps in the operationalisation of CBG approaches for people affected by skin-NTDs. Although CBGs are generally recognised as valuable platforms for self-care, peer support, and social inclusion, their implementation has very often evolved in an ad hoc and highly heterogeneous manner. As a result, organisations have frequently adapted group models based on local experience without a shared framework to guide implementation, assess effectiveness, or support replication across different settings.

The study aimed to define the core components of a harmonised and operational CBG model integrating self-care, PSS and participatory group practices based on behavioural and community development principles. The primary research question explored which elements should be included in an operational CBG package capable of strengthening wellbeing, social participation and access to services among people affected by skin-NTDs.

To address this question, the model was developed through consultations with people affected, NGOs and research experts, complemented by a scoping review [4] of available evidence on key CBG functions such as self-care, PSS, social participation, advocacy and

[1] Unlocking the Potential of Leprosy & NTD affected people, to pursue Inclusive, Fulfilling and Transformational lives

income-generating activities. The resulting implementation package was subsequently piloted and adapted across Bangladesh, Ethiopia and India through newly formed or early-stage CBGs integrating people affected by multiple chronic skin-NTDs, including leprosy, lymphatic filariasis (LF), podoconiosis and scabies, depending on context.

The study was implemented by a consortium comprising Effect Hope, the German Leprosy and Tuberculosis Relief Association (GLRA), and Lepra, with funding from the International Federation of Anti-Leprosy Associations (ILEP) Reserve Fund.

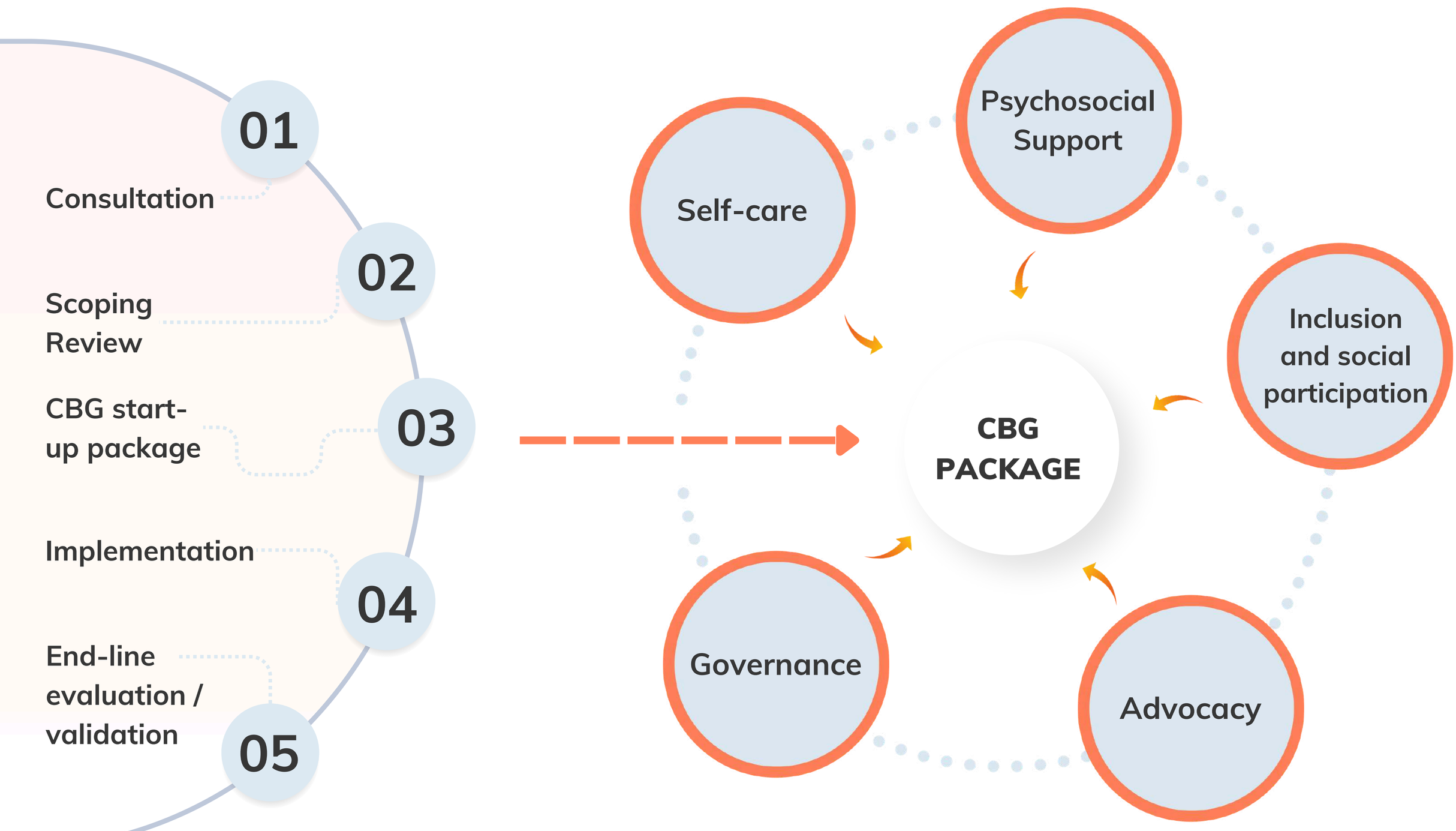
This manual translates the evidence and operational learning generated through the UPLIFT study into practical guidance for organisations seeking to establish, strengthen or replicate CBGs for integrated skin-NTD care across diverse settings.



Photo Courtesy of: Lepra



Photograph by: Tom Bradley



1.3 Conceptual Framework

The UPLIFT model is based on the understanding that CBGs evolve as dynamic community systems rather than static platforms. This framework recognizes that sustainable outcomes for people affected emerge progressively, as groups strengthen internal capacities, build trust among members, and gain legitimacy within the wider community [1, 2, 4].

The framework conceptualizes CBG development across three interrelated developmental stages. It begins with understanding members' needs and establishing basic governance structures. It continues with strengthening internal capacities, developing strategic linkages, and facilitating progressive autonomy. The framework culminates in expanding engagement beyond the group itself through participation in community initiatives or advocacy activities, contributing to the long-term sustainability and visibility of CBGs.

Community development processes rarely follow a strictly linear pathway. Groups may progress at different speeds depending on local context, group cohesion and emerging opportunities. The staged framework therefore serves as a practical implementation guide rather than a rigid pathway. In this context, progression through stages is not determined by fixed timelines but by demonstrated readiness and milestone achievement. This approach allows contextual flexibility while preventing premature transitions that could undermine sustainability.

External facilitators are expected to gradually reduce direct involvement as internal capacity increases, transitioning from direct facilitation to mentorship and technical support. This progressive transfer of responsibility is central to sustainability.

Full financial sustainability is recognised as a longer-term objective that typically extends beyond the first three stages of CBG development and is therefore not fully operationalised within this manual.

Although the UPLIFT study focused on leprosy, LF, podoconiosis and scabies, this manual may also be adapted to other chronic or disabling conditions where similar long-term care and social support needs exist.



Photo Courtesy of: Effect Hope

Conceptual Framework of the UPLIFT CBG Model

	Objectives	Milestones
STAGE 1 Foundations and governance	To understand priorities of people affected and establish initial engagement within CBGs	☐ Needs assessment ☐ Basic governance structure ☐ CBG purpose established ☐ Community asset mapping ☐ Financial protection schemes identified
STAGE 2 Trust building & capacity development	To ensure positive and supportive environment within CBGs	☐ Self-care, PSS, and facilitation autonomy ☐ Feedback mechanism ☐ Access to financial protection schemes ☐ Advocacy planning ☐ Health workforce capacity
STAGE 3 Community integration & advocacy	To identify and leverage local opportunities for CBG growth	☐ Networks with community/ government are established ☐ CBGs engage in advocacy/ community initiatives ☐ Self-assessment and sustainability plan in place
STAGE 4 Financial sustainability (out of scope)	To achieve CBG ownership and sustainability	☐ CBGs are financially independent

+ Decreasing external support -

- Increasing ownership +

CORE IMPLEMENTATION PRINCIPLES

The following principles guide implementation of the UPLIFT model across all stages and should inform decision-making throughout the development and support of CBGs.

Self-care as the entry point

Self-care is the primary organizing function of CBGs. It provides an immediate, practical focus that responds to members' daily health needs while strengthening cohesion, confidence, and peer support. Regular self-care sessions often provide the first structured opportunity for interaction among members, creating the foundation for other group functions to develop over time.

