PERSISTENT SYSTEMS LTD

Impact Assessment Report

Cleft Palate & Facial Cleft Program

Conducted by Chhaaya Strategic Advisors LLP

April 2026

Contents

Executive Summary

This third-party impact assessment evaluates the Facial Cleft Surgeries and Comprehensive Care Program supported by the Persistent India Foundation (Persistent Systems Ltd.) in partnership with the Akhila Bharatiya Mahila Seva Samaj (ABMSSS). The assessment examines the program's relevance, adequacy, effectiveness, efficiency, sustainability, and alignment with CSR mandates, while capturing both clinical outcomes and lived experiences of beneficiaries.

India carries one of the world's largest burdens of cleft lip and palate conditions, with 27,000–35,000 children born each year and nearly one million individuals living untreated. Beyond physical deformity, clefts bring feeding challenges, malnutrition, speech impairment, and social stigma. Access to care remains uneven, especially for rural and low-income families.

The program operates across multiple centres nationwide including Bangalore, Hyderabad, Pune, Nagpur, Sambhajinagar, Pandharpur, Delhi NCR, Indore, and Sangli, covering 923 cases in FY 2024–25. The assessment used mixed methods including field visits, stakeholder interviews, and data analysis.

Key Findings ascertain that the program's impact has been remarkable, with cleft palate patients experiencing a complete improvement in both feeding and speech, while those with cleft lip reported a 100% enhancement in appearance. Survival outcomes were equally impressive, with rates nearing 100%, underscoring the effectiveness of care provided. Importantly, early intervention has increased significantly, with 44% of patients receiving treatment under the age of two, ensuring better long-term outcomes. The initiative has also demonstrated strong inclusivity, reaching low-income households and ensuring equitable access to services. Beneficiaries consistently expressed high levels of satisfaction, reflecting both the quality of medical interventions and the program's commitment to holistic, community-centered care.

The challenges facing the program highlight critical gaps that need to be addressed for sustained impact. Access to speech therapy and rehabilitation remains limited, leaving many patients without the long-term support essential for recovery. Awareness of ongoing treatment needs is also low, which risks undermining progress after initial surgeries. Malnutrition continues to delay surgical interventions, compounding health risks for vulnerable children. Financial packages have not kept pace with rising costs, creating strain on families and service providers alike. Despite having the capacity to serve more patients, funding constraints have led to underutilization of resources. Finally, outreach systems lack structure and consistency, weakening the ability to identify and support those most in need.

Overall, the program demonstrates high relevance, effectiveness, and efficiency, with moderate sustainability challenges requiring strategic strengthening. In conclusion this initiative restores dignity, confidence, and opportunity for children and families. It moves beyond surgery to transformation.

The program's impact aligns closely with the Sustainable Development Goals, advancing health, education, equity, and collaboration. Under SDG 3, it has improved surgical outcomes, nutrition, and survival. By restoring confidence and recovery, it supports SDG 4, enabling children to participate more fully in school. Efforts toward SDG 5 ensure greater access to care for girls, while SDG 10 addresses inequalities by prioritizing low-income and marginalized families. Finally, its strong NGO–corporate collaboration reflects SDG 17, showcasing how partnerships can drive sustainable community change.

With continued strengthening, the program has the potential to serve as a scalable national model for inclusive healthcare.

To ensure deeper impact and long-term sustainability, the assessment of the Persistent India Foundation's Facial Cleft Program identifies five strategic priorities. The program must evolve from a one-time surgical intervention to a continuum of care that includes nutrition, speech therapy, dental treatment, and psychosocial support for holistic rehabilitation. Strengthening early identification and outreach through networks of ASHAs, Anganwadis, and district hospitals will enable timely detection and intervention, especially in underserved areas. Financial sustainability requires revising per-surgery allocations to reflect current medical costs and exploring co-funding partnerships to expand hospital capacity. At the same time, targeted communication strategies are needed to reduce stigma, encourage adherence, and build awareness of the full treatment journey. Finally, institutionalizing monitoring and follow-up through a robust MIS system will allow patient journeys to be tracked from diagnosis to rehabilitation, ensuring long-term outcomes are captured and providing evidence for scaling the program.

1. Context & Objectives

1.1 Background

Cleft lip and palate remain among the most common congenital conditions worldwide, and India bears one of the largest burdens. Each year, an estimated 27,000–35,000 children are born with clefts, yet many remain untreated due to barriers in access, awareness, and affordability. It is believed that nearly one million people in India live with untreated clefts, underscoring the scale of the challenge.

Beyond the visible facial difference, clefts pose serious health risks. Infants struggle with feeding, making them 1.5 times more vulnerable to severe malnutrition compared to their peers. Without timely intervention, malnutrition can lead to preventable deaths. Surgery is the cornerstone of treatment, but access is uneven—urban centers may offer specialized care, while rural families often face long travel distances, financial strain, and limited awareness of available programs.

The challenges extend beyond medical care. Children with clefts often endure social stigma, bullying, and isolation, which can erode confidence and hinder educational opportunities. Families may experience shame or discrimination, further delaying treatment. Comprehensive cleft care requires not only surgery but also speech therapy, nutritional support, and psychosocial counseling—services that are fragmented or unavailable in many parts of India.

Despite these hurdles, progress is being made. NGOs and initiatives such as Smile Train, ABMSS and Mission Smile have provided free surgeries and awareness campaigns, helping thousands of children reintegrate into society. Yet, systemic gaps remain: India lacks a robust national registry, coordinated cleft-care infrastructure, and consistent public health policies to ensure equitable treatment.

This report seeks to highlight the medical, nutritional, social, and systemic dimensions of cleft challenges in India, while documenting the impact of interventions that bring hope and healing to affected families.

1.2 Purpose of the intervention

Persistent Systems Ltd. (PSL) has established the *Facial Cleft Surgeries and Comprehensive Care* program as its flagship Corporate Social Responsibility (CSR) initiative. Launched in 2016–17, the program reflects PSL's enduring commitment to transforming the lives of individuals affected by facial cleft conditions. What began as partial financial support for surgeries has evolved into a holistic healthcare initiative that addresses every dimension of cleft-related care. Its purpose is to ensure that affected individuals and their families receive compassionate, comprehensive, and sustainable support for long-term well-being.

1.3 Goals of the Program

- Provide Access to Surgical Care: Enable timely and effective surgical interventions for children and adults with facial clefts.
- Deliver Comprehensive Medical Support: Extend pre- and post-operative care, rehabilitation, and allied health services to promote recovery and integration.
- Raise Awareness: Conduct outreach and education initiatives to reduce stigma, increase early diagnosis, and encourage community support.
- Ensure Accountability and Impact: Align with CSR provisions under the Companies Act 2013 by commissioning independent third-party assessments to evaluate effectiveness and outcomes.
- Expand Reach and Sustainability: Strengthen the program's scope and impact through increased funding, ensuring that more beneficiaries receive high-quality, long-term care.
- Create Measurable Social Value: Demonstrate tangible improvements in health, confidence, and quality of life for beneficiaries, reinforcing PSL's role as a socially responsible corporate leader.

2. Scope & Methodology

2.1 Scope

Over the years, the Persistent Foundation has steadily broadened the reach of its Cleft Program through its partnership with Akhila Bharatiya Mahila Seva Samaj (ABMSS). As part of this effort, several new treatment centres have been established to improve accessibility and deliver comprehensive healthcare services to children affected by facial cleft.

The evaluation considered the full range of secondary data available, complemented by qualitative primary data gathered through personal visits to four centres—two long-standing and two recently opened. In addition, primary insights were collected via video conferences with other centres, ensuring a holistic understanding of the program's operations and impact.

Centres	Locations	No. of cases
Ongoing	1. Bangalore	277
	2. Hyderabad	155
	3. Nagpur	111
	4. Pune	129
	5. Aurangabad	84
	6. Pandharpur	34
Recently added	7. Delhi NCR	108
	8. Sangli	8
	9. Indore	17
	Total cases	**923**

2.2 Methodology

A semi-structured questionnaire was employed to maintain flexibility in questioning, allowing the interviews to capture diverse aspects specific to each location. Personal interviews were conducted with doctors and patients during field visits, while video conferencing was used in centres where in-person visits were not possible.

Method	Stakeholder Respondents
Video conferencing	1. Dr. B.S. Jayanth, Bangalore -Rangadore Memorial Hospital 2. Dr Vijay Kumar Hyderabad - AVR Dentofacial Hospital
Personal Interviews	1. Dr Sagar Jangam and Dr Shrenik Oswal, Birla Memorial Hospital, Pune 2. Dr Ujwala Dahiphale, Dr Swati Pande, Dahiphale Hospital, Sambhajinagar 3. Dr Sheetal Shah, Navjeevan Children's Hospital, Pandharpur 4. Dr. Sanjay Kucheria, Coral Hospital & Research Centre, Indore 5. Dr Darshan Ramkrishna Rewanwar, Mr Pankaj, Nelson Mother and Child Care Hospital, Nagpur 6. Dr. Ravikant, Dr Mittal and Dr Pal, Delhi 7. Mr Rushikesh Barsavade (Pune) and Ms Suparna Deshpande (Nagpur) 8. Program Coordinators at Nagpur and Delhi

Apart from the above medical and CSR team members, interviews were conducted with individual patients as well.

