BAJAJ GENERAL
CARINGLY YOURS

IMPACT ASSESSMENT REPORT

IKSHA FOUNDATION (10455)

PROJECT DURATION- 15 May 2022 to 30 Nov 2023

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DevInsights

Contents

Executive Summary

Retinoblastoma, a rare yet aggressive childhood eye cancer, is both preventable and treatable if detected early. However, in India, where between 1,500 and 2,000 new cases emerge annually, survival rates remain significantly lower than those in high-income countries. This disparity is largely due to delayed diagnosis, limited awareness, and the prohibitive cost of treatment. For families surviving on daily wages or marginal incomes, the burden of repeated hospital visits, surgeries, and follow-ups is often catastrophic. As a result, many children present at advanced stages of the disease, requiring life-altering interventions such as enucleation or facing the risk of mortality.

In response to these inequities, Iksha Foundation, supported by Bajaj Allianz General Insurance Co. Ltd. funding, undertook a targeted intervention between May 2022 and November 2023 across the country. Originally designed to support 50 children, the program surpassed expectations, reaching 227 children from vulnerable households—an achievement representing more than a fourfold increase over its target. Support was provided through hospital referrals in key urban centres such as Hyderabad, Bangalore, and Pune, with assistance covering chemotherapy, laser therapy, surgeries, and prosthetic eye implants. The program also emphasized regular follow-up care and counselling, ensuring that families, despite their fragile circumstances, could sustain treatment and monitoring. Hyderabad accounted for the largest share of beneficiaries (124), followed by Bangalore (79) and Pune (24), reflecting the role of tertiary hospitals in anchoring specialized paediatric oncology care.

The evaluation of this intervention was conducted using the OECD DAC criteria—relevance, effectiveness, efficiency, impact, sustainability, and coherence—through a combination of secondary research and primary qualitative methods. In-depth interviews with caregivers, program officials, and healthcare professionals provided insight into lived experiences, challenges, and outcomes. Findings highlight that the intervention was highly relevant, filling a critical gap in the continuum of care by reducing financial strain, ensuring timely initiation of treatment, and addressing linguistic and informational barriers for families often navigating unfamiliar urban healthcare systems. The program was effective in achieving its objectives: children not only received life-saving interventions but also regained normalcy—returning to school, play, and community life. Caregivers consistently expressed that Iksha's support was the decisive factor that prevented them from abandoning treatment.

Efficiency was evident in the Foundation's full coverage of expensive hospital treatments, which families described as impossible to bear on their own. However, the evaluation also revealed persistent financial strain related to travel, food, lodging, and non-hospital medicines—costs that forced families into debt despite treatment coverage. The impact of the intervention extended beyond health outcomes. Children's survival and restored vision brought psychosocial relief and dignity to families, transforming despair into hope. Beneficiaries also became informal advocates, spreading awareness of retinoblastoma in their communities, thereby extending the ripple effect of the program. Yet, sustainability remains fragile: while medical follow-ups are maintained, economic vulnerability continues to threaten long-term care, leaving families heavily dependent on external support. Coherence was strong in complementing hospital services, but linkages with government health schemes, other NGOs, and welfare programs remain limited, suggesting opportunities for greater integration.

The evaluation identified key challenges of heavy out-of-pocket spending for non-medical needs, difficulties in securing affordable travel and accommodation, the emotional toll on caregivers facing stigma and uncertainty, and low levels of community awareness leading to late detection. Respondents and doctors alike emphasized the need for a more holistic model of support. Short-term recommendations include extending coverage to essential medicines and nutrition, providing meal

support during hospital visits, strengthening multilingual counselling, and building awareness through ASHA and Anganwadi workers. Long-term strategies involve establishing low-cost patient hostels near treatment centers, formalizing travel assistance through partnerships with Indian Railways and local transport services, supporting children's education during treatment, linking parents to livelihood opportunities, and integrating with government schemes and CSR initiatives for sustainable, system-wide impact.

