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MINISTRY OF HEALTH-ETHIOPIA

24 February 2025

# NATIONAL BIRTH DEFECTS WEEK ACTION PLAN

**Advancing National  
Prevention, Care, and  
Inclusion Systems  
for Birth Defects!**

*Organized by :- Ministry of Health Ethiopia*

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## Introduction

World Birth Defect Week will be commemorated in Ethiopia for the second time from March 3 to 8 through a collaborative effort between the Ethiopian Ministry of Health, Regional Health bureaus and various partner organizations. This annual observance aims to raise awareness, advocate for prevention, and enhance early detection and management of congenital anomalies across the country. The week-long celebration will include a range of activities, such as a Birth Defect Day celebration and exhibition, extensive social media advocacy, and nationwide campaigns spanning all 12 regional administrations and two city administrations.

The Ethiopian Ministry of Health will spearhead the initiative, supported by a core team comprising professional associations and 16 partner organizations. These stakeholders are strategically divided into five subgroups to address specific categories of birth defects: Cleft Lip and Facial Reconstructive Surgery, Neural Tube Defect Management, Musculoskeletal Problems Management, Neurodevelopmental Disorder Management, and Other Birth Defect Management. This structured approach ensures that efforts are aligned with the country's disease burden and surgical backlog, optimizing resource allocation and intervention effectiveness.

Birth defects are a major cause of infant mortality and long-term disability worldwide, affecting 1 in 33 babies annually, according to the WHO. Many can be prevented or managed through early intervention and improved healthcare, but the lack of reliable data hinders effective public health strategies.

Birth defects remain a significant public health challenge in Ethiopia. The pooled prevalence of congenital anomalies in Ethiopia was found to be about 2%. A systematic review and meta-analysis revealed that neurological defects constitute the highest prevalence at 48%, followed by orofacial clefts (19%), gastrointestinal tract anomalies (13%), musculoskeletal defects (12%), cardiovascular system defects (7%), and Down syndrome (5%) (1). By bringing together key stakeholders and prioritizing evidence-based interventions, World Birth Defect Week aims to improve health outcomes and reduce the impact of congenital anomalies nationwide.

## Overview

World Birth Defect Week in Ethiopia will be celebrated from March 3 to 8 through the joint efforts of the Ethiopian Ministry of Health and partner organizations. The event is dedicated to advocating for the prevention, early detection, and effective management of congenital anomalies. A variety of activities will take place throughout the country, including a Birth Defect Day celebration and exhibition, as well as an extensive social media advocacy campaign reaching all 12 regional administrations and two city administrations.

The celebration will officially commence on March 3 with an event and exhibition, highlighting awareness and education on birth defects. Throughout the week, campaigns will focus on increasing public knowledge and engagement, ensuring that communities across Ethiopia are informed about birth defect prevention and management strategies. This initiative underscores the commitment of health institutions and stakeholders in addressing the burden of congenital anomalies in Ethiopia.

## Objective

The main objective of celebrating World Birth Defects Day in Ethiopia on March 3 is to advocate for the prevention, early detection, and effective management of congenital anomalies in the country. Specifically, the celebration aims to

- Increase public understanding of congenital anomalies, their causes, prevention strategies, and the importance of timely intervention.
- Mobilize policymakers, healthcare providers, and stakeholders to prioritize congenital anomaly services in national health agendas and allocate adequate resources for their management.
- Promote partnerships among government bodies, non-governmental organizations, healthcare institutions, and community groups to address gaps in congenital anomaly services and improve accessibility and quality.
- Provide education and support to families and communities to reduce stigma, promote inclusivity, and encourage individuals affected by congenital anomalies to seek care and rehabilitation services.

- Showcase Ethiopia’s achievements in addressing congenital anomalies, while identifying challenges and opportunities to further strengthen the national response.
- Serve as a platform to share experiences, best practices, and innovations in congenital anomaly prevention, diagnosis, and management through campaign.

## Stakeholders

Actively engage key stakeholders including

- MOH
- RHB
- Partner Organizations
- Zonal health offices
- Woreda Health Offices
- Health Facilities
- Media (TV/Radio)
- Communities
- Families and CLP patients

## Speciality and Rehabilitation Service desk Strategic Initiatives

1. Creating Medical Centers of Excellence and Service expansion
2. Strengthening Specialty and Subspecialty Service per tier System
3. Making Ethiopia a destination for medical and wellness tourism
4. Strengthening and expanding assistive technology production and services
5. Disarmament, Demobilization and Reintegration (DDR) & Internal Displaced Persons (IDP) Program
6. Physical and Mental rehabilitation service expansion and strengthening
7. Strengthening and expanding treatment services for birth defects
  - i. Establishing a consistent data handling system for babies born with birth defects
  - ii. Initiate treatment for congenital problems (clubfoot, spina bifida and hydrocephalus and cleft lip and palate) each in 5 new health facilities.
  - iii. Prepare a strategic guide for the treatment of birth defect
  - iv. Provide supportive supervision and mentorship for institutions that provide services for birth defects.
  - v. Preparation and introduction of cleft lip and palate treatment guideline
  - vi. Provide capacity building training to 150 professionals who provide services for the treatment of birth defects (clubfoot, spinal-bifida and hydrocephalus and cleft lip and palate).
  - vii. Deliver treatment for neglected birth defect patients by conducting 8 round campaigns
  - viii. Financial support to all regional health bureaus to strengthen and expand birth defect management
  - ix. Procurement of equipments for the treatment of children born with birth defects.