2.3 Primary and Secondary Data Collection:

For primary data collection, site visits were conducted across multiple locations including Pandharpur, Sambhajinagar (Aurangabad), Indore, Nagpur, Delhi and Pune. In addition, video conferences were organized with patients and doctors from the Bangalore and Hyderabad, and centres. These interactions provided valuable insights into patients' health both before and after treatment, enabling a more comprehensive assessment of the overall impact.

For secondary data collection, existing hospital and project records were systematically reviewed and analysed. This helped in corroborating the findings from the field visits and virtual consultations, ensuring that both quantitative and qualitative aspects of patient outcomes were captured.

2.2 Sampling

The evaluation was designed to cover approximately 10% of the total treated cases during the financial year 2024–25, which corresponds to about 92 patients out of 923. This sample was intended to be assessed through direct interviews with patient families at the centres visited, as well as with those who participated via video conferencing from other locations. The overall sample size exceeded the expectations. The assessors were able to interview 134 patients through personal visits and video conferences. This comes to 15% sample size.

2.4 Evaluation Deliverables

- A comprehensive report presenting findings, impact analysis, and data-driven insights.
- Recommendations for enhancing service delivery and optimizing future expansion plans.
- Strategic inputs to strengthen the sustainability and effectiveness of the initiative.

2.5 Assessment Method and Scoring

Chhaaya has developed 6-point framework – Relevance, Adequacy, Effectiveness, Efficiency and Sustainability, and Persistent Mandate.

The evaluation questions were presented to a range of stakeholders, and their responses were systematically collected. Based on the feedback, a scoring framework was applied: projects that fully met a given criterion were awarded a score of 1, those that did not were assigned 0, and cases where the criterion was only partially fulfilled received a score of 0.5.

Parameters	**Evaluation Questions**
1. Relevance	How well do the issues addressed by the project align with the context, priorities, and needs of stakeholders
2. Adequacy	Do the interventions adequately meet community needs, with beneficiary size significant both absolutely and relative to PF coverage?
3. Effectiveness	To what extent has the project met objectives, tackled root causes, transformed the baseline, and created lasting community change?
4. Efficiency	Has the project met objectives within time and budget, used resources efficiently, and left scope for further savings?
5. Sustainability	To what extent is the community engaged, showing ownership and contribution, and what are the prospects for sustainability and stewardship of outcomes beyond Persistent's support?
6. Persistent Mandate	Does the project build Persistent's visibility, enable employee engagement, earn recognition, foster collaborations, and address a neglected issue?

- **Scoring Considerations**

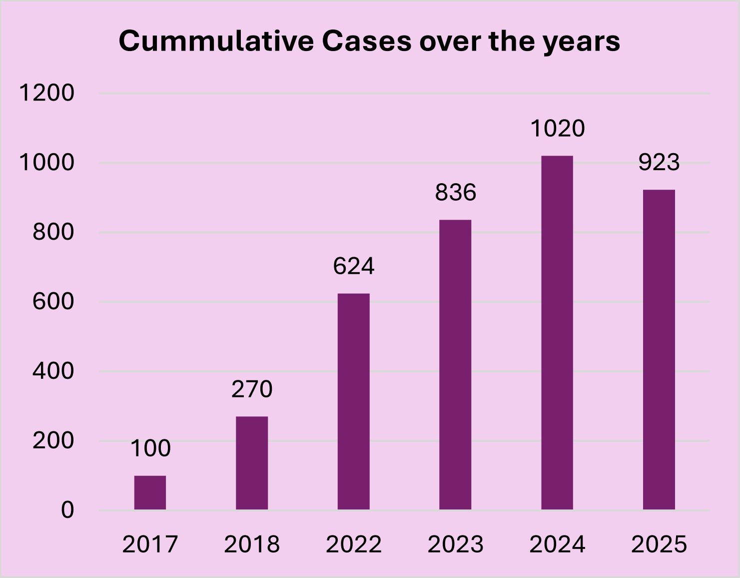
Each condition was treated as exclusive, not sequential. The methodology combined both qualitative and quantitative assessments, the Chhaaya team exercised caution in determining scores. Their professional insights and experience played a pivotal role in ensuring the evaluation process was balanced, consistent, and credible.

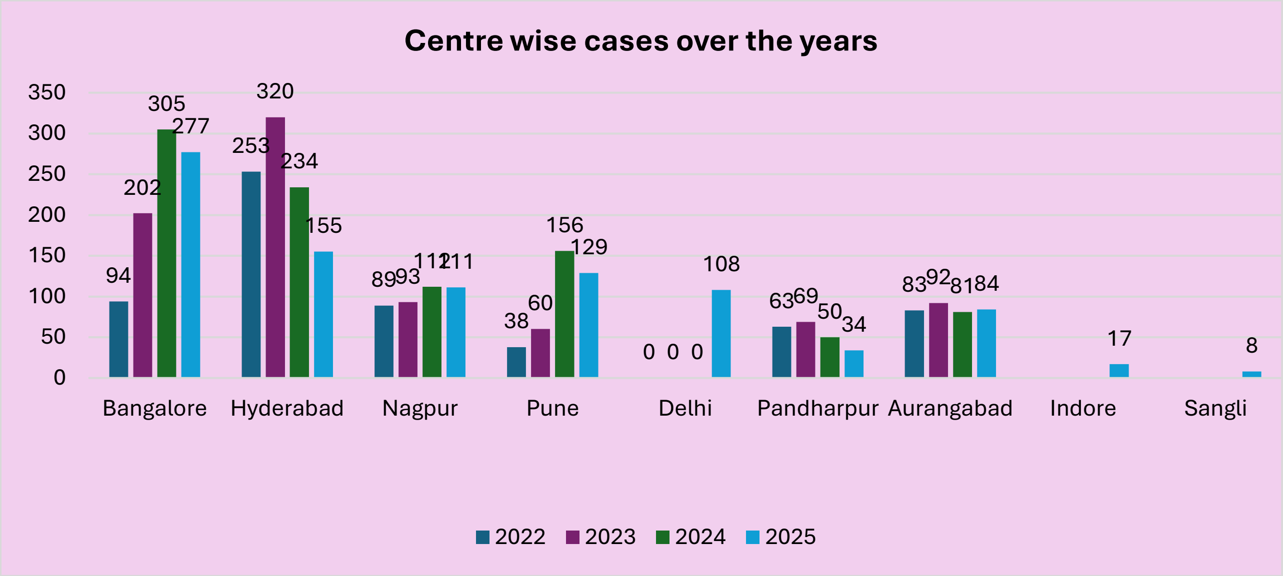
The following tables list 30 different aspects organized in 6 different parameters; hence total score is against 30.

Parameters	**If Y score 1, if N score 0, and for partially fulfilled condition score 0.5**				
Relevance of the issue being addressed	needy community targeted	mandated by CSR Law	issue relevant for implementing partners	priority for development sector	offsetting business footprint
Adequacy	adequate outreach to demonstrate impact	affected population covered adequately	key stakeholders included	different aspects of the issue covered	different types of supporting interventions included
Efficiency (resource use / design)	design included cost consciousness	external resources mobilized	costs were percolated to beneficiaries	low % of overheads	similar outreach in similar budget projects
Effectiveness in changing situation	beneficiaries satisfied	defined objectives achieved	How was impact compared to similar projects	problem symptoms removed	root cause addressed
Sustainability of project processes and outcomes	reflected in robustness of the design	prospects of continuity beyond the project period	impacts sustainable beyond project period	adaptation (of intervention, process) likely	processes institutionalized
Persistent Mandate	Visibility through Display boards, credit sharing, acknowledgement by beneficiaries, references in formal documents	Employee Engagement donations or volunteering	Recognition: Internal recognition, Awards, media clipping, case study: written documentation	Collaboration: Institutionalized collaboration with defined roles	Unique, best practices; Extremely critical and neglected issue addressed