Psychosocial wellbeing as a core function

Psychosocial support is a key component of CBGs and should be embedded from the early stages. CBGs provide a safe space for emotional expression, peer support and collective reflection on stigma and social participation.

Progressive transfer of responsibility

CBGs are designed to move from externally facilitated groups to member-led platforms. External facilitators progressively shift from direct activity delivery towards mentorship, coaching, and technical support as internal capacity strengthens.

Complementary to health systems

CBGs reinforce but do not replace public health services. Clear referral pathways and collaboration with health workers are essential at all stages. Effective coordination helps ensure continuity of care while strengthening trust between communities and health providers.

Peer-led empowerment

CBG members are central actors in planning, facilitation, and decision-making. Roles such as peer supporters and group leaders should be selected transparently and supported through training and supervision.

Inclusion and equity

CBGs must actively promote participation of women, persons with disabilities, elderly members, and individuals facing stigma or social exclusion. Governance structures should address power imbalances and ensure equal voice.

Safeguarding and ethical practice

Participation must remain voluntary, confidential, and respectful. Clear boundaries, referral mechanisms for high-risk situations, and protection of sensitive information are required.

Progression based on milestone achievement

Transition from one stage to another should be based on achievement of defined milestones rather than predetermined timelines, ensuring that groups move forward only once sufficient capacity and cohesion have been established.

1.4 Purpose and scope of the manual

This Facilitation Guide for Community-Based Groups provides implementation and strategic guidance for establishing and strengthening CBGs formed by people affected by chronic skin-NTDs and other chronic disabling conditions with similar long-term support needs. It defines core principles, minimum milestones across developmental stages and both programmatic and strategic recommendations, supporting implementers to design, supervise, and adapt CBG strategies based on the UPLIFT model.

This document is not intended as a step-by-step facilitation manual. Detailed facilitation guidance, meeting structure, tools and templates are provided in a separate companion resource (i.e. UPLIFT CBG Facilitation Guide) designed for facilitators conducting routine CBG meetings.

In this manual, CBGs refer to groups formed by people affected who come together to strengthen self-care practices, receive PSS, and collectively address challenges related to stigma, disability, and access to services.

The manual builds on the findings of the UPLIFT study and operational learnings from its implementation in India, Bangladesh, and Ethiopia. It responds to the recognized need for more harmonised, adaptable and evidence-based CBG approaches for people affected by skin-NTDs across different settings [4], and draws from learnings of other relevant community programmes, including COUNTDOWN [5] and REDRESS [6] Programme resources.

The developmental stages proposed in the conceptual framework of this manual provide a pathway for strengthening group capacities, progressing towards autonomy, and enabling engagement with communities and health systems. The manual also includes key considerations relevant to long-term sustainability. More complex domains, such as livelihood programmes, income-generating activities or health system integration, are only addressed at the strategic level, recognising that these areas often require specialised technical expertise beyond the scope of this manual.

This Implementation Manual is not intended to function as a stand-alone training product, nor as a prescriptive model. It outlines minimum requirements, recommended practices, and context-dependent options that can be adapted to different settings while preserving the core mechanisms of effective CBG functioning.

The Implementation Manual is designed primarily for stakeholders responsible for planning, overseeing or supporting CBG programmes, including:

Frontline facilitators are expected to use this manual together with the Facilitation Guide for Community-Based Groups.

- **NGOs and implementing partners**
- **Government and organisations supporting community-oriented disease management and disability prevention (DMDI) approaches**
- **Research institutions and technical advisors**
- **Donors**

Purpose and Use of UPLIFT Companion Guiding Materials

	Implementation Manual	Facilitation Guide
Purpose	» Recommendations on WHAT should be done	» Indications on HOW to implement key recommendations
Guidance	» Strategic » Programmatic	» Step-by-step guidance » Facilitation toolkit
Main content	» Core principles » Development stages » Milestones » Roles and safeguards	» Meeting structure » Facilitation techniques » Resources and tools » Practical exercises
Main users	» Those planning, supervising or evaluating CBG programmes	» Those directly implementing or facilitating CBG sessions
When used	» Programme planning and monitoring » Training » CBG model adaptations	» Before and during facilitation of CBG meetings

1.5 How to use this manual

This Implementation Manual is structured as a stage-based operational guide. Each stage includes a set of minimum milestones that indicate readiness to progress to the next stage of development with the support of external facilitators. Progression should therefore be determined by achievement of these milestones rather than fixed timelines.

Within each stage, implementation guidance is organised into three categories of strategic and programmatic recommendations:

Key Actions

These represent the minimum implementation requirements necessary to preserve the integrity and core mechanisms of the CBG model. Failure to implement these actions may compromise group functionality or progression to subsequent stages.

Recommended Actions

These actions strengthen the quality, effectiveness and potential impact of CBGs, but may require additional time, facilitation capacity or contextual adaptation. They should be implemented whenever feasible.

Context-Dependent Actions

These actions depend on local context, including social norms, health system capacity, available resources, and programme priorities. Implementers should assess their relevance and feasibility before applying them.

Role of external facilitators

External facilitators (e.g. NGO staff or trained community facilitators) play an important role in supporting the establishment and early development of CBGs. Their role is to enable group functioning, strengthen internal capacities, and facilitate connections with relevant services and stakeholders, while ensuring that ownership and decision-making remain with CBG members.

As CBGs mature, the role of external facilitators should progressively shift from direct facilitation to mentorship and technical support. This transition helps ensure that leadership, decision-making and day-to-day group functioning gradually become the responsibility of CBG members themselves.

External facilitators should therefore aim to:

- Strengthen member leadership and participation
- Encourage collective decision-making within the group
- Support linkages with health services and community stakeholders
- Provide guidance when technical or organisational challenges arise.

Facilitators should avoid creating dependency by gradually reducing direct involvement as the group develops the confidence and capacity to manage its own activities.

2

CBG Developmental Stages

In Ajaigarh, India, people affected by skin-NTDs meet with local health officials to ensure community voices help guide health services and support. Photo courtesy of Effect Hope

STAGE 1 - CBG FOUNDATIONS AND GOVERNANCE

A: Stage 1 Overview

Objective

Stage 1 focuses on establishing the foundations required for initial CBG functioning. This includes forming the group, understanding the priorities and needs of the group, and establishing basic governance structures, with a view to facilitating group commitment and ownership. The objective is to build initial trust among members, clarify group purpose and ensure that basic organisational structures are in place before moving to capacity strengthening in Stage 2.

Minimum required milestones

- ☐ Needs assessment completed
- ☐ Collective CBG purpose established
- ☐ Basic governance structure established
- ☐ Community asset mapping completed
- ☐ Financial protection schemes identified

Approximate timing: 3-4 months

Strategic and programmatic actions:

1. Group formation
2. Needs assessment and purpose
3. Governance structure and ethics
4. Community resources and linkages
5. Early linkages to financial protection schemes

B: Strategic and Programmatic Recommendations

Group Formation

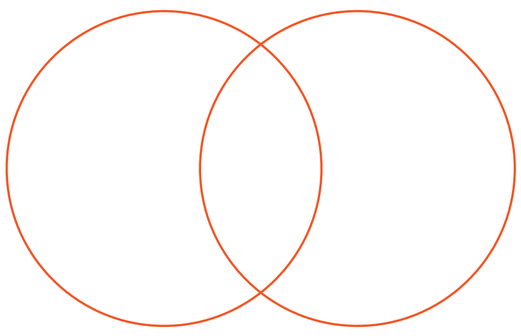
The formation of CBGs is a deliberate and participatory process, designed to ensure that groups are people-centred, equitable, and responsive to self-care and psychosocial needs from the outset.

Key Actions

- Identify people affected by skin-NTDs and other conditions who may benefit from CBG functions. Identification should prioritise. individuals with immediate self-care needs.
- Ensure participation is voluntary and that confidentiality is maintained at all times.
- Define clear inclusion criteria.
- Agree on manageable group size (typically 5–10 members).
- Address equity barriers through proactive inclusion measures to enable participation of individuals facing stigma, mobility, distance or socio-economic constraints:
  - Identify barriers through participatory. discussion and simple community mapping.
  - Adapt meeting arrangements to improve. access (e.g. flexible timing, rotating, etc.).
  - Provide practical support when feasible (e.g. transport assistance, childcare, etc.).
  - Offer alternative participation options when necessary (e.g. satellite groups or home-based meetings for severe mobility limitations).

