



**LEAVE NO
CHILD BEHIND:
TOWARDS EQUITABLE
CLEFT CARE IN INDIA
QUALITY OF LIFE
AND IMPACT
REPORT**

JUNE 2024

Jivika, Bengaluru



Smile Train

Preface



Aradhya, Dehradun



As we celebrate the 25th anniversary of Smile Train’s founding as a global nonprofit, I want to take a moment to reflect on two-and-a-half decades of remarkable achievements. Since that first Smile Train-sponsored cleft surgery in 1999, we have grown to become the world’s largest cleft organization. Central to our success is our “teach a person to fish” model, which focuses on empowerment and sustainability.

This year, we proudly supported our two-millionth surgery globally. To commemorate this milestone, we commissioned two significant studies: an Economic Impact Study to analyze our work’s impact on the global economy, and the India-specific Quality of Life and Impact Report to understand how our support has impacted the lives of individuals with clefts and their families.

I am happy to report that the results of both studies are astonishing and so validating of the work that Smile Train and our partners are doing worldwide.

The global Economic Impact Study found that for an average of \$400 USD toward one cleft surgery, as much as \$60,000 USD is put back into the local economy over a patient’s lifetime. This amounts to more than a 150x return on investment for a single cleft surgery.

The findings of these reports zoom in on the far-reaching human impact of our work in India, highlighting the profound effect of our work on children and their families across the country.

We found that Smile Train’s support for cleft care has contributed \$16 billion USD to the Indian economy — a truly staggering impact.

I am proud to share key findings and recommendations with you here, and to reaffirm our commitment to ensuring that everyone with a cleft has access to the care they deserve.

SUSANNAH SCHAEFER

President & CEO, Smile Train



Vedica, Chennai



I am immensely proud to present Smile Train India’s “Quality of Life and Impact Report,” which encapsulates 20 years of our transformative work (2000-2020) and its profound impact on the lives of countless individuals, including the medical community. This report marks a significant milestone in our unwavering commitment to equitable cleft care across India.

Since 2000, Smile Train India has not only sponsored free cleft surgeries but also pioneered a comprehensive, sustainable approach to cleft care that fosters empowerment and community well-being. Over the past two decades, we have touched the lives of over half a million individuals and their families across India, marking a remarkable journey of transformation and hope.

Developed in collaboration with KPMG India, this report offers a comprehensive evaluation of the profound effects our initiatives have had on individuals with clefts, their families, and the broader healthcare ecosystem in India. The findings highlight Smile Train’s pivotal role in bridging gaps in cleft care, from improving medical infrastructure to supporting underserved communities.

The Social Return on Investment (SROI) analysis paired with the Economic Impact Study highlights the exceptional value generated by our work, with each Indian rupee invested yielding more than five rupees in social value. This achievement reaffirms our dedication to transforming lives, fostering inclusion, contributing to national development goals, and changing the world, one smile at a time.

MAMTA CARROLL

Senior Vice President & Regional Director - Asia,
Smile Train

About the Study

Smile Train is the world's largest cleft-focused organization, supporting free cleft surgery and comprehensive cleft care to children globally. Smile Train has been supporting cleft treatment in India since 2000. The focus of operations in India has been to support the treatment of clefts among the economically disadvantaged population, to build medical infrastructure for cleft care, and to enhance the capabilities of medical practitioners in undertaking cleft surgeries and non-surgical care.

In the period 2000 - 2020, Smile Train India has partnered with 325 hospitals and supported 621,921 cleft surgeries and 15,573 non-surgical treatments. This support has benefited 531,403 individuals with clefts.



Atul, Lucknow

1st

First study in India focusing on quality of life of cleft-affected individuals

20
YEARS

Analysis of twenty-year data set of Smile Train supported cleft treatments from 2000 - 2020

KPMG

Consulting firm KPMG commissioned the study independently



Three different methodologies applied to get a holistic overview of impact



Stratified Multi-Stage Random Sampling Method used to select states and interviewees from anonymised data of 500,000+ individuals with clefts to mitigate bias