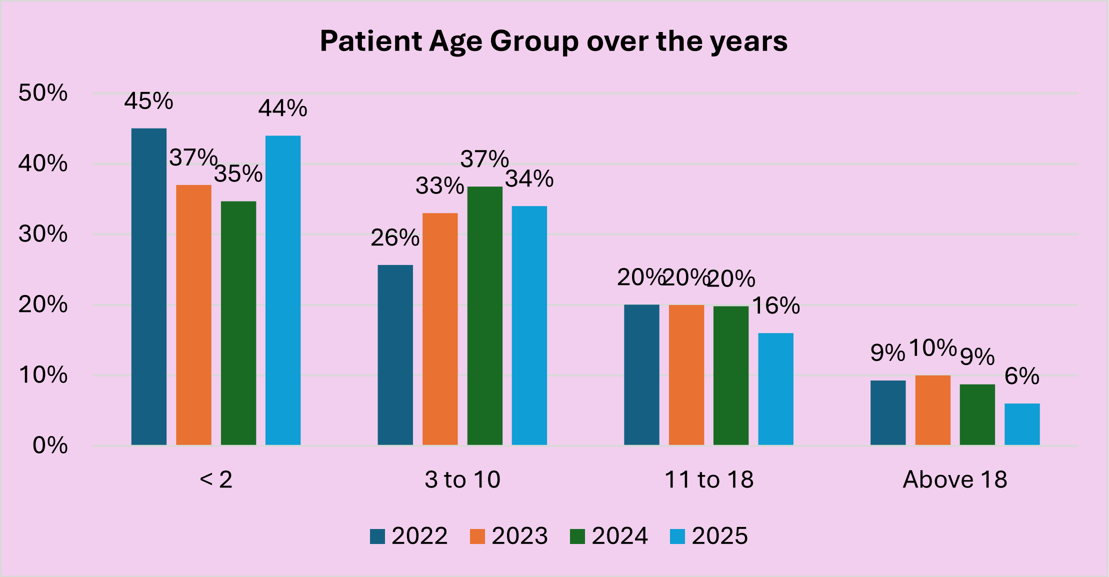
3. Secondary Data Analysis

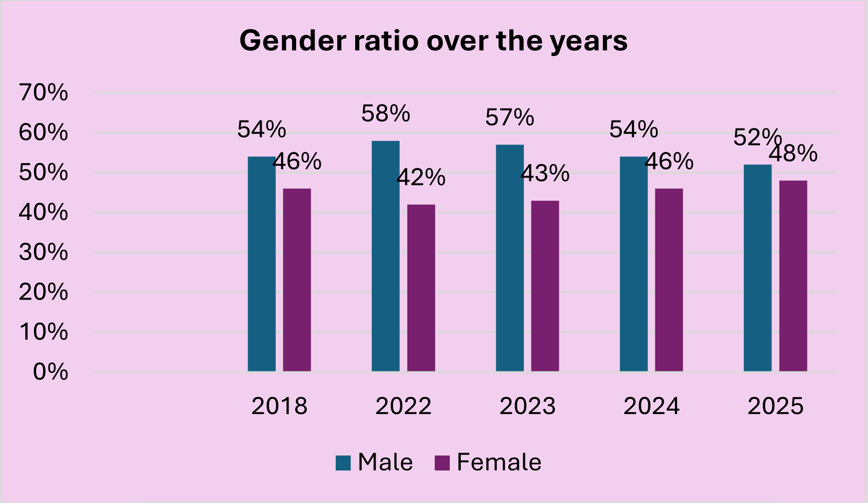
3.1 Outreach

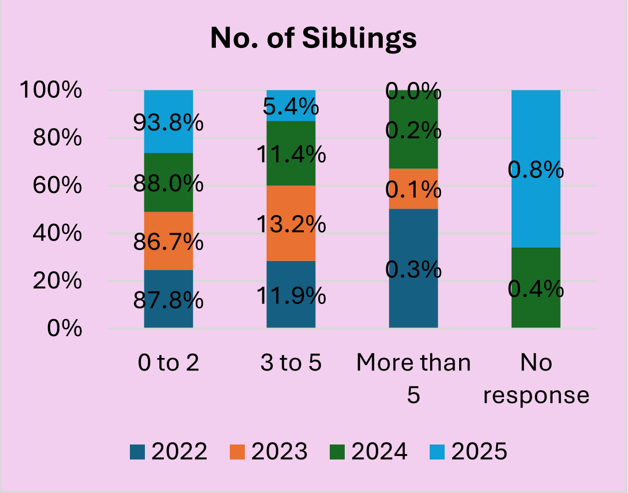


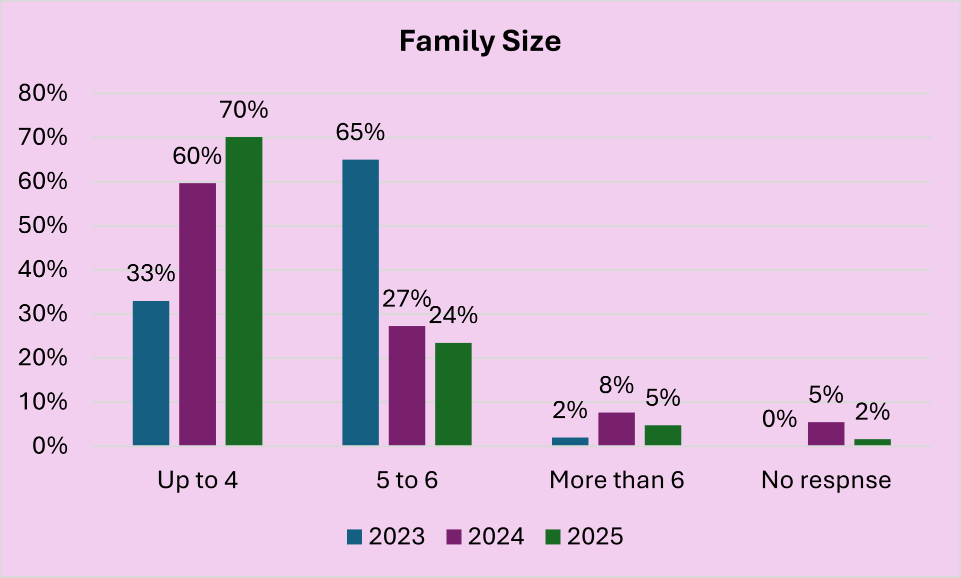


3.2 Social Aspects

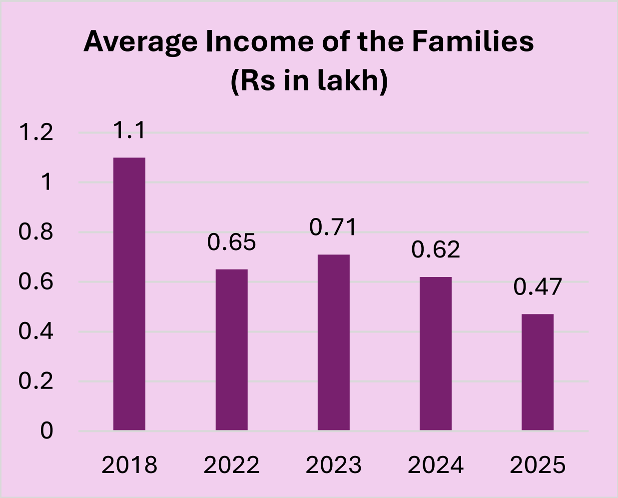


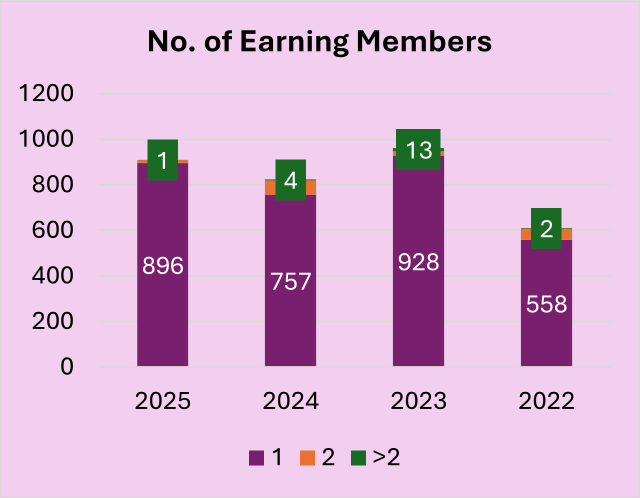






5.3 Economic Aspects





3.4 Snapshot of Secondary Data:

- **Outreach:**
  - Between 2018 and 2024, cumulative cases rose at a steady pace, reflecting consistent growth in service uptake across centres. In 2025, however, the overall number of supported cases declined by approximately 10%, despite the establishment of two new centres during the year. This suggests that expansion in

infrastructure did not immediately correspond with higher case volumes, pointing to a potential lag in integration, outreach, or referral processes. Another contributing factor may have been an overall reduction in cleft cases.

  - Looking more closely at centre-wise performance, most locations demonstrated steady or rising case numbers from 2022 to 2024. In recent years, more centres have been added as Persistent is trying to cover unreached populations in these locations. The slight downturn of the overall numbers highlights both transitional challenges in scaling services and possible shifts in demand, underscoring the need for closer monitoring to determine whether this dip represents a temporary adjustment or a longer-term trend.