Recommended Actions

- Use multiple outreach channels to reach potential members (health facilities, word-of-mouth, awareness materials, community leaders, active case finding linkages, etc.).
- Where family members or caregivers support daily self-care, engage them in self-care education early.
- Discuss and agree which disease conditions will be integrated, prioritising shared needs rather than disease categories.
- Select meeting location through collective agreement, ensuring the venue is physically accessible, affordable, acceptable to members, and offers adequate privacy to reduce stigma and encourage open participation.



Context-Dependent Actions

- Allow larger groups when context requires, considering distance and travel time to meeting venues, seasonal factors, and accessibility for people with physical impairments.
- Separate groups by gender, age, or disability status where local norms require.
- Consider merging with other chronic conditions when travel distance is large, particularly in low endemic settings, if agreed and in alignment with group purpose.

Needs Assessment and Purpose

Understanding the needs of group members and defining its purpose are foundational activities of Stage 1. A participatory needs assessment ensures that CBGs are established based on the priorities, capacities, and lived experiences of people affected. Building on the assessment of needs, CBG members should be supported to articulate a shared purpose for the group.

Key Actions

- Conduct a participatory needs assessment covering:
  - *Health and self-care needs*
  - *Psychosocial challenges and stigma*
  - *Socio-economic and service access barriers*
- Distinguish immediate priorities from longer-term aspirations.
- Identify existing skills and capacities within the group.
- Agree collectively on a clear group purpose.
- Document findings and agreed priorities.

Recommended Actions

- Use simple participatory ranking tools.

  Assess resource needs for self-care materials, prioritising low-cost, locally available, and home-based materials where possible.
- Assess early on the need for protective footwear or other assistive devices:
  - *Enable feedback mechanisms to ensure they are appropriate and meet their needs*
  - *Consider feasible delivery mechanisms*
- Clarify caregiver roles where relevant and aligned with inclusion criteria.
- Introduce exploratory discussions on long-term aspirations without committing to future structures.

Context-Dependent Actions

- Adapt assessment tools to literacy level. Include additional dimensions (nutrition, WASH, mobility, livelihoods, etc.) based on context.

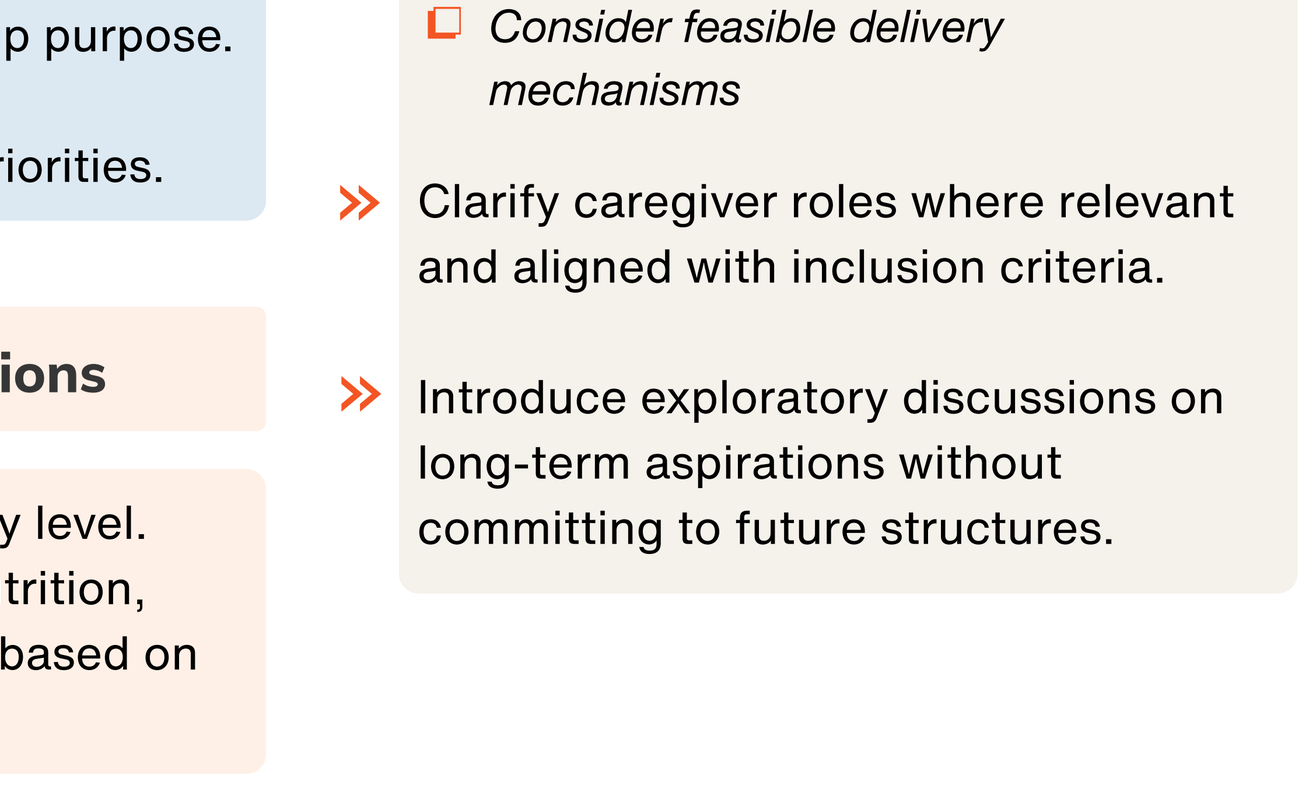


Photo Courtesy of Effect Hope

Governance Structure and Ethics

Establishing clear governance and ethical foundations is essential to ensure that CBGs function as inclusive and accountable community spaces. Governance arrangements at this stage are intentionally simple and are expected to evolve as group capacity and autonomy increase.

Key Actions

- Facilitate collective agreement on basic group principles:
  - Confidentiality
  - Respectful communication
  - Attendance expectations
  - Decision-making process
- Define meeting frequency, venue, and duration of meetings ensuring inclusive participation, with particular attention to women, the elderly, and members who may require additional support to participate meaningfully.
- Clarify responsibilities of key selected roles, starting with the participatory selection of a group leader.
- Define the facilitation role clearly and ensure external facilitators focus on progressively transferring leadership and session management responsibilities to members.
- Document agreements.

Recommended Actions

- Identify potential peer supporters within the group early.
- Identify group leaders that are motivated, willing to learn, and able to facilitate collective action, drawing on the group's shared experiences and members' own criteria for selection.
- Encourage gender balance in leadership roles.
- Plan basic leadership capacity strengthening.
- Agree on a manageable group size ensuring the group is large enough to encourage exchange but small enough to allow members to share personal experiences comfortably.

Context-Dependent Actions

- Adapt meeting structure based on seasonality, mobility, or stigma concerns.
- Establish sub-groups if size or diversity requires.
- Establish a community stakeholder panel to provide guidance and support on the relevance and quality of CBG activities, progress, and materials.



Photo Courtesy of: GLRA Ethiopia

Community Linkages and Resources

Early identification and engagement with community resources is critical to support the integration of CBG priorities into existing community systems. Networking at this stage is exploratory and foundational, laying the groundwork for deeper engagement in later stages.

Key Actions

- Conduct participatory community asset mapping, including:
  - Local health facilities
  - Community leaders
  - Relevant programmes
  - Other formal/informal support structures livelihood programmes, youth groups, schools, health, nutrition and sanitation committees, etc.).
- Encourage critical reflection on how identified assets can respond to the needs highlighted in the needs assessment.
- Document identified actors and services.
- Clarify that networking at this stage is exploratory.

Recommended Actions

- Initiate introductory contact with selected actors to build visibility and trust.
- Identify alignment opportunities with existing health or development initiatives.
- Facilitate early reflection on how community networking may support future advocacy and sustainability planning, while maintaining realistic expectations and avoiding premature external engagement.

Context-Dependent Actions

- Prioritize strengthening of existing community resources rather than introducing parallel, potentially unsustainable structures.
- Engage associations of persons affected where available.
- Link with nearby health facilities.
- Link with active NTD campaigns if ongoing.
- Invite relevant community stakeholders, including leaders and community health workers to CBG regular meetings.



Photo Courtesy of: LEPRA Society

Early Linkages To Financial Protection Schemes

Financial sustainability should be introduced early but approached cautiously. Stage 1 should just provide basic orientation to relevant financial pathways identified during the needs assessment, including individual access to social protection schemes as well as introduction of potential group-level economic opportunities. At this stage, the objective is primarily to ensure that members are aware of available options without shifting the group's focus away from its foundational functions. The timing and scope of engagement with financial pathways should ultimately be determined by group capacity, priorities and contextual feasibility.