In-depth interviews conducted by independent researchers for



1065 individuals with clefts and their parents



Nearly 100 cleft surgeons and comprehensive cleft care professionals

14
STATES

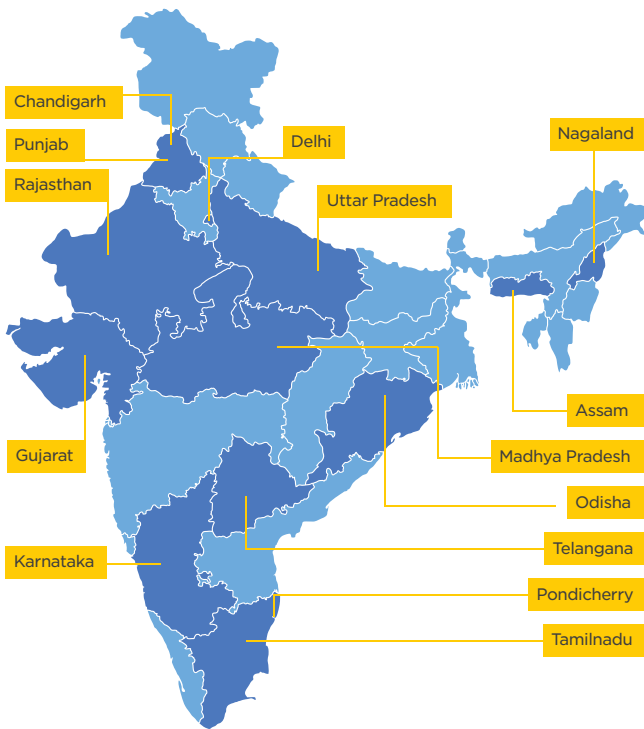
Across 14 states of India

CLEFTS ARE COMMON AND CAN HAVE DEVASTATING CONSEQUENCES

Orofacial clefts are one of the most common facial birth differences - 1 in 700 babies are born with a cleft lip and/or palate globally. An estimated 4.6 million people around the world live with untreated or inadequately treated orofacial clefts, primarily in low-resource settings. In India, an estimated 35,000+ children are born with a cleft every year.

Beyond social stigma and ostracization, clefts can also lead to difficulties eating, breathing, hearing, and speaking. This condition can prevent people from being able to participate equally in society and reach their full potential. It also poses a burden on the healthcare system and on caregivers.

DATA COLLECTED FROM 14 STATES



FRAMEWORKS FOR EVALUATION

OECD DAC Evaluation Criteria

Framework comprising a set of criteria that aid in the systemic assessment of ongoing or completed development programs. This method will **allow us to effectively assess various facets of the program and gain qualitative insights along with quantitative aspects.**

Social Return on Investment (SRoI)

This method is deployed to assess the quantitative impact of the project. SRoI (Social Return on Investment) is a framework for **measuring and accounting for the value created by organizations as a result of their activities.** It measures changes (be it positive or negative) that are created by an organization/project on the social, environmental and economic fronts and assigns monetary values to represent them.

Strengths/Difficulties and Cleft - Q

The CLEFT-Q is a rigorously developed patient-reported outcome measure that can be used internationally to collect and compare evidence-based outcome data from patients aged 8 to 29 years with cleft lip and/or palate. It is composed of 12 independently functioning scales and 1 checklist. The Strengths and Difficulties Questionnaire (SDQ) is a brief emotional and behavioral screening questionnaire for children and young people. The 25 items in the SDQ comprise 5 scales of 5 items each.

KPMG India was commissioned by Smile Train India to conduct an independent nationwide social impact assessment and evaluate the impact of Smile Train supported cleft treatment on the lives of individuals with clefts and the cleft medical infrastructure across the country.

The study aimed to assess Smile Train's role in enabling access to cleft treatment, empowering the cleft medical ecosystem at partner treatment centres, and enhancing the quality of life for individuals with clefts. Various evaluation frameworks were utilized, including OECD-DAC criteria, Social Return on Investment (SROI) analysis, and patient-reported outcome measures like Strengths/Difficulties and Cleft-Q questionnaires.