- **Social Aspects:**
  - Between 2022 and 2024, the proportion of cleft patients shifted toward older children, with fewer infants under 2 years and more cases in the 3–10 age group. Adolescents remained stable at around 20%, while adults consistently accounted for less than 10%. In 2025, however, the trend reversed: infants under 2 years rose sharply to 44%, while older age groups declined. Overall, the data indicates a temporary shift toward treating older children followed by a return to prioritizing early intervention in infants, reflecting improved awareness, earlier detection, and changing referral patterns.
  - The gender distribution of cleft patients has remained relatively balanced, though with a consistent male majority until recent years. From 2018 to 2023, males accounted for 54–58% of cases, but by 2025 the ratio narrowed to 52% male and 48% female. This gradual shift suggests improved equity in service uptake, with female representation steadily increasing toward parity.
  - From 2023 to 2025, cleft surgery patients increasingly came from smaller families. In 2023, most were from households of 5–6 members (65%), but by 2024 and 2025 the majority shifted to families of up to 4 members (60% and 70% respectively). Larger families (more than 6 members) remained a small minority, while non-responses were minimal.
  - This trend closely mirrors the sibling data, where patients with 0–2 siblings consistently dominated and rose to 93.8% in 2025, while those with 3–5 siblings declined sharply. Together, the two datasets highlight a clear demographic shift: cleft surgeries are increasingly concentrated among children from smaller households, reflecting both broader family-size trends and possible differences in healthcare access and referral patterns.

  - However, this could also be the result of early treatments and the first child having a cleft. There could be more siblings in the later years as the child gets well.

- **Economic Aspects:**
  - The data on earning members highlights the economic fragility of cleft surgery patients' families, with the vast majority depending on a single income earner. In 2025, 896 families reported only one earning member, while just 12 had two earners and only one had more than two. This reliance on single-income households aligns with the earlier findings of declining average annual income, which fell from ₹1.1 lakh in 2018 to just ₹0.47 lakh in 2025. It also correlates with the shift toward smaller family sizes and fewer siblings, where most patients came from households of up to four members and with 0–2 siblings.
  - Taken together, these patterns suggest that cleft surgery patients are increasingly concentrated in small, single-earner, low-income households, reflecting both demographic changes and growing financial vulnerability. The convergence of shrinking family structures and declining incomes underscores the importance of external support systems, as limited earning capacity may restrict access to healthcare and long-term resilience.

4. Insights from Primary Data:

4.1 Analysis of the Patient Families' Interviews

In total134 patient families were interviewed to gain deeper insight into the lived experience of the cleft journey. These interviews provided a rich understanding of both the issues families commonly face—such as late detection, feeding difficulties, emotional strain, financial vulnerability, and developmental delays—and the outcomes achieved through timely intervention, including successful surgeries, improved feeding and speech, restored confidence, and relief from financial burdens. By listening directly to families, the study captures not only the medical progress but also the emotional resilience, gratitude, and hope that define the cleft care journey.

Families often spoke of the shock and distress they felt at birth when cleft conditions were discovered—particularly when prenatal scans had failed to reveal the anomaly. Many parents recalled learning about a cleft lip during the sixth month of pregnancy, a stage when termination was no longer an option. Even with prior knowledge, the moment of seeing their baby brought fresh waves of emotion. This was often followed by the trauma of feeding difficulties, with milk escaping through the nose, recurrent infections, and the burden of social stigma in the early months.

For mothers whose children had only a cleft lip, the journey was comparatively less arduous: feeding was manageable, and typically just one surgery was required. In contrast, families of infants born with both cleft lip and palate faced a far more challenging path—marked by prolonged struggles, complex feeding issues, and the need for multiple surgeries over time.

With few exceptions, most parents had limited educational backgrounds—many were school dropouts or had studied only up to the 12th grade. The mothers in these families were generally homemakers, though women from agricultural households often worked as farm laborers. Those who cultivated their own land typically owned only small plots. In some cases, wives held degrees while their husbands had dropped out of school, underscoring the role of families in arranging marriages, which were frequently consanguineous.

The men were employed in low-income occupations such as driving, daily wage labor, tailoring, garage work, or running small grocery shops. This reflects the socio-economic reality that nearly all beneficiaries came from disadvantaged backgrounds. Within these communities, awareness of the importance of education remained low, and many parents disinclined to send their children even to Anganwadi centres.

Thus, the affordability and accessibility of care emerged as critical factors. Families emphasized that surgery would have been unattainable without external support, underscoring the program's role in bridging healthcare inequities. Beyond individual outcomes, the surgeries generated a ripple effect within communities: successful cases encouraged other families to seek treatment, gradually dismantling stigma and fostering openness around cleft conditions.

Overall, the findings indicate that while the surgeries successfully addressed the physical aspects, the softer dimensions—such as regular speech therapy sessions and prescribed exercises—were not pursued by families to the extent required. Although families acknowledged that speech outcomes still needed improvement, their efforts toward rehabilitation were not undertaken with sufficient seriousness.

Interactions with beneficiaries and families reveal profound transformation brought about by cleft surgery interventions. For many, the procedure marked a decisive turning point—restoring confidence, enabling clearer speech, and opening pathways to education and employment. Parents consistently expressed deep relief and gratitude, recalling years social isolation that were alleviated through the intervention.

At the same time, interviews highlighted the importance of sustained support—particularly in areas such as speech therapy and follow-up care—to ensure long-term impact.

Across narratives, the dedication of medical teams and volunteers was repeatedly acknowledged. Families described the care as compassionate and family-like, reinforcing trust in the intervention. Collectively, these testimonies illustrate not only the immediate medical success of cleft surgeries but also their enduring legacy: empowering families, reducing stigma, and planting seeds of sustainable change within communities.

Beneficiary Story - Nandhini: Hope Found Through an Instagram Post

I first learned about this place through Instagram. I had posted a video of my daughter, and someone commented asking whether her operation had been done or was still pending. We replied that it was still pending. At that time, we had already taken her to the medical hospital and stayed there for nearly 15–20 days, but no surgery was performed. Through Instagram, we received an address and contact details—someone mentioned the name of Mr. Pankaj and shared a phone number. After calling, we finally got the correct address and came directly here from the hospital.

When we arrived, the doctors examined her and found that she had pneumonia. She was given medicines for eight days and sent home, with instructions to return afterward. As soon as we came back, they performed the surgery the very next day. There was visible improvement, but the doctors explained that further procedures would be required. Even after the third surgery, the correction was not fully complete. Because of this, her speech is not always clear—she speaks, but some words come out through her nose.

I have studied up to graduation, and we live in Nagpur. My focus now is entirely on caring for her. We are deeply satisfied with the services here. Everything was provided properly and free of cost. We did not have to pay anything. Earlier, in Chandrapur, where she was delivered, we were sent directly to the medical hospital. There, they had said treatment was free, but later hinted that if we paid, the operation would be done faster. We did not pay, and eventually, after learning about this place, we came here.

A Surgeon's Most Unforgettable Case

Dr. Ravikant Sing from Delhi shared one case that he clearly found both professionally extraordinary and personally affecting. A twelve-year-old child arrived with a complex facial cleft, but the surgical challenge was not the cleft itself. The child's neck was severely deformed — bent twice at abnormal angles — causing the trachea and airway to follow a tortuous path through the chest. The child had been turned away from two or three other hospitals before reaching Shanti Mukund.

In the operating theatre, every time the surgical team prepared to begin, the child's oxygen saturation dropped precipitously — to fifty or sixty percent. This happened 3-4 times. Finally, the anaesthetist traced the cause: the flexible endotracheal tube, threaded through a neck bent at two acute angles, was kinking like a garden hose, blocking airflow. The only solution was for the anaesthetist to hold the tube manually, at precisely the right angle, for the entire duration of the surgery.

For three hours, while Dr. Ravi operated on the child's face, the anaesthetist stood with one hand inside the surgical field, holding a tube. The planned complete facial correction could not be finished. It was difficult for both, the anaesthetist to stand motionless holding the tube and for the surgeon whose view was obstructed due to the anaesthetist’s hand holding the tube. So, the surgery was divided into stages. A detailed explanation was sent to ABMSS.

The child's airway deformity is permanent. Every future surgery, every future anaesthetic, will carry the same risk. The family cannot be adequately counselled about this because they do not have the literacy or the medical context to understand it. And yet the child was operated on, the risk was managed, and a partial correction was achieved — because the team decided it was worth trying.

This is the texture of the work.

4.2 Doctors: What Is Working, and Where the Fractures Are

- **Surgeons:**

Surgeon and doctor teams from Indore and Delhi were interviewed to gain perspectives on these recently added centres. Though what they shared applies to the program. Dr. Ravikant Sing in Delhi and Dr. Sanjay Kucheria in Indore were specially interviewed.