# Chapter 1 - Cleft lip & Palate and facial reconstructive Surgery

## Background

Orofacial clefts are among the most common congenital anomalies, contributing significantly to global mortality, morbidity, and economic burden. These defects occur when facial structures fail to fuse properly during fetal development, affecting the lip and/or palate. The incidence varies by ethnicity, with the highest rates among Asians (1 in 500 births), followed by Caucasians (1 in 700) and individuals of African descent (1 in 1,200). Ethiopia sees over 3,350 cleft births annually.

While high-income countries have seen a decline in the incidence and severity of orofacial clefts due to improved healthcare and surgical advancements, low-income regions, especially Sub-Saharan Africa, are experiencing rising cases. From 1990 to 2019, global cases dropped from 240,000 to 190,000, yet Sub-Saharan Africa saw alarming increases: 69% in Western, 45% in Eastern, 33% in Central, and 14% in Southern regions. The region also has the highest mortality rates and ranks second in disability burden due to orofacial clefts.

Challenges such as poverty, poor maternal nutrition, and limited healthcare infrastructure continue to hinder effective treatment and management. Despite global progress, comprehensive data on orofacial clefts in Africa remain scarce, underscoring the need for better research and intervention strategies.

i. Stakeholders and Partner Organizations facilitating the campaign

- MOH
- RHB
- Health facilities
- Smile Train
- Project Harar
- Trust Charitable Association
- Operation Smile



ii. Site Selected for the campaign

- |              |           |         |
|--------------|-----------|---------|
| • Arba Minch | • Jimma   | • Adama |
| • Gonder     | • Mekelle |         |
| • Jigjiga    | • Dessei  |         |

iii. Target Audience

- Communities
- Families
- Healthcare providers (primary, secondary, and tertiary levels)
- Decision makers at different levels (MOH, RHB Officials, Zonal Health Department Officials, Woreda Health Office Officials, Hospital management), and stakeholders

iv. Key Activities

a. Prevention and Awareness

- Develop, translate and disseminate behavioural change communication materials (brochures, posters, online resources) to the public in all 14 regions.
- Provide training to PR and media staff on CLP and engage them on behavioral change communication in 14 regions
- Provide health education to families
- Reach healthcare providers with BCC materials

b. Care

- Patient mobilization
- Get hospitals ready for CLP surgery
- Registering patients and collecting reports of registered patients.
- Refer patients to the following care centres from all regions
- Prepare logistics for both patients and healthcare providers.
- Provide surgical care for 120 CLP patients.
- Provide counselling and health education to 120 families.



S/N	Hospital	Region/ City Admini stration	City	Funding Partners	Implementing Partners
1	ALERT Comprehensive Specialized Hospital	Addis Ababa	Addis Ababa	Smile Train	Trust Charitable Association & ALERT CSH
2	Yekatit 12 Medical College	Addis Ababa	Addis Ababa	Smile Train	Yekatit 12 Medical College
3	Zambaba General Hospital	Addis Ababa	Addis Ababa	Smile Train	Trust Charitable Association & Zambaba General Hospital
4	Arba Minch General Hospital	South Ethiopia	Arba Minch	Smile Train	Trust Charitable Association & Arba Minch GH
5	Yoya General Hospital	Oromia	Adama	Smile Train	Project Harar & Yoya GH
6	Dessie Comprehensive Specialized Hospital	Amhara	Dessie	Smile Train	Project Harar & Dessie CSH
7	Selam General Hospital	Amhara	Dessie	Smile Train	Project Harar & Selam GH
8	Mekelle General Hospital, Mekele	Tigray	Mekelle	Smile Train	Makelle General Hospital, Mekele
9	Worabe Comprehensive Specialized Hospital, Worabe	Central Ethiopia	Worabe	Smile Train	Project Harar & Worabe CSH
10	JU S.H.Yabare Comprehensive Specialized Hospital	Somali	Jigjiga	Smile Train	Trust Charitable Association & JU S.H.Yabare CSH
11	Alatyon General Hospital	Sidama	Hawassa	Smile Train	Trust Charitable Association & Alatyon GH
12	Jimma University Specialized Hospital	Oromia	Jimma	Operation Smile	OP Smile & Jimma USH

Table 1: Cleft lip and palate treatment center with regions, cities, and partners



Figure 1: Map of target cleft surgical care points during the World Birth Defect Management Week

c. Inclusion

- Facilitate Cleft family conversation
- Promote acceptance of people affected with cleft by community
- Raise awareness among care providers on the inclusion CLP in health facility services
- Advocate for policies that prioritize comprehensive CLP services

v. Monitoring, Evaluation

Closely monitor implementation using the following indicators and take corrective measures

Indicators:

- Number of regions reached with CLP care
- Number of health facilities involved in CLP care
- Several patients identified linked to treatment centres.
- Number of patients who received cleft surgery
- Number of BCC materials printed and distributed
- Number of regional media that covered the event
- Number of families reached by health education and cleft care counseling