OUR IMPACT IN INDIA

700,000+

Cleft Surgeries

24

Years of Service in India

200+

Partner Surgeons

120+

Partner Hospitals

250+

Partner Anesthetists

100+

Comprehensive Cleft Care Experts



Key Findings : OECD DAC Frameworkⁱ

Key findings from the OECD DAC evaluation criteria reinforce that Smile Train’s program in India is aligned with global Sustainable Development Goals^{iv} (SDGs) and national priorities^v. It demonstrates the positive impact of Smile Train’s support in improving access to cleft treatment, enhancing hospital infrastructure, and positively influencing the quality of life of individuals with clefts. Due to the challenges being faced by individuals with clefts and their families, all the respondents reported Smile Train India’s support to be relevant to their needs. The availability of funds, equipment and training supported by Smile Train India for credentialed partner treatment centres and medical professionals made it possible for centres to provide free patient management care, enabling medical professionals to provide treatment to economically marginalized people.

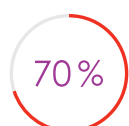
ALIGNMENT WITH NATIONAL PRIORITIES



ALIGNMENT WITH UN SDGs



CLEFT TREATMENT IMPROVED QUALITY OF LIFE FOR INDIVIDUALS WITH CLEFTS AND THEIR PARENTS



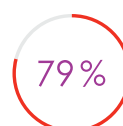
Of parents stated that they lacked financial resources to access cleft treatment without Smile Train’s support.



Of parents stated that Smile Train helped reduce financial burden and improved access to cleft treatment.



Parents’ stress and tension reduced considerably after interacting with qualified doctors who treated their children.



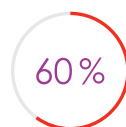
Of parents reported that cleft treatment received via Smile Train has greatly benefitted their child.



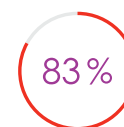
Of parents acknowledged that information on cleft and its treatment helped them understand their child’s condition.



Awareness created by Smile Train helped parents change the perception of their family members towards cleft.



Of individuals with clefts had difficulty eating certain foods and drinking liquids before cleft surgery.



After treatment, 83 % of individuals with clefts reported no difficulty in facial functions like eating and drinking.



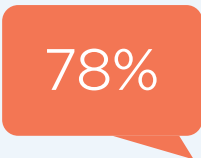
Of individuals with clefts reported improved social and peer interaction after cleft treatment.



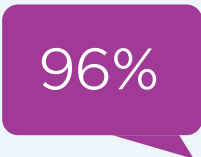
Of individuals with clefts still faced speech distress after surgery, highlighting the need for increased access to speech services.



INCREASE IN CLEFT PATIENTS AVAILING TREATMENT IN HOSPITALS



Partner doctors agreed that the number of patients seeking cleft treatment increased after support provided by Smile Train.

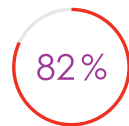


Doctors interviewed, highlighted effective outreach created by Smile Train India to cater to patients belonging to remote areas.



Doctors agreed that the hospital staff is adequate in numbers to treat the increased number of patients. The doctors interviewed, on average, conduct 278 cleft surgeries in a year.

IMPROVED CAPACITY OF DOCTORS AND CLEFT TEAMS TO TREAT CLEFTS



Doctors surveyed confirmed that they have received training from Smile Train India. On average, the **doctors spent 20-25 days** a year in trainings related to cleft treatment. This helped to **enhance their knowledge and expertise in cleft treatment**



Smile Train Partners, Cleft Leadership Centre, Bengaluru

Key highlights SROIⁱⁱ and EIⁱⁱⁱ

Social return on investment (SROI)ⁱⁱ is a methodology that allows a deeper understanding of the holistic values created by a Non-Governmental Organization implementing projects by incorporating social, health, environmental, and economic costs and benefits. It is a framework to measure and account for the value created by a program or series of initiatives, beyond financial value. SROI is a participatory, beneficiary-led approach that helps manage and communicate the social value a project created in the form of a measurable number that can be understood by all relevant stakeholders. For example, a project ratio of 1:4 indicates that a donor investment of 1 USD delivers 4 USD of social value to the direct beneficiaries of the program.

The SROI for the project was estimated to be INR 5.01. For every INR 1 of investment by Smile Train, INR 5.01 attributable social value to the direct beneficiaries of the program was created.