The Institutions and the Families They Serve

Across programme sites, the hospitals and clinical teams carrying this work do so with a seriousness that goes well beyond contractual obligation. Hospital managements feed and house patient families during extended admissions, absorb costs that fall outside the reimbursement package, and maintain clinical quality even as margins have narrowed. These institutions did not join this programme to fulfil the terms of an agreement. They joined to serve a community. The agreement is the floor, not the ceiling.

The families arriving at these centres are, in the main, among the most economically marginalised in the country — daily wage earners who have spent whatever they had to make the journey, carrying children they have watched struggle to feed, speak, and be accepted in their communities for months or years. Almost none of them know that cleft treatment is not a single surgery but a fifteen to eighteen-year journey requiring multiple procedures, speech therapy, dental correction, and sustained nutritional support. The doctors who diagnosed the condition gave a referral and moved on. No one gave these families a roadmap. For the communities this programme serves, it is not a supplement to a functioning public health system. It is the system.

What Is Working

The surgeries are being performed well and on time. Documentation workflows, while initially challenging at most sites, have become smooth and reliable. Clinical teams across the programme are experienced, dedicated, and candid about the complexity of what they manage. Reimbursement flows consistently on a monthly cycle. Coordinators have built referral relationships and community trust that sustain patient pipelines in the absence of more formal outreach structures. These are real and meaningful achievements, and they form a strong foundation on which the programme can build.

Where the Fractures Are

Incomplete recovery. Surgery without speech therapy and dental correction delivers partial outcomes. The clinical infrastructure for both exists at programme hospitals. What does not exist, for the vast majority of patients, is the ability to access it — families who have spent their savings reaching the hospital once are not in a position to return weekly for months of follow-on care. Post-discharge nutrition, equally critical to healing in children who arrive malnourished, ends the moment the family walks out the door. A practical solution has been identified — discharge kits containing protein-enriched foods produced by an affiliated organisation — and the clinical will to implement it is present. The funding mechanism is not yet in place.

Unsustainable package costs. Surgery package prices have not been revised to reflect the cost inflation of recent years, during which staff salaries have risen by 30 to 40 percent and consumable costs have climbed steadily. Some of the hospitals felt this pinch more than others. Hospitals are absorbing the difference as unreimbursed charity — on top of the informal family support they already provide outside the programme's formal scope. The gap between what the programme pays and what the surgery actually costs is being silently subsidised by the hospitals themselves. This is not sustainable in the medium term, and if left unaddressed, it risks eroding the willingness of quality institutions to remain in the programme.

Capacity constrained by funding quotas. Across sites, hospitals have significantly more clinical capacity than current funding quotas allow them to use. Dedicated cleft infrastructure — wards, nursing staff, equipment — carries fixed overheads regardless of whether it is fully utilised. When annual quotas are exhausted before the financial year closes, surgeries stop and patients wait, not because clinical capacity is absent but because the funds to deploy it have run out. An estimated 25% of patients who need surgery within a given funding cycle do not receive it.

Hidden clinical complexity. A significant proportion of patients — approximately one in five at sites assessed — arrive too unwell to operate on immediately, extending planned short admissions into stays of ten to fifteen days at full cost to the hospital with no corresponding increase in reimbursement. This patient population carries invisible clinical burdens accumulated through years of poverty, malnutrition, and untreated illness, and standard pre-operative investigations are not always designed to detect them. The absence of dedicated ward monitoring equipment at several sites means post-operative children requiring close observation must be transferred to shared ICU environments, creating infection risk for immunocompromised surgical patients.

What Is Being Asked For

The requests that emerge from programme sites are specific, practical, and modest relative to what the programme is already doing. They ask for package price reviews that reflect accumulated cost inflation; funded access to speech therapy and basic dental treatment as part of the care continuum; ward monitoring equipment that allows safe post-operative observation without infection risk; and nutritional discharge support for children returning to households where adequate recovery nutrition is unaffordable.

Taken together, these are not requests for the programme to become something fundamentally different. They are requests for what already exists to be done more completely — and for the real cost of delivering it to be seen, acknowledged, and supported.

- **Anaesthetists: Risk, and the Safety Protocols Behind Every Surgery**

Why Paediatric Anaesthesia Is a Discipline of Its Own

Cleft lip and palate surgeries are, by definition, paediatric procedures — and paediatric anaesthesia presents a category of challenge that has no adult equivalent. Children's physiology differs fundamentally from that of adults: drug dosing patterns must be precisely calibrated to weight and developmental stage, organ systems are less resilient under surgical stress, and the margin for error is narrower across every dimension of intraoperative management.

The most consistently demanding challenge, however, is airway management. In straightforward cleft cases, securing the airway is a skilled but manageable task. In children with syndromic conditions — Down syndrome, Pierre Robin syndrome, Alport syndrome, and others — the anatomy of the airway itself is altered, and what appears manageable in pre-operative assessment can become a life-critical emergency on the operating table. Programme anaesthetists across sites maintain ready access to backup equipment as standard practice: supraglottic airways, fibre optic scopes, and endotracheal tubes in a range of smaller sizes than a typical surgical list would require. Preparation for the unexpected is not an optional precaution. It is the baseline.

When the Unexpected Arrives

The value of that preparation becomes concrete in the cases that deviate from expectation — and in a patient population that carries significant underlying clinical complexity, deviation is not uncommon.

One anaesthetist at a programme site recalled a teenage patient with Down syndrome scheduled for palate surgery. Despite multiple intubation attempts, the airway could not be secured by conventional means; subglottic stenosis — a narrowing of the airway below the vocal cords — made standard tube placement impossible. With the paediatric ICU team alongside, and drawing on the full range of available equipment, the anaesthetist eventually secured the airway using a tube considerably smaller than anticipated. The child was stabilised on ventilator support and successfully extubated the following day.

At another programme site, an anaesthetist encountered an undiagnosed arrhythmia on the operating table — identified only after the child was already under anaesthesia, despite a prior paediatric evaluation. The discovery was not, in itself, a failure of the pre-operative process; arrhythmias in infants with cleft conditions can be intermittent and difficult to detect in standard assessments. But it was a sharp reminder of the population-level reality: infants born with cleft lip and palate carry a statistically elevated risk of associated congenital anomalies, and cardiac conditions — including arrhythmias — are among the most common. Anaesthesia itself can trigger unstable heart rhythms, and when an undetected condition surfaces intraoperatively, the risk profile of the procedure changes immediately and significantly.

These cases are not shared to suggest systemic inadequacy. They are shared because they accurately represent the texture of the clinical work — and because the outcomes in both instances were good, precisely because prepared teams responded with skill and adaptability rather than surprise.

How the Programme Manages Risk

Across programme sites, anaesthetic protocols for cleft surgery follow a consistent and rigorous pre-operative framework. Every child scheduled for cleft lip or palate surgery undergoes a 2D echocardiogram and a formal paediatric fitness evaluation before the procedure is confirmed. Elective surgeries are postponed when a child presents with signs of respiratory infection, however mild — a precaution that reduces intraoperative risk materially and reflects the vulnerability of a patient population already predisposed to airway sensitivity and immune compromise.

NICU and PICU backup are maintained at sites where the patient complexity warrants it. The understanding that not every intubation will proceed as planned — and that the team must be ready to manage oxygenation through alternative means if standard intubation fails — is embedded in how these teams prepare, not treated as an edge case to be managed if it arises.

The result, across the programme's surgical history, is a survival rate that effectively reaches one hundred percent — a figure that reflects not the absence of risk but the consistent capacity of well-prepared teams to contain it.

- **Orthodontist:**

Dr. Shrenik Oswal from Pune has been working with cleft patients for nearly three years as part of the Birla Memorial Hospital’s panel, following more than six years of orthodontic practice at the central hospital in Chandigarh. With guidance from Dr. Sagar who is the cleft surgeon and support from coordinator Balaji, he has managed numerous cleft cases—about 10–12 last year, with a target of 20 this year.

His work focuses on jaw modulation, teeth alignment, and overall facial improvement. He explains that cleft cases are far more complex than routine orthodontics because they involve malocclusions, speech difficulties, feeding challenges, and nasal discharge. Yet even modest improvements bring immense satisfaction to families, many of whom travel long distances for treatment.

Dr. Oswal emphasizes that treatment ideally begins around age seven and a half, when functional appliances such as expanders, face mask therapy, or chin cup therapy can guide jaw growth. After age twelve, when the jaws are fully mature, surgical options are usually required. These appliances do not interfere with eating and can often reduce the need for surgery later.

His training at PGI Chandigarh gave him extensive exposure to cleft care, including dedicated OPD days where maxillofacial surgeons, orthodontists, speech therapists, and plastic surgeons collaborated to plan cases. He has also completed fellowships in cleft care, further strengthening his expertise. Beyond routine cleft lip and palate cases, Dr. Oswal has begun treating facial clefts that extend to the eye, where prosthetic eyes can be provided. He values the multidisciplinary team approach, which allows comprehensive care under one roof.