Key Actions

- During early orientation, distinguish between immediate individual social protection schemes that eligible members should be encouraged to apply for as soon as possible (e.g. disability certification, social entitlements, etc.) and longer-term collective economic opportunities (e.g. savings groups or income-generating activities) that may be pursued once the CBG has developed sufficient cohesion, governance and operational capacity.
- Clearly communicate that self-care, PSS, and development of group cohesion remain the short-term priority.
- Provide basic information on eligibility and documentation requirements.
- Clarify that CBGs do not distribute funds.

Recommended Actions

- Support members to begin organizing required documentation to apply for social protection and financial schemes.
- Clarify that training on processes to access individual entitlements will be given in Stage 2.
- Identify institutional entry points and contact persons who may be relevant for enabling CBG applications by members themselves.

Context-Dependent Actions

- Initiate formal group application processes (e.g. For collective economic opportunities, formal connections with the health system, inclusion in NTD Programme decision making processes, advocacy, etc.), only if:
  - Governance structure is well established
  - Financial support and economic sustainability expectations are well managed and internally understood
  - External support capacity exists

STAGE 2 - TRUST BUILDING AND CAPACITY DEVELOPMENT

A: Stage 2 Overview

Objective

To consolidate trust, cohesion and capacity within CBGs by strengthening autonomous self-care and psychosocial support practices, formalizing internal governance and feedback mechanisms, and progressively transferring facilitation roles to people affected. Stage 2 also prepares groups for external engagement by strengthening linkages with health services, facilitating access to social entitlements, and developing initial planning that will support community participation and advocacy in Stage 3.

Minimum required milestones

- ☐ Self-care autonomy by CBG members
- ☐ PSS facilitation autonomy by peer supporters
- ☐ Feedback mechanism in place
- ☐ CBG facilitation autonomy by CBG leaders
- ☐ CBG members access financial protection schemes
- ☐ Advocacy plan in place to support transition to autonomy
- ☐ Community Engagement initiatives are identified
- ☐ Adequate health workforce capacity

Approximate timing: 3-6 months

Strategic and programmatic actions:

1. Self-care consolidation
2. PSS consolidation
3. Establishing CBG feedback mechanisms
4. Leadership consolidation and transition to self-facilitation
5. Ensuring access to social entitlements and financial protection schemes
6. Developing an advocacy plan
7. Developing a community engagement plan
8. Strengthening health workforce capacity

B: Strategic and Programmatic Recommendations

Self-care Consolidation

Stage 2 consolidates self-care as a sustained behavioural practice embedded in the identity of the group and daily life of members. Beyond technical instruction, effective self-care requires motivation, problem-solving, health education, and peer support. This stage focuses on strengthening autonomy, ensuring early recognition of complications and timely referral, and progressively transferring facilitation to trained members (typically peer supporters).

Key Actions

- Embed self-care sessions within CBG meetings and encourage regular home-based self-care practice (daily or minimum twice weekly).
- Provide needs-based health education covering disease knowledge, treatment pathways, prevention of complications, hygiene practices, and appropriate care-seeking to nearby public health facilities.
- Core technical components should at least include:
  - Skin care
  - Wound care
  - Active/Passive exercises (when appropriate)
  - Appropriate footwear use (when appropriate)
- Ensure access to essential self-care resources (self-care kits).
- Formalize the transition to peer-led self-care by progressively transferring demonstration and facilitation responsibilities to trained members, while external facilitators shift from direct instruction to mentorship and technical supervision.

Recommended Actions

- Base training on recognized and/ or validated international guidelines, adapting them to local context, language, literacy levels, gender norms, and age-related needs.
- Use participatory teaching methods, including peer demonstrations, role-play, and group discussion. Encourage peer observation and constructive feedback.
- Actively engage caregivers or family members to support consistent home-based practice.
- Prioritise locally available, low-cost materials for self-care kits to avoid supply dependency.

Context-Dependent Actions

- Provide initial self-care kits where strategic, to encourage regular attendance and facilitate initial dynamics.
- Establish referral pathways for footwear provision when feasible.
- Invite health staff for periodic technical reinforcement.

Example 1. Basic self-care in leprosy

Skin care	» Daily inspection for blisters, red spots, cuts and tender areas » Soaking for 20 min with clean water, remove hard skin with scrubber » Put any cooking oil to keep skin soft and supple » Apply protective measures for daily chores
Wound care	» Skin trimming of the edges/ dressing » Use local remedies when/ if available and if applicable » Health seeking behaviours
Exercise	» Physiotherapy, active/passive exercise to prevent contracts » Eye exercises (e.g. blinking frequently to prevent dryness 30 times/day)
Footwear	» Always wear comfortable footwear with insensible feet to prevent ulcers » Quality footwear with Micro Cellular Rubber (MCR) » Tailor made for grade-2 disability » Consider foot appliances when available/ applicable

Example 2. Basic self-care in lymphatic filariasis (lymphoedema), and podoconiosis

Skin care	» Wash twice daily with soap and clean water at room temperature » Pat-dry affected limb » Daily inspection for entry points (fungal infection, ulcers, wounds)
Wound care	» Antifungal/antibacterial treatment to manage infections » Health seeking behaviours
Exercise	» Massaging, active/passive exercise to reduce swelling » Elevation of affected limb at night » Keep moving as condition worsens
Footwear	» Always wear comfortable footwear to protect skin » Tailor made for disability stage 2 or higher » Insole with light weight material – Ethylene-vinyl acetate (EVA) if available

Example 3. Basic self-care in scabies

Skin care	» Wash affected part with soap and clean water » Always keep clothing cleaned with warm water and dried in sunlight » Pat dry the affected limb/ do not scratch » Cut nail regularly
Wound care	» Apply lotion/ cream prescribed » Comply with antibiotics prescribed, when necessary » Health seeking behaviours
Exercise	» Rest (exercise should not be conducted during scabies)
Footwear	» Always wear comfortable footwear for the prevention of bacterial infections on feet

Examples of commonly used self-care guidelines in skin-NTDs

Diesease	Title	Source	Link
Leprosy	I can do it myself! Tips for people affected by leprosy who want to prevent disability	World Health Organization (WHO), 2007	https://iris.who.int/handle/10665/205317
Leprosy	Leprosy: training of health workers on skin-NTDs	WHO Academy, 2026	https://whoacademy.org/coursewares/course-v1:WHOAcademy-Hosted+H0056EN+H0056EN_Q4_2024?source=edX
Leprosy	Self-care programmes for people living with leprosy: a scoping review	Ilozumba, O. et al. 2021	https://leprosyreview.org/article/92/4/20-21109

Examples of commonly used self-care guidelines in skin-NTDs cont.

Lymphatic filariasis	Lymphatic filariasis: managing morbidity and preventing disability	World Health Organization (WHO), 2021	*https://www.who.int/publications/i/item/9789240017061*
Buruli ulcer	Prevention of disability in Buruli ulcer	WHO Academy, 2026	*https://iris.who.int/items/d30ebaff-b592-48f4-bff0-fc65455a171f*
Cutaneous leishmaniasis	Manual for case management of cutaneous leishmaniasis in the WHO Eastern Mediterranean Region	World Health Organization (WHO), 2014	*https://applications.emro.who.int/dsaf/EMROPUB_2013_EN_1590.pdf?ua=1&ua=1*
Podoconiosis	Community-Based Control of a Neglected Tropical Disease: The Mossy Foot Treatment and Prevention Association	Davey, G. et al. 2009	*https://journals.plos.org/plosntds/article/file?id=10.1371/journal.pntd.0000424&type=printable*
Podoconiosis and lymphatic filariasis	Integrated morbidity management for lymphatic filariasis and podoconiosis, Ethiopia	Deribe, K. 2017	*https://pmc.ncbi.nlm.nih.gov/articles/PMC5578380/*
Skin-NTDs	Ten Steps: A guide for health promotion and empowerment of people affected by Neglected Tropical Diseases	Lehman, L.F. 2015	*Ten steps: A guide for health promotion and empowerment of people affected by neglected tropical diseases. | Infolep*

PSS Consolidation

In Stage 2, PSS becomes routine practice and progressively peer led. It strengthens wellbeing, reduces distress, promotes social participation, and supports early identification and referral of mental health conditions. CBG-based PSS does not replace clinical care.

Key Actions

- Identify peer supporters through participatory selection (if not yet done in Stage 1).
- Embed PSS within regular CBG meetings, to ensure continuity, normalize emotional discussions, and to strengthen the links between PSS, self-care and social participation.
- Facilitate discussions addressing emotions, stigma, social experiences and coping strategies.
- Promote basic mental health literacy and recognition of common emotional responses (e.g. shame, fears, etc.).
- Establish and document clear referral pathways to professional mental health services.
- Clarify that peer supporters provide basic PSS only, and do not offer diagnosis or treatment.
- Ensure discussions are voluntary, confidential, trauma-sensitive, and supported by safeguarding procedures.
- Gradually transfer PSS facilitation to trained peer supporters, with external facilitators shifting from direct delivery to mentorship and supervision.