Alisha, Darjeeling

An Economic Impact Reportⁱⁱⁱ released by Smile Train globally in May 2024 reveals

Smile Train has contributed a value of more than \$69 billion over the past 25 years. Using data from 2001 - 2023, the report tabulated the impact of primary surgeries supported and the disability-adjusted life years, or “DALYs,” that these surgeries have averted. Having a cleft affects how people feel when they wake up and look in the mirror; whether they can go to school, make friends, or find work and just about every other aspect of day-to-day life - including overall health and life expectancy. DALYs turn these experiences into data, calculating the burden of each year a person loses to their cleft. Our analysis shows that **Smile Train-supported cleft surgeries have given individuals with clefts a combined 12 million years of their lives back across the globe.**

Smile Train-Sponsored Surgeries Prevent Years Lost to Disability 2001-2023			
Country	Primary Surgery Count	Years Lost to Disability Averted	Economic Benefit
India	528,065	4,356,674	\$16,602,782,649
Global	1,486,131	12,868,842	\$69,404,271,201





Shahidabee, Thrissur



Behind these numbers
are the stories of
individuals who have
been transformed by
Smile Train's
life-altering work.

Rajesh, Bhopal





Ashmi, Siliguri

From Abandonment to Hope: Asmi's Journey to a Bright Future

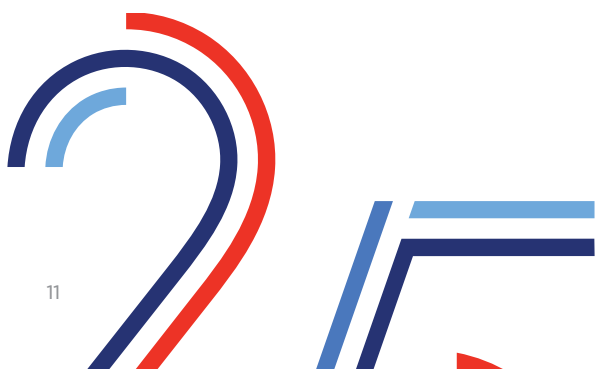
Payel was determined to do everything for her daughter, Asmi. That's how she met Smile Train.

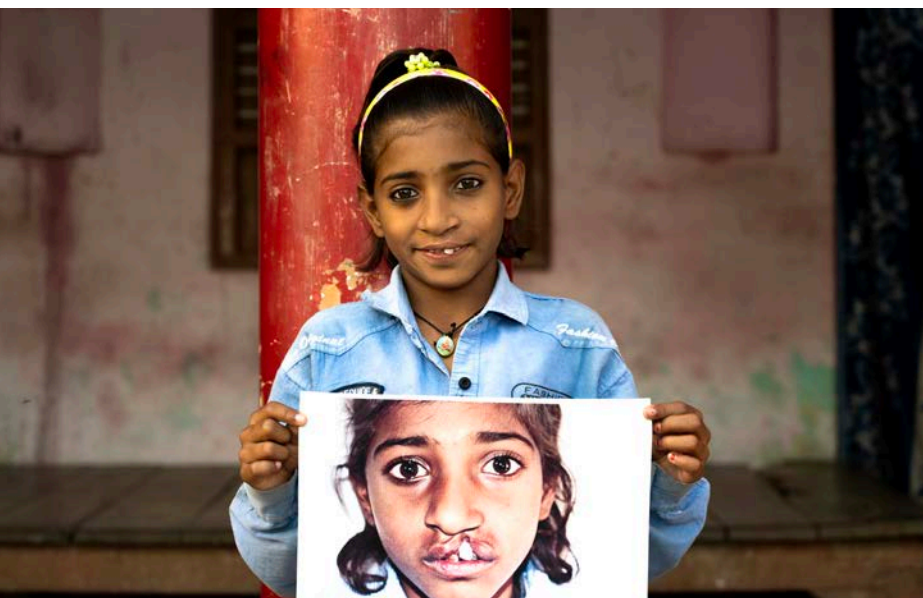
I was a teenager when I became pregnant with my first child, Asmi. Without the luxury of an ultrasound, my husband and I were unprepared for the surprise that awaited us. The day Asmi was born should have been a celebration, but instead, it was marred by shock and sadness. My tiny little infant had a cleft, a condition I had never known before.

My husband abandoned me and our newborn at my mother's place with an excuse that he didn't want to keep this child with him. His absence left a gaping void in our lives, and I was deeply worried about my daughter's health and future. But my parents stood by me, and together, we started to look for options.

In the initial days at home, Asmi struggled to feed. Her tiny mouth couldn't latch properly, which added to the stress. Doctors told me that treatment was available but expensive, but I was desperate to find a solution. That's when we got to know about Smile Train, an organization that supports 100%-free cleft treatment. We did not think twice and visited Anandaloke Hospital in Siliguri, which was the closest to our hometown.