For him, this work is deeply rewarding. It enables him to replicate the training and exposure he received during his studies and give back to society—especially to children and families who gain confidence, health, and hope through these treatments.

4.3 Programme Operations: The Work Behind the Work

Behind every surgery in this programme is a chain of administrative and outreach work that most beneficiary families never see. Across programme sites, this work is held together by coordinators who carry spans of responsibility — patient identification, family counselling, clinical coordination, documentation, billing, and reporting — that would, in a better-resourced system, be distributed across several roles. That the programme functions without significant friction is a genuine achievement, and one that depends substantially on the capability and commitment of these individuals.

In the field, coordinators identify children with cleft conditions in villages and urban communities, counsel families who are hesitant or afraid, and assess clinical fitness before connecting families to surgical teams. Convincing families is not always straightforward — some believe surgery is unnecessary, others distrust unfamiliar medical processes — and coordinators rely on clear communication and the credibility of the clinical teams behind them. The two critical parameters before any surgery can proceed are weight and haemoglobin. Many children arrive undernourished, and the consequence is delay: palate surgeries recommended at eleven months are routinely pushed to two years or beyond because the child has not grown enough to safely proceed. This is one of the programme's most persistent clinical challenges

— rooted not in any failure of the programme itself but in the nutritional poverty of the communities it serves.

At the hospital level, every free-of-cost case moves through a defined administrative sequence: income declaration and photo consent forms on arrival, pre-operative photography, portal upload, post-operative documentation, discharge summary, and monthly Excel reports with signed procedure lists and billing copies submitted to ABMSS. Reimbursement runs on a monthly cycle and has been consistent across sites. Where children require investigations beyond the standard package, supplementary funding requests are prepared with clinical rationale and considered on their merits. Documentation workflows, initially challenging for coordinators new to the programme's requirements, have become smooth and reliable over time — with early gaps around photography and portal processes resolved through direct support from clinical leads and the ABMSS team.

Across all sites, new patients arrive primarily through informal referral — families who have been through the programme passing a contact number to others in similar circumstances. Formal outreach camps are not consistently in place. This informal pipeline is functional and has sustained patient volumes to date, but it means access depends heavily on who happens to know the programme exists, leaving significant numbers of eligible families unreached.

Two structural vulnerabilities are worth addressing as the programme matures. First, in lean single-coordinator models, surgical schedules and administrative coverage need to be explicitly synchronised to prevent documentation gaps that could affect reimbursement or programme records. Second, a more structured outreach model — even a modest expansion of current practice — could meaningfully increase reach, reduce the proportion of children who arrive too late or too unwell, and ensure that the patient pipeline is driven by systematic identification rather than informal networks alone.

4.4 Program Management: ABMSSS-Challenges and Vigilance:

- **Challenges**
    - **Ethical Risks:** Partnerships can sometimes expose vulnerabilities, such as misreporting or misuse of charitable resources. These practices undermine trust and highlight the need for strong oversight.
    - **Operational Complexity:** Expanding services into new regions often brings logistical hurdles—patient outreach, balancing workloads across centres, and maintaining quality standards while scaling.
    - **Community Access:** Families from peripheral or rural areas may face barriers in reaching hospitals, making consistent care and follow-up more difficult.

  - **Administrative Burden:** Documentation, approvals, and record-keeping add layers of complexity that can slow down service delivery.

- **Importance of Vigilance**
  - **Safeguarding Integrity:** Vigilance ensures that programs remain transparent, ethical, and truly beneficial to patients.
  - **Quality Assurance:** Continuous monitoring helps maintain high standards of care, accurate reporting, and accountability.
  - **Trust Building:** By upholding ethical practices and clear communication, programs strengthen credibility with families, communities, and partner organizations.
  - **Sustainable Growth:** Vigilance supports responsible expansion, ensuring that new centres or initiatives deliver consistent, patient-centred outcomes.

5. Key Findings

1. KEY FINDINGS: SECONDARY DATA

44%

Operated under age 2

Early intervention rate

↑

Female patients rising

Parents seeking care for daughters

↑

Smaller family sizes

Corroborated by sibling data

✓

Low-income families prioritised

Financial support where most needed

REACH & ACCESS

- Geographic reach has expanded overall, though case numbers have declined — particularly at the Hyderabad centre.
- New centres have extended the programme to previously underserved areas, improving access for remote communities.
- 44% of operated children are under two years old, indicating earlier identification and timely intervention.

DEMOGRAPHICS & TARGETING

- A slight rise in female patients suggests parents are increasingly seeking treatment for daughters rather than overlooking their condition.
- Data shows a shift toward smaller family sizes, corroborated by sibling data across programme records.
- The programme effectively prioritises low-income, single-earner families — ensuring financial support reaches those who need it most.

2. KEY ISSUES: PRIMARY DATA

BENEFICIARY FAMILIES

- 100% of families were unaware that cleft treatment is a 15–18-year journey involving multiple surgeries, speech therapy, dental correction, and sustained nutritional support.
- 100% of cleft palate families reported feeding difficulties and weight gain struggles before surgery; cleft lip-only families reported no such issues.
- Without proper speech therapy, unclear speech can become a permanent condition — yet most parents do not follow through consistently.
- Surgeries were frequently delayed due to low Hb or underweight children, pushing palate surgeries to 2–2.5 years in many cases.
- Some parents perceived fistula development as a failure of the first surgery rather than a known clinical possibility.
- More than 90% of parents were aware of the cleft via sonography, but confirmation came only at six months — leaving no possibility of termination.

EDUCATION AS A BARRIER TO AWARENESS

- Most parents were school dropouts or non-degree holders; women were generally better educated than their husbands.
- Low-education parents are largely unaware of the role of maternal nutrition in preventing congenital anomalies during pregnancy.
- Consanguineous marriage is a contributing factor to cleft incidence — most families remain uninformed about this genetic risk.
- Only one couple — both degree holders — planned a precautionary sonography during a subsequent pregnancy after a cleft birth. All others did not take such steps.
- Several parents understood the need for speech therapy but did not follow through consistently or diligently in practice.
- Those who knew about a cleft lip during pregnancy were unaware it is often accompanied by cleft palate — a condition requiring additional, multi-year intervention.

3. OUTCOMES: PRIMARY DATA

100%	100%	100%	100%
Feeding & speech improved Post-surgery, all cleft palate families	**Appearance improved** All cleft lip families post-surgery	**Satisfied with care** Doctors, staff & hospital services	**Free surgery was critical** Would have struggled to fund privately

CLINICAL OUTCOMES

- Feeding and speech improved in 100% of cleft palate families after surgery — a clear and universal positive outcome.
- All parents of cleft lip children — including those with accompanying cleft palate — reported improved appearance post-surgery.
- Free surgery was described as critical by all families, who stated they would have found it difficult or impossible to fund the procedure privately.

SOCIAL & PSYCHOSOCIAL OUTCOMES

- 100% of parents now feel comfortable bringing their child into social settings without experiencing shame or stigma — a significant shift in family confidence.
- Parents who previously hesitated to enrol their child in school due to the cleft condition now feel confident doing so — removing a barrier to education and development.
- Immense satisfaction with hospital doctors and staff was expressed by 100% of patients and families across all programme sites.

4. CLINICAL FINDINGS: DOCTORS & ANAESTHETISTS

SURGEONS — KEY OBSERVATIONS

- Hospitals operate well beyond contractual obligation — absorbing unreimbursed costs and providing informal family support that is never billed to ABMSS.
- Package pricing has not been revised in years while staff salaries have risen 30–40% and consumable costs have climbed; hospitals are silently subsidising the gap.
- An estimated 25% of eligible patients per funding cycle do not receive surgery due purely to quota constraints — not lack of clinical capacity.
- Approximately one in five patients — particularly at the Delhi centre — arrives too unwell to operate on, extending stays to 10–15 days at full cost to the hospital.
- Families arrive with no understanding that cleft treatment spans 15–18 years; the diagnosing doctor gave a referral and moved on.
- Dedicated monitoring equipment in cleft wards would eliminate post-operative cross-infection risk at relatively modest cost — a specific and unmet request.

ANAESTHETISTS & MULTIDISCIPLINARY CARE

- Paediatric cleft surgeries carry high clinical risk due to physiological differences, prevalence of congenital heart conditions, and complex airway management.
- Strict pre-operative protocols — including 2D echocardiograms and paediatric fitness evaluations — are followed at all sites; elective surgeries are postponed if infections are present.
- Survival rates are virtually 100% owing to meticulous planning, NICU/PICU backup, and the adaptability of anaesthetic teams during intraoperative emergencies.
- Orthodontists focus on long-term rehabilitation: correcting malocclusions, improving speech and feeding, and guiding jaw growth across the child's development.
- Early orthodontic intervention with functional appliances around age seven can reduce the need for more invasive surgery later in the child's care journey.
- Multidisciplinary teamwork — surgeons, orthodontists, speech therapists, plastic surgeons — is the foundation of comprehensive cleft care and positive long-term outcomes.