Overall, Iksha Foundation's intervention demonstrates a transformative model for pediatric cancer care in low-resource settings. By combining financial assistance with timely medical access, the program not only saved lives and preserved vision but also restored dignity and hope to some of the most marginalized families in India. The dramatic expansion of reach—from 50 planned beneficiaries to 227 supported in just 18 months—underscores the power of targeted CSR partnerships in scaling health interventions. At the same time, the findings make clear that the battle against retinoblastoma extends beyond the hospital walls. Addressing the non-medical burdens of treatment and building systemic partnerships will be critical to sustaining progress and ensuring that no child is denied life-saving care due to poverty or geography.

Chapter 1: Introduction

Early childhood is meant to be a time of innocence and discovery silent, life-threatening danger can take root: Retinoblastoma, a rare yet aggressive eye cancer that primarily affects children under five. Often symptomless at first, it may appear as a white reflection in the pupil or a misaligned eye. Left untreated, it can lead to blindness, disfigurement, or death.

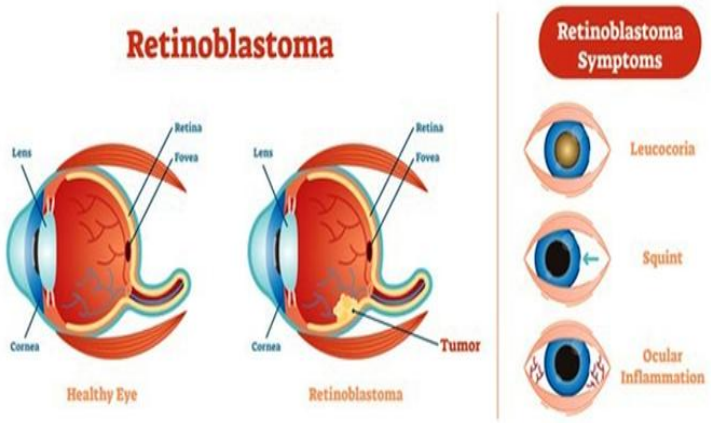


Figure 1: Retinoblastoma and its Symptoms

This cancer originates in the retina, triggered by a mutation in the RB1 gene, which normally regulates cell growth. It may arise spontaneously or be inherited, sometimes affecting both eyes. In bilateral cases, the risk of the cancer spreading to the brain or bones increases. Early detection is critical; prompt treatment drastically improves survival and vision outcomes.

Globally, around 8,000 children are diagnosed with retinoblastoma each year, approximately one in every 16,000–18,000 births. In high-income countries, survival rates exceed 95%, thanks to early diagnosis and advanced care.[1] However, in many low- and middle-income countries, lack of awareness, delayed diagnosis, and limited access to treatment lead to avoidable deaths and life-altering surgeries. Notably, over 40% of retinoblastoma-related deaths occur in Asia, despite the disease being curable if caught early[2].

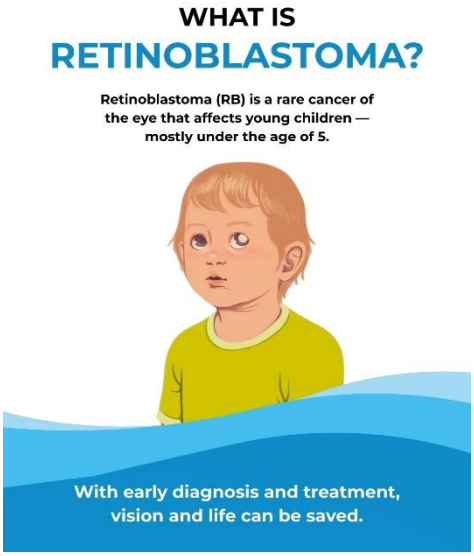


Figure 2: What is Retinoblastoma

India bears a significant burden, with 1,500 to 2,000 new cases annually. While urban centres may offer advanced care, large swathes of rural and low-income populations face delayed diagnoses due to poor awareness and inadequate access to medical services. This delay often results in irreversible outcomes[3].