## vi. Timeline

Table 2: Cleft lip and palate management week activities with timeline

Major Activities	Sub-activities	Coordinator from CLP sub-team	Responsible person/body	Date
Develop BCC materials (banners, poster and leaflet)	Final content	Getaneh	Reconstructive surgery team	14-Feb-25
	Final Design	Getaneh	MOH/ PR	20-Feb-25
	Final Print out	Getaneh	MOH/ PR	28-Feb-25
	Distribution	Geleta, Dassie	MOH, RHB and partners.	
Engage regional media	Write letters from regional health bureaus to local medias	Geleta	RHB	17-Feb-25
	Organize media and stake holders training	Dr. Semiret	MOH/ RHB	Feb 20/2025
	Follow up	Geleta & Dessie	Partners	Starting from 17 Feb 2025
Patient mobilization	Cascade letter from MOH to the grassroots level	Geleta & Dessie	RHB	21-Feb-25
	Get hospitals ready for cleft surgery	Geleta & Dessie	Partners.	14-Feb-25
	Patient mobilization and registration	Geleta & Dessie	RHBs & partners	28-Feb-25
	Compiling reports of patient list			
	Prepare logistics to move patients to and from care point	Geleta & Dessie	PHE & TCA	25-Feb-25
Provide service	Provide free cleft surgical care	Geleta & Dessie	Plastic surgeons.	4 to 8 March 2025
	Create awareness on CLP( health education in the health facilities; regional media; distribution of BCC materials)	Geleta & Dessie	PHE& TCA	3 to 8 March 2025

## vii. Budget and Resources

Table 3: Budget breakdown

Activity	Total cost for 120 patients' cleft lip and palate surgery and awareness activities (ETB)	Budget Source
Surgery cost	8,500,000	Smile Train, Project Harar, and Trust Charitable and target hospitals
Patient logistic	1,125,000	
Awareness activities and materials	50,000	
Total	10,000,000.00	

## 9. Communication Plan

Table 4: Communication objectives, audience, materials and target regions

Communication objective	Audience	BCC materials	Channel of communication	Region	Language
<p>Improve prevention of cleft lip and palate</p> <p>Increase awareness of the community on the availability of cleft lip and palate care</p> <p>Enhance awareness of health care provides on provision of patient-friendly cleft care for all people with cleft.</p> <p>Promote acceptance of people with cleft by the community.</p>	<p>Community, family, health care providers, decision-makers (MOH, RHB, ZHD, Wor HO, Hospital Management, health care providers)</p>	<p>Flyers</p> <p>Poster</p> <p>Banner</p>	<p>Print media</p> <p>Radio</p> <p>TV</p>	<p>Addis Ababa</p> <p>Oromia</p> <p>Amhara</p> <p>South Ethiopia</p> <p>Sidama</p> <p>Somali</p> <p>Tigray</p> <p>Central Ethiopia</p>	<p>Amharic</p> <p>Afan Oromo</p> <p>Somali</p>

## Chapter 2- Neural Tube defect

### Background

Ethiopia has the highest recorded prevalence of neural tube defects (NTDs) in Africa, posing a serious public health challenge. A meta-analysis estimated the pooled prevalence of NTDs among Ethiopian children at 63.3 cases per 10,000 births, with spina bifida at 41.09, anencephaly at 18.90, and encephalocele at 1.07 per 10,000 births. This rate is significantly higher than the global average of 2 to 5 per 1,000 births, with developing countries experiencing the highest burden.

NTDs, including spina bifida, hydrocephalus, and anencephaly, contribute to high neonatal morbidity and mortality while imposing lifelong medical, social, and economic burdens. Family history and unplanned pregnancy are key risk factors, while folic acid supplementation during early pregnancy is protective. Ethiopia urgently needs stronger prevention strategies, early detection, and improved access to specialized care to mitigate the impact of NTDs.

World Birth Defects Day plays a crucial role in raising awareness about NTDs and their effects on individuals and families. It promotes early diagnosis, better management, and inclusive policies while working to reduce stigma. Key objectives include increasing public and healthcare provider awareness, strengthening early detection and treatment, improving care services, and fostering inclusion.



i. Stakeholders and Partner Organizations facilitating the campaign

- MOH
- RHB
- Hope SBH
- Hospitals
- Healthcare providers (Primary, secondary, tertiary levels)
- Communities & general public

ii. Site selected

- Clinical care and Inclusion and advocacy - Dire Dawa & Hawassa Regions
- Prevention, early detection and referral Pathway:
  - Afar Region
  - Amhara Region
  - Central Ethiopia Region (New)
  - Dire Dawa City Administration (Chartered City)
  - Gambela Region
  - Harari Region
  - Oromia Region
  - Sidama Region
  - South Ethiopia Region (New)
  - Addis Ababa

- iii. Key Activities
  - a. Prevention & Early Detection

**Table 1: Prevention & early detection activities**

Activity	Stakeholder	Deliverable	Timeline	Location
Training sessions (2) for 116 regional focal persons (HoPR, RFB, REB, WCB, Mayor, MDCT, HC, HEW, RHB, Regional medias, Cheshire Homes, community reps).	MoH, RHBs, HOPE-SBH	Sensitization of regional officials on SBH prevention (LSFF), Technical capacity-building for early detection & referral.	March 5-6, 2025	Dire Dawa & Hawassa
Develop & distribute awareness materials (20,000 brochures, 3000 posters, online content).	MoH, HOPE-SBH	Design, print, and distribute materials on prevention (fortified food consumption, Supplementation) & early case detection.	Feb 2025	All regions
Community outreach activities (2)	HOPE-SBH, RHBs	Awareness on consumption of foods fortified with folic acid, supplementation, early detection, aftercare and referral pathways by trained professionals using the 10000 brochures and 500 posters.	From March 6, 2025	Dire Dawa & Hawassa
Media Briefing Event document preparation (Virtual & Physical)	MoH, HOPE-SBH and Media	National-level awareness campaign launch.	March 4, 2025	MoH HQ & Online

- b. Clinical Care & Multidisciplinary Care Team Support (MCTS)

MCTS is a structured medical & rehabilitation team that ensures comprehensive care for children with NTD.