5. PROGRAMME COORDINATION & MANAGEMENT

COORDINATION — KEY ISSUES

- Outreach relies on RBSK and community networks for identifying children; formal identification camps are not consistently in place across sites.
- Family fears and misconceptions about surgery remain the primary challenge in field outreach — requiring sustained, trust-based communication.
- Coordinator responsibilities span patient evaluation, surgeon coordination, and haemoglobin and weight checks before proceeding to surgery.
- Delays are common — many children are underweight, pushing palate surgeries from the recommended 11 months to 2–2.5 years.
- Funding is covered by ABMSS; the main administrative hurdles are approvals, patient records, and timely photograph documentation.

PROGRAMME MANAGEMENT — CHALLENGES

- Challenges include ethical risks, operational complexity, rural access barriers, and heavy administrative requirements across programme sites.
- Vigilance is essential to safeguard programme integrity, ensure consistent quality of care, and build the institutional trust required for sustainable growth.
- A patient-centred approach must remain the organising principle of programme management — growth in case numbers should not come at the cost of care quality.
- Rural access barriers mean that informal referral chains — word of mouth and community contacts — remain the primary route through which eligible families reach the programme.
- Administrative burden on single coordinators at hospital sites is significant; synchronisation between clinical scheduling and documentation coverage is an ongoing vulnerability.

6. PROGRAMME COORDINATION STATUS

Monthly reimbursement — no delays reported	**On track**
Documentation & portal workflows	**Functioning**
Pre-operative photography protocols	**Resolved**
Surgical survival rate	**~100%**
Case volumes vs available clinical capacity	**Underutilised**
Palate surgery timing (target: under 12 months)	**Frequently delayed**
RBSK referral pipeline	**Partial only**
Formal outreach / identification camps	**Absent**
Post-discharge speech therapy access	**Not accessible**
Post-discharge nutritional support	**Not in place**
Surgery package price vs actual cost inflation	**Not revised**
Dedicated ward monitoring equipment	**Not available**

7. WHAT THE PROGRAMME NEEDS

These requests do not ask the programme to become something different. They ask for what already exists to be done more completely.

- Package price review reflecting three years of accumulated cost inflation — staff salaries have risen 30–40% since the last revision.
- Funded access to speech therapy and basic dental correction as a formal part of the care continuum, not an optional follow-on.
- 6–8 patient monitors for dedicated cleft wards — enabling safe post-operative observation without transfer to infection-risk ICU environments.
- Post-discharge nutritional discharge kits — protein-enriched foods that malnourished children will actually consume, distributed at the point of discharge.
- Increased funding quotas to utilise existing clinical capacity — the infrastructure is in place; the funds to deploy it are not.
- Structured outreach model to complement informal referral networks and ensure eligible families are systematically identified and reached.
- Better pre-pregnancy counselling and awareness campaigns targeting low-education communities on nutrition, consanguinity, and early screening.

5.1 Key Findings: Secondary Data:

- Overall, geographic reach has expanded but number of cases has gone down- especially in Hyderabad.
- New centres have helped extend the program's reach, ensuring access to areas that were previously underserved.
- 44% of babies that are operated for cleft lip/palate are under the age of two, which shows that they are caught younger ensuring a normal life for them as they grow up.
- The slight rise in female patients indicates that parents are increasingly seeking treatment for their daughters, rather than overlooking their condition.
- The data shows there is a shift to higher number of smaller families. This is also corroborated by sibling data.
- The program effectively prioritizes low-income, single-earner families, ensuring financial support for surgeries where it is most needed.

5.2 Key Findings: Primary Data:

- **Issues**
    - Most of the parents of the patients with a few exceptions were either school dropouts or were not degree holders.

- In most cases, women were better educated than their husbands.
- More than 90% of parents reported awareness of the cleft during sonography. However, all stated that they only received confirmation in the sixth month of pregnancy, leaving no possibility of termination.
- There was only one case where the doctor had suggested termination, all the rest were assured that they could go ahead as the cleft could be corrected with surgery. This aligns with the medical guidelines, which permit recommending termination of pregnancy only in life-threatening situations or in cases where independent adult living would not be possible—for example, in conditions such as Down syndrome.
- Those who knew about the cleft during the pregnancy, did not know that cleft lip is often accompanied by cleft palate, a condition requiring multiple interventions—including teeth alignment, jaw correction, nasal reconstruction, and management of fistula formation, which can necessitate repeated surgeries.
- without proper speech therapy, a child may fail to develop clear speech, and this lack of clarity can become a permanent condition.
- 100% parents of the babies who had only cleft lip said that they had no issues with feeding the baby.
- 100% of the parents of the cleft palate babies reported difficulties in feeding the babies and struggles with weight gain.
- Many times, the surgeries were delayed due to either low Hb or low weight of the child.
- A few parents saw development of fistula as failure of the first surgery.
- A few parents expressed unhappiness with the fact that the child did not gain as much speech clarity as they expected.
- 100% of the patients said that they had no idea when they came to know about the cleft lip during pregnancy that those may be accompanied by cleft lip and multiple surgeries over a period of years would be required to correct the anomalies.

Low Levels of Education: A Barrier to Awareness

- Parents with little or no formal education, often employed in low-income jobs, are generally unaware of the importance of maternal nutrition during pregnancy, which is vital for the baby's healthy development.

  - Many remain uninformed about the causes of congenital anomalies, with consanguineous marriage being one of the primary contributing factors.
  - Although several parents recognized the need for speech therapy and exercises to improve their child's speech, most did not follow these practices consistently or diligently.
  - In interviews with patient families, only one couple—both degree holders—reported that after their first child was born with a cleft, they ensured a three-month sonography during the next pregnancy to confirm the baby's health. The rest did not consider such precautions when planning subsequent pregnancies.

- **Outcomes**
  - 100% of the families with cleft palate patients said that the feeding and speech improved after the surgeries.
  - 100% of the parents who had children with cleft lip said that the appearance of the children improved after the surgeries – this includes the parents with children who had cleft lip accompanied by cleft palate.
  - 100% of parents reported that, with the improved appearance of their child, they now feel comfortable bringing their child into social settings without experiencing shame or stigma.
  - Parents who previously hesitated to send their child with cleft condition to school now feel confident to enrol them in formal education.
  - 100% of the patients and families expressed immense satisfaction with the doctors and staff of the hospitals where surgeries had taken place.
  - 100% of the patients said that they appreciate free surgeries which otherwise they would have found difficult to manage financially.

- **Doctors:**
  - Hospitals operate well beyond contractual obligation. The gap between what the programme pays and what care actually costs is silently subsidised by the hospitals themselves.
  - Families arrive with no roadmap for the journey ahead as they are unaware of the entire gamut of treatments spanning multiple years.

  - For these communities, the programme is the entire system of care - For the economically marginalised families this programme is the only door. The absence of functional alternatives makes programme continuity and quality a matter of clinical urgency.
  - Surgeries are performed well, but recovery remains incomplete for the centres which do not provide the entire package of services required for full recovery.
  - Sometimes funding quotas exhaust before the year closes. An estimated 25% of eligible patients within a given funding cycle do not receive surgery due purely to funding constraints.
  - Package pricing has not kept pace with inflation. Surgery package prices have not been revised in recent years while staff salaries have risen 30 to 40 percent and consumable costs have climbed steadily.
  - Approximately one in five patients arrives too unwell to operate on - particularly in Delhi Centre. They come from too far to send them back. This extends the hospital stay and cost of treatment.
  - Dedicated monitoring equipment in cleft wards would eliminate cross infection risk at relatively modest cost.
  - Paediatric cleft surgeries are high-risk due to physiological differences, congenital heart conditions, and complex airway management.
  - Anaesthetists follow strict preoperative protocols (2D echocardiograms, paediatric fitness checks) and postpone surgeries if infections are present.
  - Survival rates are virtually 100% because of meticulous planning, NICU/PICU backup, and adaptability during emergencies.
  - Orthodontists focus on long-term rehabilitation: correcting malocclusions, improving speech and feeding, and guiding jaw growth.
  - Early intervention with functional appliances around age seven can reduce the need for surgery later.
  - Multidisciplinary teamwork (surgeons, orthodontists, speech therapists, plastic surgeons) ensures comprehensive care.

- **Program Coordination:**
  - Focus on RBSK and community outreach for identifying children.

  - Main challenge: family fears and misconceptions about surgery.
  - Responsibilities: starting with evaluation first, then surgeon coordination and checking weight/haemoglobin thereafter.
  - Delays common—many children underweight, pushing palate surgeries to 2–2.5 years.
  - Funding covered by ABMSSS; hurdles are mainly administrative (approvals, records, photos).