Several epidemiological studies conducted in India reveal that retinoblastoma disproportionately affects underprivileged and rural populations, with many patients presenting at advanced stages of the disease. According to Kaliki, Mishra, and Mishra (2015), based on their comprehensive study at the LV Prasad

[1] https://pmc.ncbi.nlm.nih.gov/articles/PMC10478474/

[2] https://bmcophthalmol.biomedcentral.com/articles/10.1186/s12886-023-02980-8

[3] https://journals.lww.com/retinajournal/abstract/2019/02000/retinoblastoma_in_india__clinical_presentation_and.20.aspx#:~:text=India%20peaks%20the%20predicted%20incidence,new%20cases%20diagnosed%20each%20year.

Eye Institute in Hyderabad, a significant number of children with retinoblastoma arrived too late for vision-preserving treatments, often requiring enucleation or even exenteration[4].

The authors emphasize that financial constraints, lack of awareness, and poor access to specialized healthcare facilities are primary factors contributing to delayed diagnosis and treatment discontinuation among these vulnerable groups. To address this gap, Kaliki et al. (2015) highlight the importance of public-private partnerships, corporate social responsibility (CSR) initiatives, and non-profit programs that facilitate early detection, provide financial assistance, and ensure long-term follow-up care for children from marginalized communities.

Their findings underscore that while retinoblastoma is highly treatable if caught early, systemic socioeconomic barriers continue to drive poor outcomes, necessitating targeted efforts to improve awareness, affordability, and healthcare accessibility [4].

State-specific challenges highlight the disparity in access to retinoblastoma care across regions.

In Karnataka, while urban areas such as Bangalore offer advanced treatment options, rural populations still lack accessible services and struggle with maintaining consistent follow-up appointments. In Maharashtra, cities like Pune provide quality care, but families from remote or economically weaker backgrounds face significant hurdles related to travel, cost, and sustaining long-term treatment. Telangana, despite housing capable hospitals like Centre for Sight in Hyderabad, continues to see delayed diagnosis and treatment among rural and tribal populations due to low awareness and systemic healthcare access barriers. These regional differences reveal that the fight against retinoblastoma is not only medical but also socio-economic. A child's chance of survival still too often depends on where they live and how quickly they can reach appropriate care.

[4] Kaliki, S., Mishra, D., & Mishra, R. K. (2015). Retinoblastoma in India: Epidemiology, clinical presentation, and management challenges. *Indian Journal of Ophthalmology*, 63(1), 20-25. https://doi.org/10.4103/0301-4738.152647

Chapter 2: About the Project

Between 15 May 2022 and 30 November 2023, Iksha Foundation implemented a targeted intervention to address these inequities across Karnataka, Maharashtra, and Telangana. Originally aiming to support 50 children, the project ultimately reached 227 beneficiaries an increase of over 450 due to the CSR funding from Bajaj Allianz General Insurance Co. Ltd. These children, mostly from socio-economically vulnerable families, were identified through hospital referrals in urban centers like Bangalore, Pune, and Hyderabad. Each underwent diagnostic screening and clinical assessments to confirm eligibility and treatment needs.

The initiative provided full or partial financial aid for chemotherapy, surgeries such as enucleation, laser treatments, and prosthetic eye implants. For families relying on daily wages or informal work, this support proved critical in enabling uninterrupted care. Follow-up and long-term monitoring were also emphasized, with Iksha staff and hospital teams working closely with families to ensure continued appointments and rehabilitation a notable challenge highlighted in the report.

Regionally, Telangana saw the highest volume of children supported, with 124 treated through hospitals in Hyderabad. Karnataka followed with 79 children treated across three centers in Bangalore. Maharashtra accounted for 24 children, treated primarily in Pune. These figures reflect both populations reach and the accessibility of partner hospitals. The report also featured case stories, including Advik, a toddler with bilateral retinoblastoma who received chemotherapy, surgery, and ongoing laser treatment, and Yash, an 11-year-old boy from Maharashtra who underwent six cycles of chemotherapy and continues with laser therapy both examples of how early intervention and financial aid changed lives.

Ultimately, the project's success showcases how targeted outreach, financial support, and hospital coordination can overcome the barriers that too often prevent timely care. With continued awareness efforts and structured support systems, more children can be saved from avoidable blindness and given the chance at a better future.