Seeing Asmi thrive after surgery has filled me with a renewed sense of purpose and determination. Now 10 years old, Asmi is very interested in her studies, and I want her to have the opportunities I never had, to break free from the constraints that once held me back. I envision her growing into a confident, independent woman who can stand on her own and make her mark on the world.





Devika, Gorakhpur



Devika, Once Shy and Friendless, is Now Blooming with Confidence

Her ambitions are sky high now.

Devika was born with a cleft in Titihari village, Uttar Pradesh. She grew up struggling to eat because her father could not afford an expensive cleft surgery. She was always underweight.

As a child, she found it difficult to make friends, as the other children in her community often bullied her and mocked her for her cleft. To shield her from the harsh comments, her parents used to keep her mostly at home.

Through a neighbor, the family got to know about Smile Train-supported surgery at Savitri Hospital in Gorakhpur. The surgery marked a significant turning point. Seeing Devika's transformed face for the first time brought immense joy and gratitude to her family.

Post-surgery, Devika's life took a dramatic turn. The acceptance from her peers, who had once shunned her, greatly boosted her confidence. Now in the 6th standard, she dreams of a career in the medical field, inspired by the compassionate care she received from her doctors.



Md. Arsh, Lucknow

From Fear to Hope: A Story of Transformation

**Arsh is growing as a young and
confidant teenager.**

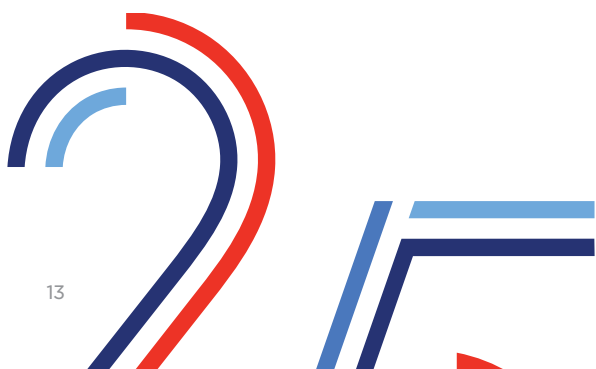
When Md. Arsh was brought out of the operation theater, the first sight of him left everyone, especially his mother, deeply unsettled. Tears streamed down her face as she grappled with fears about his future — how would she raise him? How would their community react? Despite the doctors mentioning treatment options for his cleft, his parents received hardly any guidance.

The early days were full of struggles. Feeding him was a challenge, and he failed to gain weight. Desperation drove them to seek support, and their search led them to Smile Train treatment partner Sushrut Institute of Plastic Surgery in Lucknow. There, the compassionate doctors provided the clarity and guidance they so desperately needed.

At three months old, Arsh underwent his first cleft surgery, for his lip, and the transformation was immediate. At ninth month, he received a second surgery, for his palate, marking a turning point that brought hope and normalcy back into their lives.

Today, Arsh is a vibrant, confident boy who is undergoing speech therapy. Reflecting on his journey, Arsh says, “My surgeries and follow-up treatments have given me confidence. I love how I look now compared to my early days and feel more positive in life.”

Arsh’s story is a testament to resilience, love, and the transformative power of quality cleft care.





Aruthra, Thanjavur



A Story of Hope and Healing from Thanjavur, Tamil Nadu

As a small farmer, Aruthra's father thought he could never afford cleft surgery for his daughter — but miracles do happen!

Aruthra's parents were taken aback by an unexpected revelation during the ninth month ultrasound: their to-be-born daughter had a cleft. The diagnosis came as a shock; they had no prior knowledge about clefts. But despite their uncertainty, they decided to look to the future with a blend of apprehension and hope.

Aruthra was born in a private hospital, and the initial joy of her arrival was clouded by confusion. The hospital provided no clear direction on her treatment, leaving her parents in a state of worry. For the first month and a half of Aruthra's life, her family struggled to understand how to feed her and where to go for treatment.

Luckily, they came across a senior nurse from Meenakshi Hospital, Thanjavur, who informed them about Smile Train sponsored free cleft surgery at her hospital.