Minimum Standard Members (to be discussed further):

1. Neurosurgeon / General Surgeon
2. Pediatrician / Neonatologist with referral link to Pediatric Surgeon
3. Physiotherapist with basic Occupational therapy training
4. Nutritionist (nutrition education)
5. Psychologist/ Parent counselor
6. Social Worker

<b>Activity</b>	<b>Stakeholder</b>	<b>Deliverable</b>	<b>Timeline</b>	<b>Location</b>
Define & promote MCTS initial standards	MoH, Hospitals	Develop guidelines for team coordination & patient care.	Feb 2025	MoH, Hospitals
Timely referrals & case mapping	Hospitals, RHBs, HOPE-SBH	Ensure early detection & referral pathways. Posting referral pathway posters in health centers and hospitals.	Ongoing	Dire Dawa & Hawassa
Capacity-building training for specialists	MoH, HOPE-SBH	2 Trainings for medical teams on best practices in NTD management and referral pathway.	Feb 2025	Referral Hospitals
Surgical campaign for NTD patients	Hospitals, Neurosurgeons	Perform at least 20 surgeries	March 6-8, 2025	Referral Hospitals
Post-surgical rehabilitation support strengthening and follow-ups	Physiotherapists, Hospitals	Follow-up care, therapy, and support groups.	Post March 9, 2025	Hospitals & HOPE-SBH

c. Inclusion & Advocacy

<b>Activity</b>	<b>Stakeholder</b>	<b>Deliverable</b>	<b>Timeline</b>	<b>Location</b>
Family & peer support groups capacity strengthening	HOPE-SBH, NGOs	Organize meetings for affected families to empower them as change agents in inclusion and regional advocacy	March 4-8, 2025	Community Centers in Dire Dawa & Hawassa
Inclusive education accessible health service sensitization and Advocacy event aligning with prevention and early detection trainings	REB, Schools	Sensitize on the need to ensure children with NTD have access to education.	Feb-March 2025	Dire Dawa & Hawassa



iv. Monitoring & Evaluation (M&E) Framework

Key Performance Indicators (KPIs)

Indicator	Target Number	Responsible	Data Source
Workshops with training sessions conducted	2 (1 per region)	MoH, RHBs	Training attendance sheets, session reports
Community engagement & feedback surveys completed	150+ participants	HOPE-SBH	Survey responses, event participation records
Cases detected & referred	200+	Hospitals, RHBs	Hospital referral logs
Surgeries conducted	20+	Referral Hospitals	Surgical records & patient follow-up data
Regions served through surgeries	2 (Dire Dawa, Hawassa)	MoH	Regional health reports
Shunts distributed	19	HOPE-SBH, Partners	Supply distribution records
Awareness materials distributed	10000 brochures, 500 posters	MoH, HOPE-SBH	Printing & distribution records
Media events & reports published	3 (TV, Radio, Online), 1 Short Documentary	Media, MoH	Media coverage tracking
TV & radio reach	Audience size & engagement	Media, MoH	Broadcast analytics & audience surveys
Social media engagement	Shares, comments, impressions	MoH, HOPE-SBH	Social media analytics tools
Community participation in outreach events	300+ attendees	HOPE-SBH, MoH	Event attendance records

v. Data Collection Methods

**Health & Training Data Collection:**

- Pre & post-training assessments to measure knowledge improvement among healthcare providers.
- Hospital records on surgeries, referrals, and patient follow-ups.
- Community feedback surveys post-campaign to assess awareness impact.

## Media & Communication Impact Measurement:

- Broadcast & social media analytics to track audience engagement.
- Press coverage monitoring to measure campaign visibility.
- Event participation tracking to evaluate community involvement.

### vi. Review & Reporting Timeline

Phase	Activities	Date	Responsible
<b>Mid-Campaign Review</b>	Initial assessment of training effectiveness, media reach, and community engagement.	March 5, 2025	MoH, HOPE-SBH, Media
<b>Post-Campaign Analysis</b>	Full evaluation of KPIs, media impact, and feedback surveys.	March 10, 2025	MoH, RHBS, Partners
<b>Final Impact Assessment Report</b>	Comprehensive report on campaign outcomes & recommendations.	March 30, 2025	MoH, HOPE-SBH

### vii. Timeline Overview

Phase	Activities	Dates
<b>Preparation</b>	Develop materials, plan logistics, mobilize teams.	Feb 1-28, 2025
<b>Implementation</b>	Trainings, community outreach, surgical campaign.	March 5-8, 2025
<b>Follow-up &amp; Evaluation</b>	Data collection, reporting, policy advocacy.	March 9-30, 2025