2.1. Theory of Change

Goal

To support underprivileged children with retinoblastoma by providing financial assistance for timely diagnosis, treatment, and follow-up care.

Impact

Improved health outcomes, increased survival rates, and early identification of retinoblastoma among underprivileged children by greater awareness have contributed to a better quality of life and a reduced financial burden on families.

Outcomes

Intermediate	Long term
• Early diagnosis and protocol-based treatment for children. • Families supported for timely, uninterrupted treatment. • Enhanced referral and follow-up between Iksha and hospitals. • Increased family awareness on routine follow-up and monitoring.	• Increased survival and vision preservation among treated children. • Reduced financial burden on families from vulnerable communities. • Enhanced health-seeking behaviour and follow-up adherence among families affected by Retinoblastoma.

Outputs

- Number of children identified, screened and evaluated.
- Chemotherapy, laser therapy, and prosthetic eye implants administered as needed.
- Routine follow-ups conducted in coordination with hospitals.
- Follow-up counselling sessions conducted with caregivers of patients with Retinoblastoma.
- Case documentation and reporting.

Inputs

- Financial resources for surgeries.
- Experienced staff for identification, screening, eligibility evaluation, and treatment initiation of Retinoblastoma.
- Counselling sessions
- Partner hospitals and clinical expertise.

Problem

Lack of financial resources and limited awareness about retinoblastoma significantly restrict access to timely and appropriate treatment for underprivileged children, adversely affecting their quality of life.

Chapter 3: Approach and Methodology

3.1. Sampling Design:

Considering the nature and framework of the assessment and intervention, a qualitative study design was adopted for the present assignment. The study employed cross-sectional qualitative methods to capture diverse perspectives from participants representing various sections of society. This approach was deemed appropriate for the proposed end-line evaluation, as it enabled a comprehensive understanding of the project's effectiveness, efficiency, relevance, coherence, impact, and sustainability.

The qualitative component of the study provided in-depth, contextual insights into how the project influenced individuals and communities. It also offered a nuanced understanding of the key challenges encountered and the successes achieved during the implementation of interventions.

Secondary Research

Secondary data analysis was undertaken to review existing information from a range of sources, including government reports, national surveys, academic literature, hospital records, and data from previous projects. This analysis served to contextualize the issue under study, identify knowledge and service gaps, and guide the design and implementation of the current intervention.

By examining data related to the prevalence of retinoblastoma, demographic trends, and healthcare access, the study aimed to support evidence-based decision-making, prevent duplication of efforts, and ensure that resources are directed toward areas of greatest need.

Primary Research

Primary data collection for this study employed qualitative methods, focusing on three key respondent groups. In-depth interviews were conducted with parents of children who have received treatment for retinoblastoma to explore their experiences, challenges, and perceptions related to access to care and the support they received.

Key Informant Interviews (KIIs) were conducted with healthcare professionals involved in the diagnosis and treatment of retinoblastoma to gather clinical insights, understand treatment pathways, and identify barriers to early and effective intervention. Furthermore, KIIs with program officials from the Iksha Foundation provided valuable perspectives on implementation strategies, resource allocation, and operational challenges in delivering financial assistance and support services.

3.2. Sample Size:

Qualitative distribution:

A participatory approach was adopted to ensure that the voices of all relevant stakeholders—particularly survivors and children at risk—were meaningfully integrated into the evaluation process. This approach emphasized inclusivity and aimed to capture diverse perspectives on the project’s outcomes. In-depth interviews were conducted with parents of children who had undergone treatment for retinoblastoma, while Key Informant Interviews (KIIs) were held with doctors and program officials. These engagements ensured that the assessment reflected lived experiences, clinical insights, and programmatic viewpoints critical to understanding the project’s overall impact and effectiveness.

Participants	Tools to be administered	Number of interviews conducted
Parents of children who treated for Retinoblastoma	In depth Interview	22
Doctors	Key Informant Interview	1
Program Officials	Key Informant Interview	1
Case Stories from Caregivers	Case Stories	3
	Total	**30**

3.3. Study Tools

The study tool implemented for this study will be-

In-depth interviews

In-depth interviews was conducted with parents of children who have received financial aid and treatment support through Iksha Foundation. These interviews aimed to capture first-hand narratives on the treatment journey, including barriers faced, emotional and financial challenges, and the overall impact of the assistance provided.