Recommended Actions

- Train peer supporters in facilitation skills, active listening, stigma-sensitive communication, recognition of warning signs of distress, referral procedures, and monitoring of psychosocial wellbeing indicators.
- Use adapted community-based tools drawing on recognised materials such as Basic Psychological Support for Persons Affected by Neglected Tropical Diseases (BPS-N), Problem Management Plus (PM+), WHO Essential care package to address mental health and stigma for persons with neglected tropical diseases (WHO ECP).
- Engage caregivers or family members where appropriate to reduce stigma.
- Conduct baseline and periodic wellbeing assessments using simple qualitative and/or quantitative tools.

Context-Dependent Actions

- Formally link PSS within health system services to strengthen referral completion.
- Use screening tools (e.g. PHQ-9, GAD-7, WEMWBS) only where referral systems are functional and capacity to respond needs exists.
- Facilitate time-bound outreach support from trained mental health professionals in higher-burden settings.

Role and definition of peer supporters in the context of CBGs

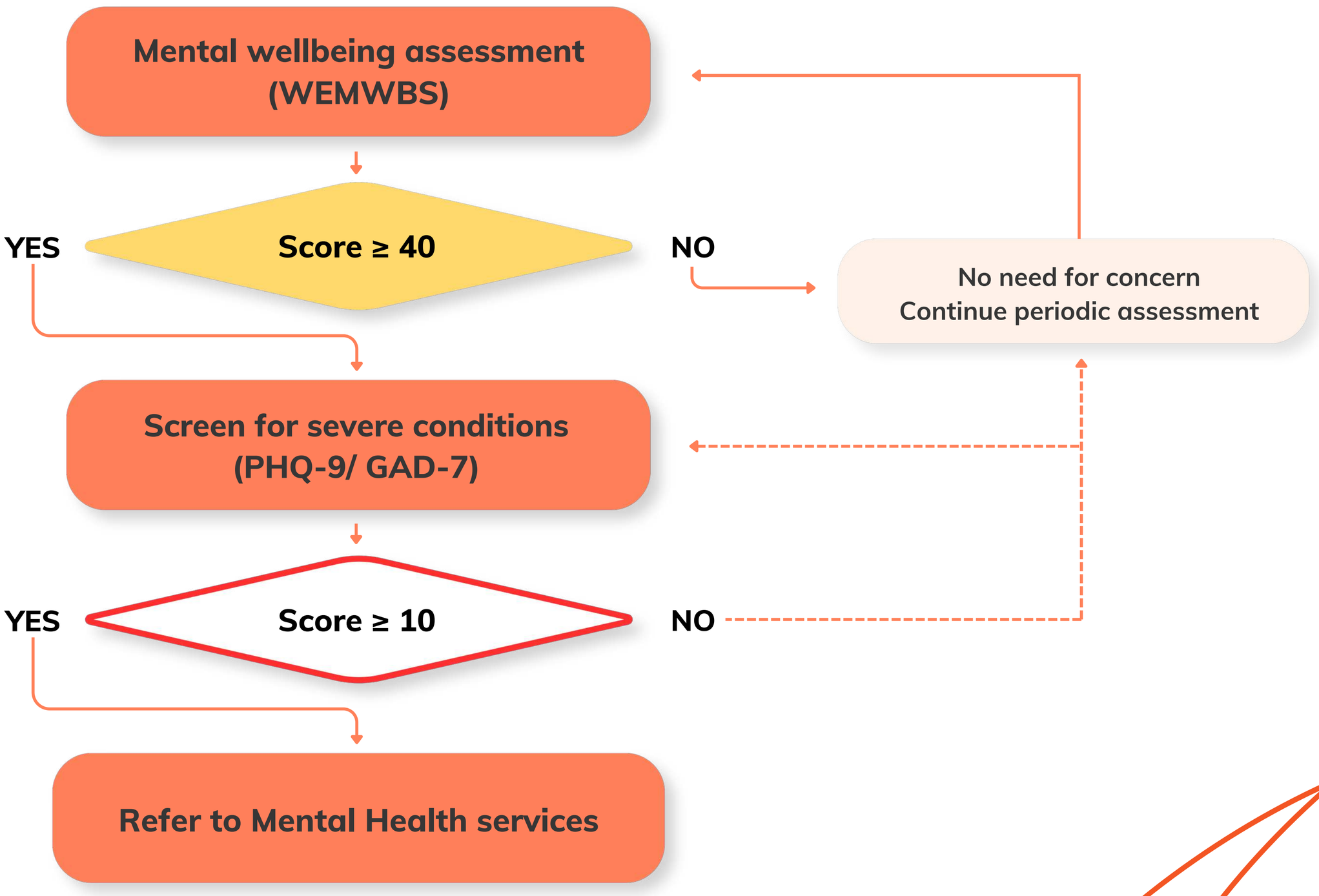
Who is a peer supporter?

A peer supporter is a person affected by a chronic skin-NTD or related disabling condition, and an unpaid CBG member who uses their lived experience, training, and empathy to provide basic PSS to other CBG members, voluntarily, through active listening, mutual encouragement and group discussion [7].

Core functions of peer supporters

- Facilitate basic PSS through CBG meetings
- Reinforce autonomy in self-care practice
- Support distress management by promoting coping strategies
- Support early identification of warning signs of severe distress and initiate appropriate referral

Example of a recommended screening and referral pathway



Selected resources to support development of PSS training programs within CBGs

Title	Source	Link
Basic Psychological Support for Persons Affected by Neglected Tropical Diseases (NTDs) (BPS-N)	NLR India (2011)	https://nlrindia.org/wp-content/uploads/2024/06/BPS-N-Guide_English_final.pdf
Look Listen Link Support for Skin Sickness Job Aid	LSTM (2023)	Intervention Manual [Combined] 181023.pdf
Group Problem Management Plus (Group PM+)	WHO (2020)	https://www.who.int/publications/i/item/9789240008106
WHO Essential care package to address mental health and stigma for persons with neglected tropical diseases (WHO ECP)	WHO (2025)	https://www.who.int/publications/i/item/9789240118461
MhGAP Community Toolkit	WHO (2019)	https://www.who.int/publications/i/item/the-mhgap-community-toolkit-field-test-version
One-to-one peer support by and for people with lived experience	WHO (2019)	https://iris.who.int/server/api/core/bitstreams/ed73f83e-e8b8-4128-8a8c-4e12bbedc6da/content
Person-centred recovery planning for mental health and well-being self-help tool	WHO (2019)	https://www.who.int/publications/i/item/9789241516822
Peer support groups by and for people with lived experience	WHO (2019)	https://iris.who.int/server/api/core/bitstreams/bbc15064-56ae-4261-aa9e-b24c82278bda/content
Community Mental Health Good Practice Guide: Peer Support	CBM (2021)	https://cbm-global.org/resource/community-mental-health-good-practice-guide-peer-support

Establishing CBG Feedback Mechanisims

In Stage 2, feedback mechanisms are formalised to strengthen trust, transparency, and collective accountability. Feedback processes help ensure that group processes remain inclusive, responsive to member needs, and aligned with the agreed purpose of the CBG defined under Stage 1. Importantly, these are not just administrative tools, but core instruments for sustaining cohesion, preventing power imbalances, and reinforcing collective ownership.

Key Actions

- Establish a simple and systematic process to gather and document member feedback.
- Integrate regular collective reflection sessions into CBG meetings, where members can discuss overall satisfaction with group functions including self-care and PSS, participation dynamics, unmet needs, emerging concerns, and suggestions for improvement.
- Encourage group leaders or relevant focal persons within CBGs to document key concerns, agreed actions, and timelines in meeting records.
- Review agreed actions at subsequent meetings to ensure accountability.
- Ensure equal opportunity to speak, with attention to gender, age, and disability-related power dynamics.
- Maintain confidentiality and safe reporting mechanisms for sensitive issues.
- Clarify distinction between internal group matters and issues requiring external referral or support.

Recommended Actions

- Assign a designated focal person to receive confidential feedback.
- Train peer supporters and/or group leaders to facilitate feedback sessions neutrally.
- Monitor participation patterns to identify underrepresented members or subgroups.
- Periodically review and update group principles and governance rules.
- Use simple feedback tools (e.g. short satisfaction checklists or guided reflection prompts).