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viii. Communication Plan

<b>Activity</b>	<b>What</b>	<b>When</b>	<b>Where</b>
<b>National TV &amp; Radio Campaigns</b>	Public awareness programs, expert panel discussions, testimonials from affected families.	March 3-8, 2025	National & Regional TV and Radio Stations (ETV, Fana, Sheger, Bisrat FM)
<b>Press Releases &amp; News Article</b>	Official press release highlighting key campaign messages, event coverage.	March 1 & March 8, 2025	MoH website, Media Houses, Newspapers (The Reporter)
<b>Social Media Advocacy</b>	Daily posts, infographics, short videos, testimonials. Hashtags: #NumberWorldBirthDefectsDay #NumberNTDAwareness #NumberInclusionMatters	March 3-8, 2025	Facebook, Twitter, LinkedIn, Instagram, TikTok (MoH, HOPE-SBH, RHBs)
<b>Community Engagement</b>	Local radio programs, Q&A sessions, market outreach activities.	March 5-7, 2025	Addis Ababa, Dire Dawa, Oromia and Hawasa
<b>Side Exhibition</b>	Awareness materials, success stories, partner booths.	March 3, 2025	Addis Ababa (MoH HQ)

ix. Stakeholder Recognition & Visibility

<b>Activity</b>	<b>What</b>	<b>When</b>	<b>Where</b>
<b>Partner Logo Inclusion</b>	Communication materials (brochures, posters, banners, online content).	February-March 2025	All campaign materials (print & digital)
<b>Public Recognition</b>	Acknowledgment during campaign launch & media interviews.	March 3, 2025	Live on TV & social media
<b>Official Event Report</b>	Documentation of campaign outcomes, partner contributions.	March 10, 2025	MoH website, donor reports

x. Budget & Resource Mobilization

Estimated Budget: **4,125,000 ETB**

Funding Sources: MoH, HOPE-SBH, Partners

<b>World Birth Defects Day in Ethiopia 2025, Neural Tube Defects (NTD) Awareness &amp; Management Week Plan</b>			
<b>Activity</b>	<b>Description</b>	<b>Estimated Cost (ETB)</b>	<b>Regions</b>
<b>Prevention</b>			
Workshop on NTD prevention (LSFF), technical capacity-building for early detection & referral.	Training for 116 High-level government officials and healthcare providers on birth defects prevention (covering LSFF), detection, and referral.	<b>2,201,000.00</b>	Diredawa and Sidama
Dissemination of Information Materials through Community Outreach Programs.	Printing and distribution of 10,000 brochures and 500 posters indicating preventive measures including LSFF, detection and referral of SBH.	<b>400000</b>	Addis Ababa Central Ethiopia Region Dire Dawa City Administration Gambela Region Oromia Region Sidama Region
<b>Care</b>			
Specialized Training for Healthcare Providers	Training on the management of neural tube defects for MDCT teams.	<b>180000</b>	Sidama and Dire Dawa
<b>Inclusion</b>			
Support Groups advocacy capacity building trainings	Implementing support groups and counseling for affected families.	<b>120000</b>	Sidama and Dire Dawa
<b>Monitoring and Evaluation</b>			
Progress Reviews and Monitoring	Conducting regular progress reviews and reporting findings to stakeholders.	<b>10000</b>	MoH & HOPE-SBH
<b>Communication Plan</b>			
Communication material print (brochures and posters for health centers)	Utilizing media, social media, and community events for information dissemination.	<b>1000000</b>	HOPE-SBH and MoH
Short documentary on the National birth defect day commemoration	Utilizing media, social media, and community events for information dissemination.	<b>60000</b>	HOPE-SBH and MoH
<b>Total Estimated Budget</b>		<b>3,971,000.00</b>	
<b>Admin and miscellaneous 9%</b>		357,390.00	
<b>Grand total ETB</b>		<b>4,328,390.00</b>	

## Chapter 3 – Neurodevelopmental Disorder

### Background

Neurodevelopmental disorders, including Autism Spectrum Disorder (ASD), Down syndrome, Intellectual Disability, ADHD, and Developmental Delay, present significant challenges for affected individuals and their families. Limited awareness, inadequate screening, and insufficient support services hinder early diagnosis and effective intervention, particularly in low-resource settings. The true prevalence of ASD in Sub-Saharan Africa remains unclear due to limited research. A community-based study in Uganda estimated an ASD prevalence of 6.8 per 1,000 children, while a Nigerian study based on pediatric neurological clinic visits reported 2.3%. Most studies suggest a higher prevalence in boys than girls, with a 4:1 male-to-female ratio. However, due to reliance on hospital-based samples and a lack of large-scale studies, the actual burden of ASD in the region is not well-documented.

i. Stakeholders and Organizations participating

- Ministry of Health (MoH)
- Regional Health Bureaus (RHBs)
- Civil Society Organizations (CSOs) working on Neurodevelopmental Disorders, including:
  - Nia Foundation – Addis Ababa
  - Deborah Foundation – Addis Ababa
  - Fikir Ethiopia – Addis Ababa
  - Milu’ Foundation – Addis Ababa
  - Birhan Lehitsanat – Addis Ababa
  - Nehemia Autism Center – Addis Ababa
  - Bethel Autism Center – Adama
  - Libam Autism Center – Wolayta Soddo
  - Bright Autism Center – Hawassa
  - Letaric Autism Center – Dire Dawa
  - Betemihret Development Organization – Addis Ababa
  - Igbet Intellectual Disability Association – Tigray

ii. Target Audience

- Neurodevelopment Disorder Intervention and Rehabilitation Centers,
- Families and caregivers,
- Communities and the general public,
- Policy makers and stakeholders at all levels