Key Informant Interviews

Key Informant Interviews was conducted with individuals who have specialized knowledge or are involved in the planning and implementation of retinoblastoma care and support services. In the context of this project, KIIs was held with doctors who treat retinoblastoma and with program officials from Iksha Foundation.

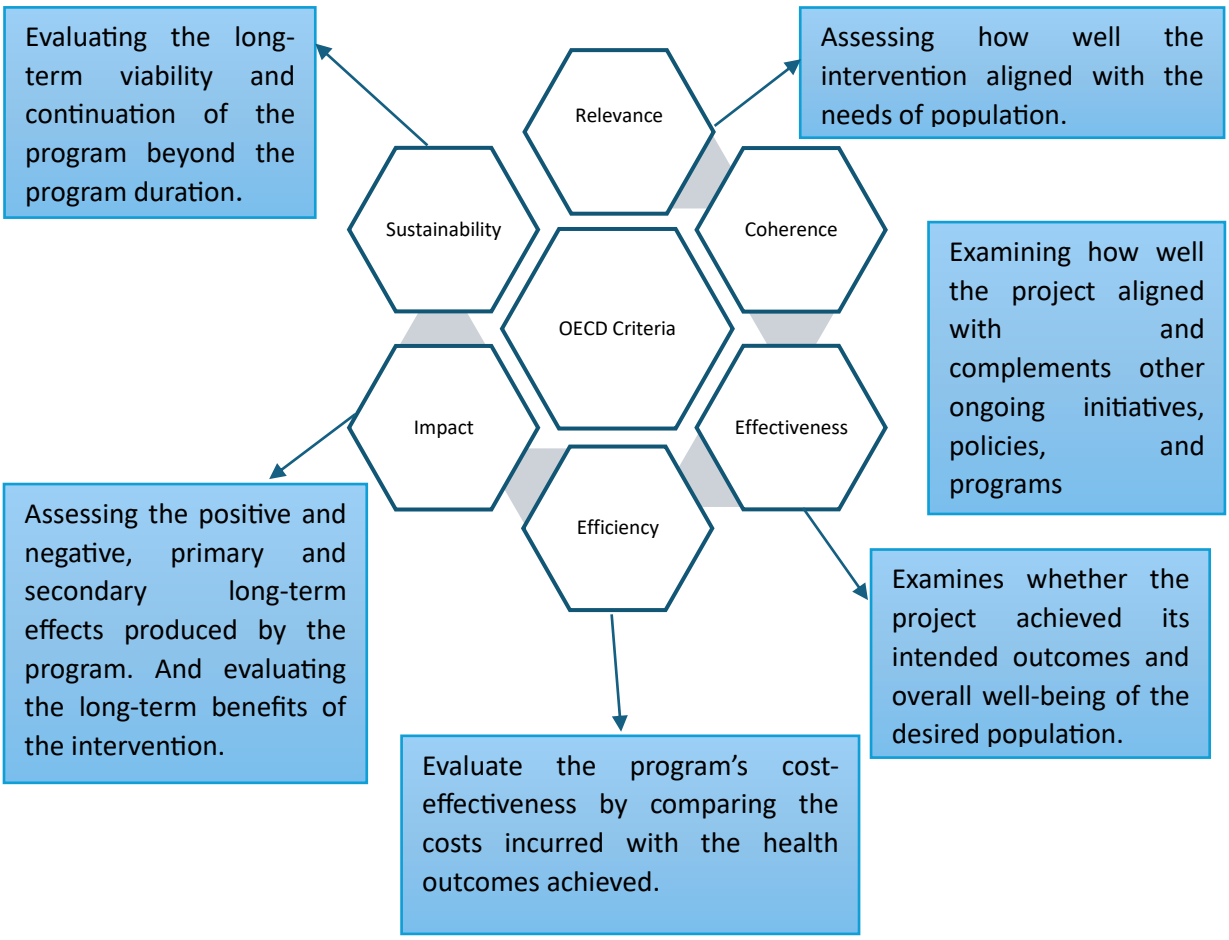
3.4. Key Indicators Measured

Thematic Area	Key Indicator	Source
Identification & Outreach	Number of children identified with retinoblastoma	Secondary (Iksha Foundation MIS/records). Primary- Qualitative (KII – Iksha Staff)
	Number of new hospital referrals received	Secondary (Hospital Records). Primary- Qualitative (KII – Doctor, Iksha Staff)
Treatment Support	Number of children receiving full/partial financial support	Secondary (Iksha Financial Records). Primary- Qualitative (IDI – Caregiver, KII – Iksha Staff)
	Type of treatment provided (chemotherapy, laser, surgery)	Secondary (Hospital Records).

Thematic Area	Key Indicator	Source
		Primary- Qualitative (IDI – Caregiver, KII – Doctor)
Access & Continuity	Number of children completing treatment	Secondary (Iksha Tracker); Primary- Qualitative (IDI – Caregiver, KII – Iksha Staff)
	Number of children lost to follow-up	Secondary (Iksha Tracker). Primary- Qualitative (IDI – Caregiver, KII – Iksha Staff)
Financial Contribution	Average amount of financial support per child	Secondary (Iksha Financial Reports). Primary- Qualitative (IDI – Caregiver, KII – Iksha Staff)
	Total treatment cost covered under the project	Secondary (Iksha MIS). Primary- Qualitative (KII – Iksha Staff)
Patient Outcome	Survival rate of supported children	Secondary (Hospital Records, Iksha MIS). Primary- Qualitative (KII – Doctor, Iksha Staff)
	Number of children fitted with prosthetic eye (if applicable)	Secondary (Hospital Records). Primary- Qualitative (IDI – Caregiver, KII – Doctor)
Follow-up	Number of follow-up visits completed per child	Secondary (Iksha Follow-up Records). Primary- Qualitative (IDI – Caregiver, KII – Doctor)
	No children receiving long-term monitoring	Secondary (Iksha Foundation Report/MIS). Primary- Qualitative (IDI – Caregiver, KII – Doctor, Iksha Staff)
Counselling Impact	Change in perception among children and caregivers after the treatment	Primary- Qualitative (IDI – Caregiver)