Context-Dependent Actions

- Conduct periodic group evaluations to assess satisfaction and group functioning.
- Engage external facilitators for mediation if internal conflict exceeds group capacity.

Leadership Consolidation and Transition to Self-facilitation

In Stage 2, leadership capacity is strengthened and facilitation responsibilities are progressively transferred from external actors to CBG members. The objective is to ensure that self-care, PSS, feedback sessions, and routine meetings can be sustainably led by the group itself, while external facilitators shift to mentorship and supportive roles.

Key Actions

- Confirm or select new group leaders through transparent and participatory processes.
- Clearly define role boundaries between leaders, peer supporters, and any additional roles.
- Specify responsibilities for facilitation, documentation, communication with external actors, and ethical conduct.
- Gradually transfer facilitation of self-care, PSS, and meetings to trained members.
- Ensure CBG leaders set agendas and guide discussions independently.
- Transition external facilitators from direct delivery to mentorship and technical support.

Recommended Actions

- Train leaders and peer supporters in facilitation skills, participatory methods, conflict resolution, inclusive communication, and gender-sensitive facilitation.
- Strengthen documentation and record-keeping skills.
- Introduce simple leadership rotation mechanisms.

Context-Dependent Actions

- Create additional functional roles (e.g. meeting/logistics coordinator, advocacy focal person, community engagement, etc.) based on group size and capacity.
- Facilitate peer exchange visits between CBGs or multi-CBG feedback meetings to strengthen leadership skills.
- Introduce more formal governance structures if the group is preparing for registration or federation.

Access to Social entitlements and Financial Protection Schemes

While Stage 1 focuses on early identification of financial protection schemes, Stage 2 may support in ensuring individual access. Engagement at this stage should remain aligned with CBG priorities while maintaining focus on consolidating self-care and psychosocial support.

Key Actions

- Clarify that social protection schemes are individual entitlements and that CBGs do not function as financial distributors.
- Monitor social entitlement or financial scheme-related discussions through existing feedback mechanisms to prevent conflict or dependency dynamics.



Photo Courtesy of: LEPRA Society

Recommended Actions

- Support members to complete documentation requirements (e.g. disability certification, identification documents, bank accounts, etc.).
- Clarify application procedures and eligibility criteria.
- Accompany members through administrative processes where feasible.
- Track application progress and document recurring obstacles that may inform future advocacy priorities.

Context-Dependent Actions

- Link with disability organisations, legal aid actors, or social welfare officers where available.
- Escalate systemic access barriers into collective advocacy planning in later stages.

Developing an Advocacy Plan

Stage 2 introduces advocacy preparation to enable collective and strategic action to influence services, policies, or institutional practices impacting member's wellbeing. The focus is skill-building and realistic planning, not full external mobilization (reserved for Stage 3). Advocacy must remain based on the agreed purpose of CBGs.

Key Actions

- Build basic understanding of advocacy, including rights related to health, disability, and social protection.
- Distinguish clearly between individual case support and collective advocacy priorities.
- Build advocacy priorities drawing on the needs assessment and agreed CBG purpose developed under Stage 1.
- Develop a simple written advocacy plan defining:
  - The issue
  - The desired change
  - Relevant stakeholders
  - Timelines
  - Basic risk considerations
- Ensure internal cohesion, agreed messaging, and clear roles/ responsibilities before any external. engagement.
- Confirm that ownership and decision-making. remain with the CBG, even where external technical guidance is provided.

Context-Dependent Actions

- Initiate low-risk advocacy activities (e.g. participation in community meetings, sharing of lived experience, contribution to awareness campaigns).
- Postpone higher-level or more confrontational advocacy actions to Stage 3 once autonomy and governance are consolidated.
- Engage external facilitators for technical. mentoring where advocacy experience is limited.

Recommended Actions

- Use participatory tools (e.g. visual timelines, problem trees) to ensure inclusive planning.
- Conduct a brief situational analysis identifying barriers, discrimination patterns, policy gaps, and structural obstacles.
- Map stakeholders, allies, and relevant supportive networks.
- Review and update the advocacy plan periodically through feedback mechanisms.

Developing a Community Engagement Plan

Stage 2 prepares interested CBGs for meaningful participation in community initiatives that will take place in Stage 3. While the focus of Stage 2 remains on strengthening internal capacities, it is also important to begin identifying practical opportunities for constructive engagement with community and government initiatives.

Community engagement planning allows CBGs to anticipate relevant activities within their local environment and to clarify how the group could participate in a realistic manner. Early planning helps ensure that future engagement is aligned with the CBG's purpose and builds member confidence before participation takes place.

Key Actions

- Conduct a participatory planning session to identify relevant community or government initiatives that may occur during the upcoming months (e.g. MDA campaigns, awareness events, case finding activities, community meetings, etc.).
- Build community engagement priorities drawing on the needs assessment, agreed CBG purpose, and community asset mapping developed under Stage 1.
- Use simple tools such as seasonality calendars to identify when these initiatives typically occur.
- Discuss potential roles the CBG could play in these initiatives (e.g. awareness support, participation in meetings, community mobilisation, etc.).
- Identify members who may be interested in participating in future community engagement activities.
- Document identified initiatives, potential roles and timing in the CBG notebook or community engagement plan.

Context-Dependent Actions

- Discuss which communication approaches are culturally appropriate and preferred by CBGs (e.g. testimonies, community meetings, posters, peer discussions).
- Invite community health workers or local actors to briefly explain upcoming health initiatives where appropriate.

Recommended Actions

- Facilitate participatory discussions on barriers and misconceptions within the community related to skin-NTDs and potential messages that could address them.
- Identify local actors who may support future initiatives (e.g. community health workers, local authorities, teachers, religious leaders).

Strengthening Health Workforce Capacity

CBGs do not replace formal health services. However, their effectiveness depends to a large extent on accessible, responsive, and trusted care. Stage 2 consolidates structured referral pathways and strengthens collaboration with health providers to ensure continuity of care and sustained community trust.

Health workforce strengthening is primarily an external responsibility and is out of CBG control. CBGs contribute by maintaining clear linkages and promoting appropriate care-seeking.

Key Actions

- Map relevant primary health facilities, specialised services, and community health workers.
- Clarify referral procedures for skin-NTD complications, mental health concerns, and other priority conditions.
- Train members to recognise warning signs of physical ill health and mental distress requiring professional care and promote timely self-referral.
- Monitor referral completion and document barriers to access.
- Position CBGs and health services as complementary systems, reinforcing appropriate care-seeking and accurate service information.

Context-Dependent Actions

- Support training of health workers in integrated skin-NTD management and DMDI approaches.
- Promote familiarity with relevant mental health frameworks where referral pathways include mental health services.
- Strengthen health system responsiveness to CBG referrals and promote stigma-sensitive care practices.
- Use simple referral tracking mechanisms to identify systemic gaps and inform later advocacy.

Recommended Actions

- Facilitate periodic engagement between CBGs and community health workers or primary healthcare providers.
- Encourage health staff participation in selected sessions to reinforce self-care practices and clarify treatment pathways.
- Promote mutual understanding of roles between CBGs and health providers.
- Support gender-sensitive engagement in referral and service access.



Photo Courtesy of: GLRA Ethiopia



Photo Courtesy of: LEPRA Society



Photo Courtesy of: Effect Hope

STAGE 3 - COMMUNITY INTEGRATION AND ADVOCACY

A: Stage 3 Overview

Objective

To enable interested CBGs to engage externally through structured networking, community participation and advocacy, while consolidating ownership, visibility and long-term sustainability with reduced NGO facilitation.

Stage 3 does not introduce new internal strengthening domains. Self-care, PSS and collective feedback should continue through maintenance sessions but are no longer the primary focus. The emphasis shifts to external visibility, community engagement, collective voice and long-term continuity.

Minimum required milestones

- ☐ Networks with community and government stakeholders established
- ☐ CBGs actively engage in community and/ or advocacy initiatives
- ☐ CBG self-assessment conducted
- ☐ Sustainability roadmap agreed and in place

Approximate timing: 3-6 months

Strategic and programmatic actions:

1. Operationalising stakeholder relationships:
   - ☐ Pathway A: Participation in community initiatives
   - ☐ Pathway B: Advocacy implementation
2. Sustainability and transition planning

B: Strategic and Programmatic Recommendations

i. Operationalising Stakeholder Relationships

Evidence demonstrates that mature and engaged CBGs can evolve into formal collaboration structures with health authorities, civil society actors, and community leaders, enabling people affected to contribute to decision-making and programme implementation [8].