Her mother, Vijaya Lakshmi, said, "This news was a beacon of hope which turned our despair into a proactive quest for treatment. The hospital gifted a new life to our daughter. Post her surgery, her smile fills our home with immense joy."

Aruthra's smile transformed, and so did the reactions of their community. In Vijaya Lakshmi's words, "The society had almost outcast us; they wouldn't invite us to any social functions, and nobody visited us to see how our daughter was growing. We were extremely worried that as Aruthra grew, she would not have any friends in the community. But everything changed after her surgery, and we are profoundly grateful to Smile Train and Meenakshi Hospital for their support."

With her successful surgery and the support from Smile Train and Meenakshi Hospital, Aruthra now has a bright future ahead. Her family's journey from worry to joy is a testament to the power of compassion and medical care in transforming lives.

Advancing Equitable Cleft Care: Way Forward in India

EXPAND OUTREACH EFFORTS

Smile Train will continue to strengthen efforts to reach underserved and economically disadvantaged communities across the country thereby extending Smile Train's impact to those who may not have accessed cleft care services otherwise.

STRENGTHEN PARTNERSHIPS AND BUILD CAPACITY

To ensure the sustainability of cleft care services, Smile Train will continue to strengthen partnerships with local healthcare providers. Smile Train will continue to invest in training and education of the surgical work force and invest in surgical fellowships to build capacity of young surgeons to enhance the reach and effectiveness of Smile Train's initiatives, fostering long-term support and care for individuals with cleft conditions.

ESTABLISH CONTINUOUS FEEDBACK MECHANISM

To maintain and enhance service quality, Smile Train will strengthen its feedback mechanisms with the treated beneficiaries of the program

as well as the partner hospitals, enabling Smile Train to monitor and improve supported services effectively, ensuring ongoing responsiveness to beneficiaries' needs and preferences over time.

EXPAND NON-SURGICAL ESSENTIAL CARE

To further enrich the cleft care program, Smile Train will expand comprehensive care services such as nutrition, speech therapy, and orthodontic support to more partner hospitals to ensure greater outreach and holistic care for individuals with clefts across India.

ADDRESS WELL-BEING AND COMMUNITY-SUPPORT NEEDS OF INDIVIDUALS WITH CLEFTS

By addressing the broader needs of individuals with clefts, including psychosocial and emotional well-being, Smile Train can enhance the overall effectiveness and impact of its cleft care programs, fostering long-term positive outcomes for beneficiaries. Smile Train will explore collaborating with cleft-support forums beyond Cleft Con India.

Kinjal, Ahmedabad



Policy Recommendations

Supporting comprehensive cleft care confers significant value to the health and productivity of individuals with a cleft. Government, in collaboration with civil society organizations, development partners, and the private sector should consider the following:

1. Invest in surgical and anesthesia care as part of national health priorities, including the training and education of the surgical health work force and the development, funding, and implementation of national surgical, obstetric, anaesthesia, and nursing plans to prioritize surgical care within national health and development priorities.
2. Invest in the distribution and on-going maintenance of critical patient monitoring equipment, including pulse oximetry and capnography.
3. Develop or revise newborn healthcare guidelines to include palate examination to ensure appropriate support with nutritional and surgical referral.
4. Develop national guidelines for cleft care training and optimal cleft treatment pathways and ensure that cleft-care training for maternal and newborn care providers is aligned.
5. Put protocols in place for reporting cleft cases and ensure referrals to cleft care teams/ treatment centres
6. Establish and maintain population-based registries for reporting and counting clefts and other birth differences and make the data available for research, health promotion, and health systems improvement, and to help determine resource allocation.
7. Educate communities about clefts, in collaboration with trusted community leaders, to combat the stigma and social exclusion of children with clefts and their families.
8. Build social protection programs to support mothers of children with clefts, who are more likely to be socially excluded and need counselling, guidance, social transfers, cash, vouchers, and food to support their livelihoods.
9. Develop or revise national nutrition guidelines to consider the needs of all infants and young children and highlight adaptations to address the needs of the most vulnerable, including children with clefts.

Sahil, Majhauri



References

I OECD-DAC FRAMEWORK

Given the fundamental approach for conducting an impact study, the OECD-DAC (Development Assistance Committee) Evaluation Network's framework is well regarded for assessing the efficacy of development programs. In response to the need for a method through which bilateral development agencies could monitor the financing supplied to multilateral organizations for various development initiatives, the DAC Evaluation Network developed a set of evaluation criteria for measuring the performance of any development project (UNICEF, 2012).