Qualitative Impact	Case studies showing changes in emotional and health status	Qualitative (IDI – Caregiver, KII – Iksha Staff)
	Caregiver satisfaction with support received	Qualitative (IDI – Caregiver)

3.5. OECD DAC Evaluation Criteria-

The study adhered to the OECD DAC evaluation criteria. These criteria, which consist of efficiency, effectiveness, relevance, impact, coherence, and sustainability, formed the foundational principles guiding the evaluation. Applying these criteria allowed for a rigorous assessment of the intervention's impact.



3.6. Ethical considerations

Some of the measures that was undertaken to uphold ethical standards are as follows:

INFORMED CONSENT

Before conducting the interviews, informed consent was obtained from all participants. They were clearly informed about the purpose of the study, what the interview would involve, and their rights as participants. It was emphasized that participation was entirely voluntary and that they could choose whether their responses could be quoted verbatim in any study outputs.

CONFIDENTIALITY

Confidentiality was maintained at all stages of the research, including data collection, storage, analysis, and reporting. All electronic records, including expanded field notes, pre-analysis forms, and interview logs, were stored on password-protected computers, while physical notes were kept securely in locked cabinets. Care was taken when using quotations in the report to ensure that no participant or organization could be identified. The identities of all interviewees were kept anonymous in the study outputs.

Chapter 4: Secondary Data Analysis

Retinoblastoma (RB) is a rare but highly aggressive childhood eye cancer that typically affects infants and toddlers. Globally, RB occurs in about **1** in every **15,000–20,000** live births, translating to an estimated **7,000–8,000** new cases annually. Nearly two-thirds of RB patients are diagnosed before the age of two, and about **95%** by the age of five, underscoring its early onset nature. With its large and young population, India shoulders the **highest RB burden worldwide**, with **1,500–2,000 new cases annually**. National Cancer Registry data identify RB as the **fifth most common paediatric cancer** among children aged 0–14 and accounting for approximately **5% of all childhood cancers**.