In Stage 3, stakeholder relationships move from mapping to external engagement. Here, interested CBGs establish formal networks and strategic relationships with community and government actors activating clear entry points for collaboration, visibility, and constructive influence, strengthening the group's external legitimacy while reinforcing long-term sustainability.

External engagement should build on the trust, confidence and collective identity developed during earlier stages, recognising that many members may have experienced stigma or exclusion and may require gradual exposure to public roles.

Engagement may take two pathways: A) Participation in community and/or B) Advocacy initiatives.

Before initiating any of the two pathways, CBGs should confirm that the following elements are in place. Many of these may already have been addressed during Stage 2 planning.



Photo Courtesy of: LEPRA Society

Checklist for External Engagement

- [ ] Community engagement and/or advocacy priorities, as well as priority stakeholders for immediate engagement have been identified.
- [ ] Key engagement objectives are agreed and aligned with the CBG purpose and priorities.
- [ ] The community engagement plan and/ or advocacy plan developed in Stage 2 has been reviewed, and the group has agreed which engagement pathway to pursue.
- [ ] Roles and responsibilities for external engagement are clearly assigned to trained CBG members (e.g. leader, spokesperson, liaison with stakeholders).
- [ ] CBG members participating in external activities do so voluntarily, particularly when sharing lived experiences.
- [ ] Informal engagement with priority stakeholders has been initiated (e.g. courtesy visit, invitation to CBG session, participation in local event, etc.) and expectations clearly understood.
- [ ] Self-care, PSS and feedback sessions are functioning regularly and continue alongside external engagement.
- [ ] Potential risks related to stigma, confidentiality or unintended consequences of public engagement have been discussed and mitigation measures agreed.
- [ ] Mechanisms for internal feedback are in place before and after external engagements.
- [ ] CBG members selected for external roles feel sufficiently confident and supported, recognising that confidence often develops progressively through participation and peer encouragement.
- [ ] Basic principles for representation have been agreed (e.g. inclusiveness, gender balance where possible, respect for diversity of conditions and experiences, etc.).
- [ ] Opportunities for collaboration with a broad range of actors have been explored, including health authorities, community leaders, civil society organisations and informal actors.

Pathway A: Participation in Community Initiatives

This pathway applies to CBGs that prioritise participation in community initiatives as their main form of external engagement. These groups focus on contributing to existing health programmes led by health services or local authorities (e.g. awareness campaigns, MDA activities, screening initiatives, hygiene promotion, community meetings, etc.).

Participation helps positioning CBGs as credible community actors, strengthens trust with health services, improves service uptake and case identification, and reinforces the visibility and legitimacy of people affected by skin-NTDs beyond the boundaries of CBGs themselves. In addition, participation in such initiatives can increase member confidence, reduce stigma, and promote positive health-seeking behaviours within communities.

Key Actions

- Participate in identified community initiatives included in the community engagement plan.
- Support representation of CBGs in relevant community forums, meetings or programme activities organised by health services, local authorities or community organisations.
- Coordinate with community health workers or programme staff during activities to ensure accurate community messaging and appropriate referral guidance.
- Record participation, outcomes and lessons learned to inform future planning.

Recommended Actions

- Ensure CBG participation in existing government-led NTD or community health programmes where relevant.
- Contribute to discussions or activities that address stigma, access to care, disability inclusion or community health.
- Collaborate with local actors (e.g. teachers, religious/community leaders, local associations, etc.) to maximize coverage and reinforce health messaging.
- Encourage rotation of CBG representatives participating in community initiatives to build confidence and leadership capacity among members.
- Reflect periodically within the CBG on participation experiences to identify successes, challenges and opportunities for improvement.

Context-Dependent Actions

- Support community awareness using agreed messages developed by CBGs themselves.
- Encourage CBGs to participate in multi-stakeholder coordination platforms or district-level forums when these exist and when the CBGs demonstrate sufficient maturity.
- Collaborate with media, community radio or local communication channels to increase awareness and visibility of skin-NTD issues and CBGs as community actors.



Photo Courtesy of: LEPRA Society

Pathway B: Advocacy Implementation

This pathway applies to CBGs that prioritise collective advocacy to address structural barriers affecting people affected by skin-NTDs. Pathway B focuses on influencing policy, services or institutional practices that affect access to care, social protection, stigma reduction or disability inclusion among others.

Advocacy in the context of CBGs should remain constructive and aligned with the agreed CBG purpose. Early advocacy actions typically focus on dialogue, awareness-raising and relationship-building with relevant authorities and service providers. More formal or higher-level advocacy initiatives may emerge progressively as CBGs gain experience and legitimacy. Sustained advocacy is strengthened when it is grounded in documented group experiences and supported by recognised structures, clear governance and collective voice.

Key Actions

- Implement priority actions defined in the CBG advocacy plan.
- Ensure advocacy messages are based on documented group experiences, needs assessments and/or evidence generated through CBG activities.

Context-Dependent Actions

- Share testimonies and/or lived experiences of people affected by skin-NTDs in appropriate forums to strengthen awareness and influence decision-making.
- Collaborate with community stakeholder panels, civil society networks or federations of persons affected to strengthen collective advocacy efforts.
- Engage media or communication platforms to raise awareness on priority issues.
- Support leaders within the CBG to represent the group in broader advocacy initiatives or networks.

Recommended Actions

- Use simple communication tools to support advocacy messages.
- Monitor progress on advocacy priorities through periodic reflection sessions within the CBG.
- Adjust advocacy strategies over time based on feedback from stakeholders and experience gained through engagement.

ii. Sustainability and Transition Planning

As CBGs increase their external engagement and visibility, it becomes important to reflect on the group's progress and prepare for long-term continuity.

At this stage, sustainability should be understood primarily as organisational continuity, rather than immediate financial independence (Stage 4). The objective is to ensure that CBGs can maintain core functions, such as self-care practice, PSS, feedback sessions, and appropriate external engagement, while progressively strengthening linkages with community structures and local institutions.

Key Actions

- Conduct a participatory CBG self-assessment to reflect on progress across the main domains developed during Stages 1–3.
- Identify remaining capacity gaps or support needs that may affect long-term functioning.
- Facilitate discussions on future priorities of the group, considering member interests, community needs and realistic opportunities.
- Develop and document a simple roadmap for the continuity of CBG activities, outlining key objectives, revising long-term aspirations, priorities, governance, roles and responsibilities, and approximate timelines for the next 6-12 months.
- Confirm arrangements for continuation of regular CBG meetings, including meeting coordination and logistics.

Context-Dependent Actions

- Encourage rotation of leadership roles to ensure continuity and shared responsibility.
- Explore opportunities for formal registration of the CBG.
- Identify potential partnerships with disability organisations, community groups, or local authorities that could support future activities.
- Sustain temporary technical guidance from implementing partners or external facilitators to refine sustainability planning where needed.
- Explore opportunities to participate in networks or federations of people affected to strengthen long-term collective voice and representation.

Recommended Actions

- Identify potential opportunities to strengthen programmatic and financial sustainability through existing community resources and existing local programmes.
- Reflect on possible income generating activities or savings mechanisms in alignment with the revised needs assessment and purpose conducted in Stage 1.
- Define how CBG members will continue engaging with community initiatives or advocacy priorities identified during Stage 3.

Stage 4 - FINANCIAL SUSTAINABILITY OF CBGs

The scope of CBG development presented in this manual follows the conceptual framework tested through the UPLIFT study, which primarily captures the early phases of community group evolution. More advanced developments, shifts to savings or loan groups, large-scale advocacy engagement, multi-level partnerships, or deeper integration within health systems, extend beyond the timeframe and validation scope of the model.

Nevertheless, sustainability should be considered from the outset of CBG formation, rather than only after Stage 3. While the three stages progress sequentially, sustainability strategies may evolve in parallel depending on the purpose, priorities and context of each CBG. In particular, financial sustainability or livelihood initiatives may be pursued earlier where these align with group interests and available opportunities.

Evidence from the scoping review and practical learning from UPLIFT implementation suggest that sustainable CBGs may evolve when they progressively strengthen ownership, community legitimacy, institutional linkages and access to economic opportunities. The considerations below outline possible directions that organisations and CBGs may explore beyond the initial three stages proposed in this manual.

Strengthening CBG Ownership

Long-term sustainability depends primarily on the degree to which CBG members perceive the group as their own initiative rather than an externally driven programme. CBGs are more likely to remain active when members feel capable of shaping decisions, mobilising resources and adapting activities to changing circumstances.