iii. Key Activities

a. Prevention/ Promotion

- Participate and Engage on National Birth Defect Workshop, ensure the participation of all organizations working on Neurodevelopment Disorder,
- Contribute Theme for Panel or Workshop Technical Presentation under the Theme “Magnitude, Challenges, Prospects and Inspiring Lessons in Neuro-developmental Disorders and Lessons from Interventions in Ethiopia, (Collaborations with MOH)
- Ensure the participation of organizations on the Exhibition, promote and showcase their services, Interventions, products, and establish linkage and partnerships,
- Music and Circus Performance of Children and Youth with Neurodevelopmental Disorders o the Opening Ceremony of the National BDD Workshop.
- Prepare 3 Inspiring Testimonials (Mothers of Children with Autism Spectrum Disorder, and Intellectual Disability improved with Interventions and Therapy ) Story Sharing Presentation at Workshop)
- Play role in the coordination of the National Workshop and Exhibition in specific roles assigned by the core team.
- Selected Regions, Addis Ababa, South Ethiopia, Tigray, Dire Dawa, Central Ethiopia, Oromia, Sidama
- Engage with the respective regional health office and cascade the regional engagement plan with respective Centers.
- Conduct screening of NDD and create linkage with Autism Spectrum Disorder and Down syndrome, and Intellectual Disability rehabilitation facilities, Number 200

b. Inclusion

- Prepare info-directory sheet on family support groups and rehabilitation counseling services centers in Ethiopia (Directory). We will avail it online and Number 500 copies
- Organize counseling services for affected Parents or families in Nuro-developmental Centers,
- Produce advocacy materials and brochures on Promoting inclusive education and employment opportunities for individuals with Nurodevelopmental Disorders for region. Number Brochures Number 1000.
- This is Window of opportunity to be a Voice for Voiceless for policies that protect the rights and dignity of individuals with Nuodevelopmental disorders,

iv. Collaborations and Partnerships

- Work closely with Core and Sub Teams ,Engage with MOH, Regional Health Offices and partners to fast track the implementation.
- Actively engage Intellectual and Developmental Disability Network (EIDDN).
- Coordinate and Lead organizations/ Service Centers under (ASD, Down Syndrome, Intellectual Disability, ADHD and others nuro-developmental Disorders with regional and local health authorities to ensure consistent implementation across all levels.
- Integrate the plan with Other specialty Teams,
- Foster partnerships with community-based organizations and advocacy groups.
- As these areas are gray in terms of Getting adequate budget for this particular event we will work with the support of the ministry to approach partners

v. Monitoring and Evaluation

Preparation activities will be monitored with frequent status follow-up meetings at core team as well as sub team level. The over all monitoring of on the accomplishment of the initiative will be monitored on the evaluation based on the concise report on the following indicators,

- Number of organizations and families participated on National Workshop,
- Number of organizations/CSOs working on Nurodevelopmental Disorders engaged on exhibition,
- Number Testimonials documentaries produced
- Number children screened/ assessments made on for nurodevelopmental disorders,
- Number parents/ counseling sessions conducted at ASD and Intellectual Disability Centers,
- Number Regions engaged on awareness and promotion, inclusion of nurodevelopmental disorders,

vi. Timeline

<b>Preparation Phase: April 1<sup>st</sup>- April 30/20</b>					
	<b>Activity</b>	<b>Due Date</b>			<b>Responsible</b>
		<b>February</b>			<b>Nia and Deborah Foundation</b>
	Finalize plan Alignment	x			NDD Sub Team
	Discussion & Endorse the plan on NDD Network	x			Nia/ Deborah and NDD Network
	Discussion with Regional Counter parts alignment,		x		NDD network and RHB
	Progress update Meetings with the sub team (NDD Network )		x	x	Nia/ Deborah and NDD Network
	Finalize Presentation/ Panel on selected theme , with insights from different nurodevelopmental disorders,	x			Nia and NDD Network
	Identify the Panelist and Communicate	x			Nia Foundation
	Identify Organizations an Families / communicate MoH, Invitation for National Workshop Participation	x	x		Nia and Other members of NDD network
	Identify and Confirm organizations, Engage on Exhibition and communicate with MOH	x	x		Nia and Other members of NDD network
	Finalize Preparation for Music and Circus Performance / Fikir Ethiopia Int. Disability Team	x	x		Fikir Ethiopia



	Select and Finalize Documenting Testimonials		x	x		Nia Foundation
<b>Implementation Phase: March 3- 9/2025)</b>						
	<b>Activity</b>		<b>Due Date</b>			<b>Responsible</b>
			March 4-9			
	Engage and Participate on the National Workshop	x				All NDDN member organizations
	Fikir Ethiopia Music and Circus Team Performance at Opening	x				Fikir Ethiopia
	Presentation/ Panel Deliberation on Neurodevelopmental Disability n NBDD Workshop , on selected theme	x				Nia Foundation and Selected Organizations
	Engage and take part on Exhibition Program, show casing organizational Services, Products and Best Practices by Organizations	x				All NDDN member organizations
	Assign organizations for technical contribution to regional Birth Defect awareness raising campaign Team on Selected regions,	x				Network
	Conduct parents counseling, Screening and Assessment on Selected regions (Center Providing (ASD, Down Syndrome, Intellectual Disability and ADHD )	x				NDDN member organizations
	Testimonials deliberation	x				Selected
	Engage on the Recognition and Closing Program			x		
<b>Monitoring and Evaluation Phase</b>						
	<b>Activity</b>		<b>Date</b>			<b>Responsible</b>
	Draft report					
	Evaluation and Learning Session with the core team					
	Final Report					

vii. Communication Plan (To be aligned with PR Plan)

- Develop 3 flayer materials on Autism Spectrum Disorder, Down Syndrome and Intellectual Disability,
- Content development for active engagement on social media outlets in collaborations with the PR team.
- Media Training,
- Brochure production and Distribution.