- **Program Management**
  - Challenges include ethical risks, operational complexity, rural access barriers, and heavy administrative requirements.
  - Vigilance is essential to safeguard integrity, ensure quality, build trust, and enable sustainable, patient-centred growth.

- **Challenges**

Cleft palate surgery is only the first step in treatment and must be followed by speech therapy, dental care, and orthodontic interventions to achieve full recovery. Without consistent speech therapy, children cannot regain complete functionality. However, families who travel long distances to reach treatment centres often struggle to continue with these follow-up requirements. For daily wage earners, the challenge is compounded by income loss when they take time off for therapy sessions. Although Persistent is making significant efforts to provide comprehensive services at each centre, these practical barriers mean that some patients are unable to access the full continuum of care, leaving gaps in their recovery journey.

6. Conclusion

The ABMSSS cleft program stands as a powerful example of how structured outreach, free surgical care, and multidisciplinary teamwork can transform lives. Over the years, its geographic expansion has brought services to underserved regions, ensuring that more children—particularly those from low-income, single-earner families—receive timely interventions. The program’s contributions align strongly with the Sustainable Development Goals, weaving health, education, equity, and collaboration into its impact story. Under SDG 3: Good Health and Well-being, it has advanced surgical outcomes, improved nutrition, and ensured high survival rates. By supporting recovery and confidence, it also strengthens SDG 4: Quality Education, enabling children to participate more fully in school. Efforts toward SDG 5: Gender Equality are evident in the increased access to care for girls, ensuring they are not left behind. At the same time, the program addresses SDG 10: Reduced Inequalities by prioritizing low-income and marginalized families, making care more inclusive and equitable. Finally, its model of strong NGO–corporate collaboration reflects SDG 17: Partnerships for the Goals, demonstrating how collective action can drive sustainable change across communities.

The program still continues to face recurring challenges. Families often struggle with misconceptions about surgery, low levels of education, and limited awareness of the long-term needs associated with cleft conditions. Medical delays due to underweight children or low haemoglobin remain common, while administrative burdens such as documentation and approvals slow service delivery. These issues highlight the importance of strengthening parental education, nutritional support, and streamlined processes. Despite these hurdles, the program's outcomes are consistently positive: improved feeding, speech, and appearance for children, alongside immense satisfaction from families.

Ultimately, the program's success rests on vigilance—safeguarding ethical integrity, maintaining quality standards, and building trust with communities. By reinforcing outreach, parental awareness, and comprehensive follow-up care, ABMSSS can continue to grow sustainably while ensuring that every child born with a cleft has the opportunity to live a healthier, more confident, and socially integrated life.

7. Recommendations

A. Strategic Recommendations for Persistent India Foundation (Program Level)

1. Move from Surgery to Full Continuum of Care

The program must evolve from a **surgery-led model to a lifecycle care model**.

- Develop a strategy to address the access challenges faced by families who travel long distances for speech therapy after cleft surgeries.
- Create and upload speech therapy lessons online in local languages to make them more accessible beyond treatment centres.
- Establish a system of follow-up calls with parents to check whether they are accessing the online lessons (e.g., on YouTube), following the instructions, and observing any improvement in their child's speech.

Why it matters: Surgery restores form; **continuum care restores function and future**.

---

2. Introduce a Structured Nutrition Support Protocol

Establish a **pre- and post-surgery nutrition pathway**, including:

- Pre-surgery nutrition kits for underweight children
- Post-discharge protein-rich nutrition kits
- Linkages with ICDS / local nutrition programs

Why it matters: Malnutrition is the silent gatekeeper delaying surgery and recovery.

---

3. Revise Financial Model to Reflect Real Costs

Undertake a **comprehensive package cost revision**, considering:

- 30–40% rise in hospital costs
- Case complexity (extended stays, comorbidities)
- Tiered pricing for complex vs standard cases

Why it matters: Sustainability of partner hospitals is **non-negotiable for program continuity**.

---

4. Expand Funding to Utilise Existing Clinical Capacity

Increase annual funding allocations to:

- Eliminate the ~25% unmet demand
- Fully utilise existing hospital infrastructure

Why it matters: The constraint is not capacity—it is **capital deployment**.

---

5. Institutionalise Structured Outreach & Early Detection

Shift from informal referrals to **systematic identification**, through:

- Periodic screening camps
- Stronger integration with **RBSK, ASHA, Anganwadi networks**
- Digital referral tracking

Why it matters: Early detection reduces cost, complexity, and lifelong burden.

---

6. Launch a National Awareness & Behaviour Change Campaign

Design targeted IEC interventions on:

- Nature of cleft (lip + palate awareness)
- 15–18 year treatment journey
- Importance of speech therapy

- Nutrition during pregnancy
- Risks of consanguinity

Why it matters: Awareness is the **first surgery the system must perform**.

---

7. Strengthen Program Governance & Monitoring Systems

- Develop a **real-time dashboard** (cases, delays, outcomes, follow-ups)
- Standardise documentation and reporting across centres
- Introduce **outcome tracking beyond surgery**

Why it matters: What gets measured, gets sustained.

---

8. Introduce Care Navigators / Case Managers

Deploy dedicated **“Cleft Care Navigators”** to:

- Guide families through the full journey
- Ensure follow-ups (speech, dental, nutrition)
- Build trust and compliance

Why it matters: Families do not drop out due to disinterest—but due to **distance, cost, and confusion**.

---

9. Strengthen Hospital Ecosystem Support

Provide targeted support for:

- Ward monitoring equipment
- Infection-safe post-operative care
- Coordinator capacity (reduce single-point dependency)

Why it matters: Small investments here deliver **disproportionately large quality gains**.

---

10. Position the Program as a National Model

Document and scale the model as:

- A **best practice case study**
- A replicable CSR–healthcare partnership
- A platform for multi-stakeholder collaboration

Why it matters: This program is not just impactful—it is **demonstrative**.

B. Location-Specific Recommendations

1. Pune

1.1 Strengthen Advanced Rehabilitation Services

Leverage Pune's strong medical ecosystem to:

- Establish **centre of excellence for speech therapy & orthodontics**
- Pilot integrated care pathways

1.2 Develop a Model Referral Hub

- Create structured referral linkages with nearby districts
- Use Pune as a **regional anchor centre**

1.3 Introduce Digital Follow-up Systems

- Pilot tele-consultation for speech therapy
- Track long-term outcomes digitally

---

2. Sambhajinagar (Aurangabad)

2.1 Focus on Early Identification & Rural Outreach

- Conduct village-level screening camps
- Strengthen ASHA and Anganwadi linkages

2.2 Address Malnutrition Before Surgery

- Introduce pre-surgery nutrition support programs
- Partner with local health systems

2.3 Build Family Awareness & Counselling Systems

- Conduct structured counselling sessions
- Simplify communication on long-term treatment journey

---

3. Nagpur / Vidarbha Region (or similar emerging centres)

3.1 Strengthen Coordinator Capacity

- Reduce dependence on single coordinators
- Provide training and administrative support

3.2 Improve Access for Remote Patients

- Provide travel support / cluster scheduling
- Explore mobile outreach camps

3.3 Enhance Community Trust Networks

- Build local champions (treated families)
- Formalise referral networks

This program has already achieved something rare—it has turned medical intervention into social transformation. The next step is not just its expansion but deepening—so that every child who enters the system does not just receive a surgery, but completes a journey from vulnerability to voice, from stigma to selfhood.

8. Impact Assessment Framework

Relevance of the issue being addressed from the point of view of					**Total**
Beneficiary Community	The CSR mandate	Implementing partners	Development sector	Business footprint	
1	1	1	1	0	4
Most relevant	Child health	dedicated to cause	Contributes to SDGs	Not directly related	
Adequacy of Project outreach to demonstrate impact					
Absolute outreach	Extent of coverage of affected populations	Inclusion of key stakeholders	Various aspects of the issue addressed	Variety of interventions	
1	1	1	1	1	5
Covers all the selected	Saturation approach	Families, doctors, govt	All aspects addressed	Comprehensive model	
Efficiency in resource Use / project design					
Cost Consciousness	Mobilization of external resources	Percolation to the beneficiaries	% Overhead costs	Outreach in similar budget projects	
1	0.5	1	1	1	4.5
Effectiveness in changing situations					
Beneficiary satisfaction	Achieving defined Objectives	Impact compared to similar Projects	Removal of problems symptoms	Addresses root causes of the problems	
1	1	1	0.5	0	3.5
Sustainability of project processes and outcomes					
Reflected in design	Prospects of continuity beyond the project	Sustainability of impacts	Adaptation (of intervention, process)	Institutionalization	
0.5	0.5	1	1	0.5	3.5
PSL's mandate (impact, visibility, employee engagement)					
Visibility	Neglected issue	Employee volunteerng	External Recognition	Collaboration (scale up)	
0	1	0.5	0.5	0.5	2.5
23					