Compared with high-income countries where survival rates approach **95%**, India's five-year survival for RB is much lower at **79%**, reflecting late presentation, diagnostic delays, and systemic treatment barriers. Many Indian children are diagnosed at advanced stages, and treatment outcomes are further complicated by high rates of therapy abandonment and socioeconomic vulnerabilities.

4.1 Incidence and Clinical Profile

RB incidence is highest among children under five, with significant **regional variation**. Population-based cancer registries (PBCRs) highlight especially high age-specific incidence rates in **Chennai (Tamil Nadu)** and **Kolkata (West Bengal)**, while **Bangalore (Karnataka)** also shows elevated rates due to the presence of major eye hospitals. Delhi's cancer registry records a high proportion of RB cases, partly because patients travel from multiple states to access specialist care. Despite these data, RB remains under-reported in rural areas where diagnostic and referral systems are weak.

Male predominance is a recurring pattern in Indian RB series, with approximately **60% of cases in boys**. This skew likely reflects **gender bias in health-seeking behavior**, where families may be more willing to invest in healthcare for male children than for females.

Clinically, Indian children typically present at a **median age of 24–36 months**. About **25–30% of cases are bilateral**, while the majority are unilateral. **Leukocoria (white pupillary reflex)** is the most common presenting symptom, reported in up to **90%** of children in some state-level series. Strabismus (eye misalignment) is also frequent, while **10–15%** of children present with proptosis or orbital mass, signaling late-stage or extraocular spread. Alarmingly, **over 70%** of eyes present in advanced intraocular stages (Groups D/E), and **40–45%** of children already have orbital or metastatic disease at diagnosis. For example, a study from Chandigarh reported **42% of children with orbital extension at first presentation**.

These patterns shape treatment practices. **Enucleation (surgical removal of the eye)** remains the dominant therapy, with more than half of Indian patients undergoing primary enucleation. In several tertiary centers, children who initially received chemotherapy ultimately required enucleation after poor response. Histopathology reports from Ahmedabad and other centers consistently show a high prevalence of high-risk features, such as **>3 mm choroidal invasion (43% of cases) and post-laminar optic nerve invasion (27%).**

While newer therapies such as intra-arterial and intravitreal chemotherapy have improved **globe salvage rates (13–55%)**, the majority of Indian children still lose vision in at least one eye. Overall survival, at around **79%**, lags far behind global standards. **Relapse or metastasis occurs in 7–36% of patients**, and **treatment abandonment rates range from 10% to as high as 58%** in certain centers, reflecting the compounded effects of poverty, long travel distances, and lack of parental

understanding. Diagnostic delays are significant: one Hyderabad study found an average lag of **five months from symptom onset to first medical contact**, equivalent to nearly **10 tumour doubling cycles**, worsening prognosis.

4.2 Regional Disparities

India's RB burden and care pathways are profoundly shaped by geography. Population-based cancer registries primarily cover urban centers and unevenly represent states, meaning rural incidence is likely under-reported. Southern urban hubs like **Chennai, Bangalore, and Hyderabad** consistently record higher incidence, in part because of established tertiary eye hospitals, while poorer northern and central regions show lower numbers, reflecting missed diagnosis rather than true lower burden.

In **Karnataka**, past PBCR data revealed significant RB incidence, concentrated in Bangalore where major centers such as Narayana Nethralaya and Mazumdhar Shaw Cancer Centre are located. Rural Karnataka, however, likely harbors many undetected cases, as poorer families struggle to access specialized care. Similarly, in **Telangana**, Hyderabad is home to leading RB institutions like LV Prasad Eye Institute and Centre for Sight. Yet, local studies highlight the severe diagnostic delays: children from rural Telangana often reach hospitals only after months of symptoms, resulting in advanced disease and limited survival chances.