Key considerations:

- *Reinforce from the outset that external (typically NGOs) facilitation is temporary and enabling, while long-term continuity depends on member leadership, participation and collective responsibility.*
- *Promote co-creation approaches, ensuring that members actively shape planning, implementation and evaluation of activities, including periodically revisiting the group's shared purpose and priorities as these evolve over time.*
- *Apply an asset-based approach, prioritising local knowledge, capacities, and solutions before seeking external support.*

Key considerations continued:

- *Support CBGs to develop a shared understanding of sustainability, recognising that sustained impact and member wellbeing are more important than maintaining specific programme activities.*
- *Encourage peer learning and sustained member engagement by facilitating exchanges between CBGs, recognising group contributions within the community and using accessible communication to maintain connections and mutual support.*

Facilitating Access to Livelihood Opportunities

In many settings, livelihood improvement is a central priority for people affected by skin-NTDs. While livelihood initiatives may strengthen motivation and group cohesion, they often require technical expertise beyond the scope of health-focused programmes.

Organisations implementing CBG models should therefore focus on facilitating linkages with specialised livelihood actors, rather than directly implementing economic programmes where expertise is limited.

Key considerations:

- *Early mapping of organisations providing livelihood training, vocational support or micro-enterprise development.*
- *Facilitating connections between CBGs and government livelihood schemes, vocational programmes or microfinance initiatives.*
- *Supporting peer learning through documentation and sharing of livelihood success stories across CBGs.*
- *Ensuring economic initiatives are introduced gradually and only when CBG governance and cohesion are sufficiently strong. Where appropriate, groups may progressively explore savings or cooperative livelihood structures.*

Institutionalising CBGs Within Community and Health Systems

Sustainability is strengthened when CBGs become recognised actors within existing community and health governance structures.

Institutionalisation does not necessarily imply formalisation, but rather the gradual development of stable relationships with relevant institutions and community stakeholders.

Key considerations:

- *Prioritise engagement with existing local governance and community participation platforms related to health, disability, social protection or development, encouraging CBG representatives to participate in relevant committees, community initiatives or local planning processes.*

- *Strengthen collaboration with primary health services and community health workers to reinforce referral systems, improve service responsiveness and position CBGs as trusted community actors.*

- *Explore opportunities for formal recognition or registration of CBGs, federations or similar structures where this may facilitate representation, access to opportunities or participation in decision-making processes.*

- *Whenever possible, organisations should prioritise strengthening of existing platforms rather than creating parallel structures, supporting long-term integration of CBGs within community systems.*

3

Monitoring and Evaluation



Photograph by: Brian Cotie

Monitoring and Evaluation

Monitoring and evaluation (M&E) approaches should aim to support implementation quality, learning and accountability. Monitoring should remain simple, practical, and integrated into routine CBG activities. Its primary purpose is to track progress of CBGs across the three developmental stages, identify implementation gaps requiring support, capture operational learning, and document changes in wellbeing, social participation, and access to services among people affected. In addition, periodic evaluation may be conducted to assess broader outcomes and impact related to physical health, mental wellbeing, stigma reduction, social participation, and empowerment.

Monitoring and evaluation therefore serve as learning tools for both CBG members and implementing organisations, helping strengthen group functioning, inform programme management and contribute to the broader evidence base on community-based approaches for skin-NTDs.

3.1 Monitoring progression across CBG developmental stages

The present manual structures CBG development across three progressive stages, each defined by a set of milestones. Monitoring therefore focuses primarily on milestone achievement.

Facilitators, CBG leaders and peer supporters should periodically review whether required milestones for each stage have been achieved before progressing to the next stage. Importantly, progression should be determined by demonstrated readiness rather than by rigid timelines. This helps ensure that CBGs progress at an appropriate pace, preventing premature transitions that may affect group cohesion or sustainability.



Photograph by: Tom Bradley

Recommended Monitoring Approaches

Monitoring Tool	Data Collection
Meeting records	· Meeting attendance · Key decisions/ actions · Self-care and PSS session summaries · Feedback session discussions and follow-up actions · Community participation and/or advocacy activities
Observation notes	· Group participation · Self-care practice and knowledge · Peer supporter facilitation of PSS · Leadership capacity · External engagement activities
Qualitative/ Quantitative outcome monitoring	· Self-care practice · Mental wellbeing · Social participation · Access to healthcare services · Access to social entitlements or financial support schemes · Experiences of stigma

Milestone	Suggested Output Indicators
Stage-1: Foundations and governance	
Basic governance structure in place	# of CBGs with an action plan for membership developed # of CBGs with governance structure documented # of CBGs with a trained group leader in place # of local stakeholder panels established #of CBGs with records kept by a trained group leader
Needs assessment completed	#of CBGs with needs assessment conducted
Collective CBG purpose established	# of CBGs with CBG purpose developed

Community asset mapping completed	# of CBGs with community asset mapping completed
Financial protection schemes identified	# of CBGs with a list of financial protection schemes
Stage-2: Trust building and capacity development	
Feedback mechanism in place	# of CBGs conducting collective feedback sessions quarterly # of CBGs conducting feedback surveys quarterly
Self-care autonomy by CBG members	# of CBG members carrying out self-care regularly
PSS facilitation autonomy by peer supporters	# of CBGs with trained peer-supporter # of CBGs of which PSS is independently facilitated by a trained peer supporter # of CBGs providing positive feedback to peer-supporters
CBG facilitation autonomy by CBG leaders	# of CBGs of which meeting facilitation is independently facilitated by a trained leader # of CBGs providing positive feedback to the leader
CBG members access financial protection schemes	# of CBG members who access financial protection schemes
Advocacy plan in place to support transition to autonomy	# of CBGs with an advocacy plan in plan
Community Engagement initiatives are identified	# of CBGs with plan for community engagement
Stage-3: Community integration and advocacy	
Networks with community and government stakeholders established	# of CBGs who have established contact with community and government stakeholders
CBGs actively engage in community and / or advocacy initiatives	# of CBGs who have engaged in community and / or advocacy initiatives
CBG maturity framework completed	# of CBGs who have completed maturity framework
Sustainability plan agreed and in place	# of CBGs who have completed sustainability plan

3.2 Participatory Reflection Sessions

Typically structured under regular feedback sessions, monitoring should be complemented by reflection and learning processes involving both facilitators and CBG members. These discussions reinforce collective ownership of the group. Where possible, implementing organisations should also facilitate exchange meetings between different CBGs or gathering events, inviting leaders and peer supporters together for collective feedback.

Discussions should at least cover:

- *Progress of achievements*
- *Challenges encountered*
- *Lessons learned*
- *Areas requiring improving or sustained technical support from external organizations*

3.3 Evaluating Outcomes and Impact

Organizations may also conduct periodic evaluation to assess broader outcomes, according to available resources, programme objectives and learning priorities. Possible areas for evaluation include:

- *Improvements in physical health and self-care practice*
- *Changes in mental wellbeing*
- *Reduction of stigma and discrimination*
- *Access to healthcare and social services*
- *Increased social participation*
- *Increased self-efficacy or empowerment of CBG members*
- *Community awareness and attitudes*

3.4 Learning for Programme Improvement and Replication

M&E findings should ultimately contribute to continuous programme improvement and knowledge generation, helping in:

- *Improving facilitation approaches*
- *Adapting CBG functions and activities to different contexts*
- *Strengthening collaborations with health systems as key community actors in NTD programmes*
- *Informing advocacy priorities*

4

References and Sources



Women in Pawai Village, Madhya Pradesh, India during a community gathering.
Photo Courtesy of: Effect Hope

References and Sources

References and Sources Used

1. WHO, Ending the neglect to attain the Sustainable Development Goals: A strategic framework for integrated control and management of skin-related neglected tropical diseases. 2022, World Health Organization: Geneva.

2. WHO, Essential care package to address mental health and stigma for persons with neglected tropical diseases. 2025, World Health Organization: Geneva.

3. WHO, Ending the neglect to attain the Sustainable Development Goals: A road map for neglected tropical diseases 2021–2030. 2020, World Health Organization: Geneva.

4. Hotopf I, et al., Community-based models for neglected tropical diseases affecting the skin: a scoping review. Frontiers in Tropical Diseases, 2025. 6: p. 22.

5. COUNTDOWN, Establishing community-led support groups for people affected by skin-NTDs. 2021.

6. REDRESS, Intervention Manual. Case Management of Neglected Tropical Diseases Training Manual. 2023: p. 212-247.

7. CBM, Community Mental Health Good Practice Guide: Peer Support. 2021.

8. Zaizay E, et al., Network for persons affected by NTDs, Liberia (NEPA NTDs): Striving for persons affected by NTDs to be seen as agents of change in Liberia. 2025, REDRESS.

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