The OECD DAC Network has identified six evaluation criteria and two principles for their application: relevance, coherence, effectiveness, efficiency, impact, and sustainability. These criteria are meant to help facilitate evaluations. They were revised in 2019 to improve the accuracy and utility of assessment and to strengthen the evaluation's contribution to sustainable development (OECD, 2020).

RELEVANCE

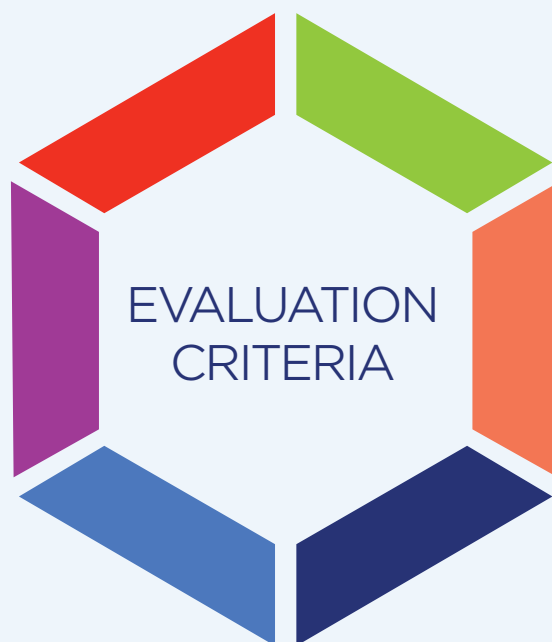
is the intervention doing the right things?

EFFECTIVENESS

is the intervention achieving its objectives?

IMPACT

what difference does the intervention make?



COHERENCE

how well does the intervention fit?

EFFICIENCY

how well are resources being used?

SUSTAINABILITY

will the benefits last?

OECD DAC Framework

ii https://www.undp.org/sites/g/files/zskgke326/files/migration/eurasia/Appendix-SROI-methodology_ENG.pdf

III ECONOMIC IMPACT METHODOLOGY

To calculate how many years of disability patients avoided by receiving cleft surgeries, researchers estimated the patients' lifespans using data from the World Health Organization. Then they calculated the burden of the disability caused by having a cleft for each patient using disability weights determined by the World Health Organization's Global Burden of Disease

data. This burden is calculated for the years of life before receiving surgery. For years lost to disability averted, the new years of life after surgery with a much-reduced disability was calculated, which were then subtracted from the years the patient would have lived with the disability from an unrepaired cleft.

To assign an estimated economic value to the years of “disability-free” life lived by the patients, researchers used the United States Value of a Statistical Life, which was set by the U.S. court system at \$8,280,743. The researchers multiplied this amount with the ratio of Gross National Income of the patient country / Gross National Income of the United States for the year when the surgery took place. Then they converted that to a yearly amount and applied the value to the years of relatively disability-free life that the patient would live after their primary surgery.

The methodology also accounted for additional variables such as patient age and economic valuation changing from child economic value to adult economic value, at around 16 years of age. The authors applied a 3% discount to avoid any overestimation of values.

iv. https://sdgs.un.org/goals_goal3#targets_and_indicators

v. The Ministry of Health & Family Welfare, Government of India, under the National Health Mission launched the Rashtriya Bal Swasthya Karyakram (RBSK), an innovative and ambitious initiative, which envisages Child Health Screening and Early Intervention Services, a systemic approach of early identification and link to care, support and treatment. RBSK is one of its kind program to improve the overall quality of life of children enabling all children achieve their full potential; and also provide comprehensive care to all the children in the community. This program involves screening of children from birth to 18 years of age for 4 Ds - Defects at birth, Diseases, Deficiencies and Development delays, spanning 32 common health conditions for early detection and free treatment and management, including surgeries at tertiary level. <https://rbsk.mohfw.gov.in/RBSK/>

Harvansh, Delhi







Gulam, Jabalpur



Smile Train India
Plot No 3, LSC, Sector C
Pocket 6/7
Vasant Kunj
New Delhi 110070

TOLL-FREE CLEFT HELPLINE
1800 103 8301