viii. Budget and Resources

NO	Key Activities	Description of costs	Est Total	Source
1	National Workshop	50 participants from Organizations working Nurodevelopmental Disorders	275,000.00	Organizations
		Music and Circus Performance by Fikir Ethiopia Team	50,000.00	Partners Organizations
2	Exhibition	Lump sum costs for participation at 12 organizations	150,000.00	Partners
3	Parent Counseling	Conduct counseling sessions for 200 parents in 7 regions	150,000.00	Partners MOH
4	Assessments	Conduct assessment for 200 children in 7 regions	150,000.00	Partners MOH
5	Production, Duplication and Distribution of Brochure Posters and	Printing of brochures in 1000 copies	100,000.00	Partners MOH
6	Social Media Content production and campaign	Social Media Content production and campaign	87,000.00	Partners MOH
7	Production, Duplication and Distribution of Information tool Kit	Printing of Information directory 1000 copies	100,000.00	Partners MOH
<b>Total expenditure</b>			<b>1,062,000.00</b>	



## Chapter 4 – Musculoskeletal Associated Disorder

### Background

Musculoskeletal birth defects, including clubfoot, congenital hip dislocation, and limb deficiencies, are among the most prevalent congenital anomalies worldwide. These conditions can cause significant disability if left untreated, necessitating early intervention for better outcomes. Clubfoot alone affects approximately 200,000 children annually, with the majority occurring in low- and middle-income countries.

While high-income countries have seen improvements in early diagnosis and treatment accessibility, musculoskeletal birth defects remain a major public health concern in low-resource settings, particularly in sub-Saharan Africa. The prevalence of congenital anomalies in the region is estimated at 20.4 per 1,000 births, with musculoskeletal defects accounting for 3.90 per 1,000 births. Factors such as inadequate prenatal care, nutritional deficiencies, and environmental risks contribute to the high incidence.

Ethiopia experiences a significant burden of musculoskeletal birth defects, mirroring regional trends. An estimated 4,136 babies are born with clubfoot each year, with 67% of cases occurring in males and 50% affecting both feet. Without timely treatment, clubfoot can result in lifelong disability, social stigma, and economic hardship. Many affected individuals in Ethiopia face challenges accessing quality care, leading to a high prevalence of neglected clubfoot cases requiring surgical intervention.

- i. Stakeholder organisation participating
  - Ethiopian Ministry of Health (MoH)
  - Regional Health Bureaus (RHBs)
  - Clinton Health Access Initiative (CHAI)
  - Cheshire Services Ethiopia (CSE)
  - Hope Walks
  - International Committee of the Red Cross (ICRC)

- ii. Target audience
  - Children with Clubfoot and Their Families/Guardians
  - Healthcare Providers - 168 professionals across primary, secondary, and tertiary healthcare levels.
  - Community Members - Approximately 350,000 individuals from selected regions and the general public.
  - Policymakers and Stakeholders
- iii. Key activities
  - a. Prevention:
    - Awareness Creation
    - Informational Materials
  - b. Care
    - Early Detection Referral: Establish a dedicated team at facility levels to screen beneficiaries for clubfoot and facilitate referrals to clinics.
    - Clinical Management: The clinical team will manage serial casting and prepare patients for tenotomy surgery as needed.
    - Surgical Treatment: Provide tenotomy surgery for beneficiaries requiring surgical intervention.
    - Training for Healthcare Providers: Offer on-the-job training for healthcare providers on clubfoot surgical management
  - c. Inclusion
    - Counselling Services
    - Facility Accessibility Audit: Evaluate the physical accessibility of service facilities and collaborate with facility leaders
    - Policy Advocacy
    - Awareness Advocacy
    - Skills Training for Beneficiaries: Provide skill-building training during
- iv. Timeline
  - Preparation Phase: 12 February – 03 March 2025: Activities include stakeholder meetings, resource mobilization, training materials preparation, and community outreach planning.

- Implementation Phase: 04 March – 16 May 2025: Conduct workshops, training sessions, and awareness campaigns. Initiate identification and treatment of affected children.
- Evaluation and Reporting Phase: Initial Phase – 09 March 2025: Begin collecting data for evaluation and prepare interim reports to assess initial outcomes.

v. Budget breakdown

S.N			CSE	ICRC	HWs	CHAI	Respective regions and health facilities
1.	Non Surgical case management [ 0-2 years]		191,678	479,195	998,547	NA	
2.	Advanced management [2-12 years ]	treatment cost	754,200	484,200	290,400	NA	
		Facilitation cost	NA	NA	NA	1,263,200	
3	Meal and Accommodation, and Medication Cost during Surgical Admissions		NA	NA	NA	NA	400,000
4	communication		90,000	180,000	150,000	NA	
	<b>Total</b>		<b>1,035,878</b>	<b>1,143,395</b>	<b>1,438,947</b>	<b>1,263,200</b>	<b>400,000</b>
	<b>Grade total</b>		<b>5,281,420</b>				

Identified health / behavioral problem	Intervention areas	Recommended behaviors	Communication-related root causes (barriers)	Audience analysis	Core message
<p>“Clubfoot is a common congenital deformity affecting approximately 1 in every 8,00 live births. It can lead to significant mobility issues if not treated early. Early diagnosis and intervention are crucial to ensure that affected children can lead active, healthy lives”<sup>1</sup></p> <p><sup>1</sup> Preventing Lifelong Impairment: Access to Clubfoot Treatment in Low- and Middle-Income Countries An AT2030 Innovation Insight <a href="http://www.AT2030.org">www.AT2030.org</a> <a href="#">Microsoft Word - AT Clubfoot Narrative April 2021 Final.docx</a></p>	<p><b>Prevention:</b> Clubfoot cannot be prevented; awareness and education can help with early detection and intervention</p> <p><b>Care:</b> Emphasizing the importance of early and continuous treatment for children born with clubfoot by using the ponseti method can help to ensure a child walks, run, is free from Clubfoot, and thrive in a healthy life.</p> <p><b>Inclusion:</b> Promoting the inclusion of children with clubfoot in all social, educational, and recreational activities to support their overall development and well-being</p>	<p><b>-For Parents:</b> Seek immediate medical consultation if your child is born with clubfoot or shows signs of it. Adhere to the recommended treatment plan, including follow-up visits and wearing braces as prescribed.</p> <p><b>-For Healthcare Providers:</b> Provide accurate information and support to families about clubfoot and its treatment options. Ensure early detection and timely intervention.</p> <p><b>-For the Community:</b> Support and include children with clubfoot in all social, educational, and recreational activities. Promote understanding and reduce stigma</p>	<p><b>-Lack of Awareness:</b> Address this by using various media platforms to educate parents and caregivers about clubfoot.</p> <p><b>-Stigma:</b> Combat stigma by sharing success stories of individuals with clubfoot who lead normal, active lives. Educate the community to foster acceptance.</p> <p><b>-Access to Treatment:</b> Advocate for better access to affordable and effective treatment options. Support initiatives that provide treatment in underserved areas.</p>	<p><b>-Parents and Guardians:</b> Primary audience who need to understand the importance of early detection and treatment.</p> <p><b>-Healthcare Providers:</b> To enhance awareness and training on clubfoot management.</p> <p><b>-Community Leaders and Organizations:</b> To promote awareness and address cultural stigmas.</p> <p><b>-Policy Makers:</b> To advocate for better healthcare access and funding for treatment programs</p>	<p>-Clubfoot is treatable! The absence of early detection and intervention can lead to a lifetime disability.</p>

## Chapter 5 – Other Birth Defects

### Background

Birth defects affect 3%–6% of all births, with approximately 8 million newborns worldwide born with serious congenital anomalies each year. According to the Global Children’s Surgery Study (GICS 2021), 1.7 billion children lack access to safe surgical care, leading to 3.3 million deaths annually. In Ethiopia, congenital birth defects remain a significant burden due to limited pediatric surgical services and long waiting times. This campaign aligns with Ethiopia’s National Surgical and Anesthesia Plan and Sustainable Development Goal (SDG) target 3.2, aiming to reduce preventable newborn and child deaths by 2030.

- i. Stakeholders and Organizations participating
  - Ministry of Health (MoH)
  - Regional Health Bureaus (RHBs)
  - Public and private health facilities
  - Regional media (TV/Radio)
  - Kids OR Foundation
  - Children Surgery International
  - Pediatric Surgery Foundation
  - Bethany Kids
- ii. Target Audience
  - Communities and the general public
  - Families and caregivers
  - Healthcare providers (primary, secondary, and tertiary levels)
  - Policymakers and stakeholders

### iii. Key Activities

#### a. Prevention and Awareness

- Develop and distribute informational materials 14 regions.
- Engage media to raise awareness about urogenital and anorectal malformations (ARM).
- Provide health education sessions to families and communities.

#### b. Care

- Patient Mobilization: Prioritize patients from high-waiting-list regions and mobilize referrals.
- Targeted Surgery Campaign:
  - Total waiting list exceeds 3,000 cases; the campaign will address 300 cases.
  - Selected sites: Adama (200 cases), Assela, Bahir Dar (300), Gondar (350), Dessie (200).
  - Potential new sites: Arba Minch and Afar due to high referral rates.
  - Hospital Preparation: Coordinate with surgeons, ensure supply availability, and assign three pediatric surgeons per site.
  - Training Sessions: Educate healthcare providers in Afar, Mizan, Somalia, and Arba Minch on case screening, detection, and referrals.

#### c. Inclusion and Advocacy

- Address misconceptions and religious beliefs surrounding birth defects.
- Promote social acceptance and inclusion of affected children through community engagement.
- Advocate for policies prioritizing pediatric surgery and comprehensive care.

### iv. Monitoring and Evaluation

Key indicators for campaign success:

- |   |   |
|---|---|
| • Number of patients screened for congenital surgical defects | • Reduction in average waiting time for surgery                   |
| • Number of surgeries performed per site                      | • Number of healthcare providers trained                          |
| • Types of congenital defects treated                         | • Number of community members reached through awareness campaigns |
| • Surgical outcomes and complication rates                    |   |



v. Timeline

Major Activity	Sub-Activity	Responsible Party and Date
Preparation Phase	Mobilize patients and prioritize surgical cases finalize communication materials	Feb 10-15, 2025
Implementation Phase	Engage regional media Provide training sessions for healthcare providers Perform pediatric surgeries at selected sites	Feb 25 - Mar 8, 2025
Evaluation Phase	Collect data and assess impact Finalize and publish reports	Mar 8, 2025

vi. Budget

Travel and Accommodation	400,000 ETB
Awareness and Training Materials	100,000 ETB
<b>Total</b>	<b>500,000 ETB</b>