Maharashtra includes PBCR sites like Mumbai and Pune, which report moderate RB incidence. Still, rural and tribal belts such as Vidarbha show weak detection and poor outcomes due to lack of screening infrastructure. In **Gujarat**, a tertiary center in Ahmedabad documented **136 enucleations between 2017 and 2023**, with a mean age of presentation at 38 months, a predominance of unilateral disease (**96%**), and very high rates of high-risk histopathology—again underscoring late detection.

Overall, survival outcomes in India correlate strongly with **where a child lives and how quickly they can access care**. Urban, resource-rich states detect and treat more cases earlier, while remote or poor areas see late presentations, more enucleations, and worse prognosis. National surveys such as NFHS, NSSO, or the Census do not track RB specifically, so reliance on registries and hospital data leaves large knowledge gaps.

4.3 Iksha Foundation's Supportive Role

Amid this complex burden, the **Iksha Foundation** has emerged as a vital support system for families facing RB. For over 13 years, Iksha has worked with children from highly vulnerable, low-income households, where parents are daily wage labourers or small farmers. By 2021, despite the severe disruptions of the COVID-19 pandemic, the foundation had **supported treatment for 175 children in its first 11 years** and a cumulative total of **264 children across India**. During the pandemic years, Iksha confronted enormous challenges—restricted travel, hospital closures, added costs from PPE and COVID testing, and increased risk of delayed diagnosis. Yet the foundation ensured continuity of care: in 2020–

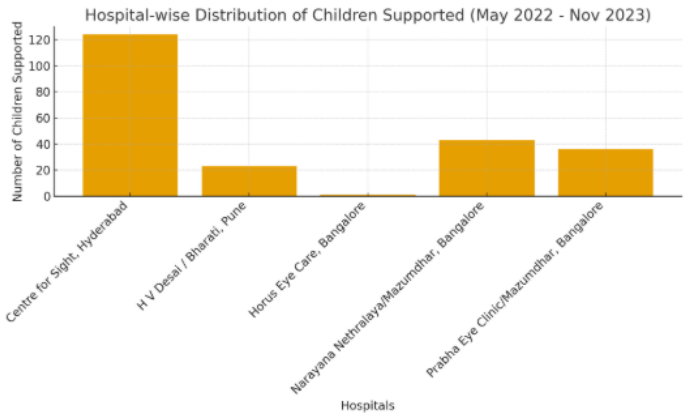


Figure 3: Hospital wise distribution of Children supported by IKSHA

21 alone, it supported **13** new children, while also monitoring **15** under active treatment, **48** under close observation, **58** in stable condition, **26** survivors, **18** lost to follow-up, and **10** who unfortunately passed away.

4.4 Post-Pandemic Surge and CSR Support

A turning point came in May 2022, when Iksha received **corporate social responsibility (CSR) support from Bajaj**. Initially targeting 50 children, the programme's reach expanded dramatically: in just **18 months (May 2022–November 2023)**, Iksha supported **227 children**—over four times the original target. This represented a quantum leap in scale, with the number of children supported per month rising from an average of five in the early years to nearly **22 in 2023**.

Hospital distribution data highlight how this expansion was concentrated around India's RB hubs. Of the **227** children supported, **124 (55%) were treated at Centre for Sight, Hyderabad**. Another **43 children** received care at Narayana Nethralaya and Mazumdhar Shaw Cancer Centre in Bangalore, while **36 were supported at Prabha Eye Clinic, also in Bangalore**. In Pune, H V Desai and Bharati hospitals collectively treated **23 children**, and Horus Specialty Eye Care in Bangalore handled one case. Overall, **Hyderabad and Bangalore accounted for nearly 90% of Iksha-supported cases**, reflecting their role as critical treatment hubs for paediatric ocular oncology.

4.5 Demographic and Geographic Reach

Iksha's cohort reflects the early onset nature of RB. Among **83** children with detailed demographic data, ages ranged from newborns (born in December 2022) to adolescents born in 2010, with the majority under age 10. Linguistic and cultural diversity was wide: while Hindi was spoken by about **60%** of families, beneficiaries also included Kannada, Marathi, Telugu, Bengali, Odia, Malayalam, Punjabi, and Chhattisgarhi speakers, demonstrating Iksha's **pan-India footprint**.

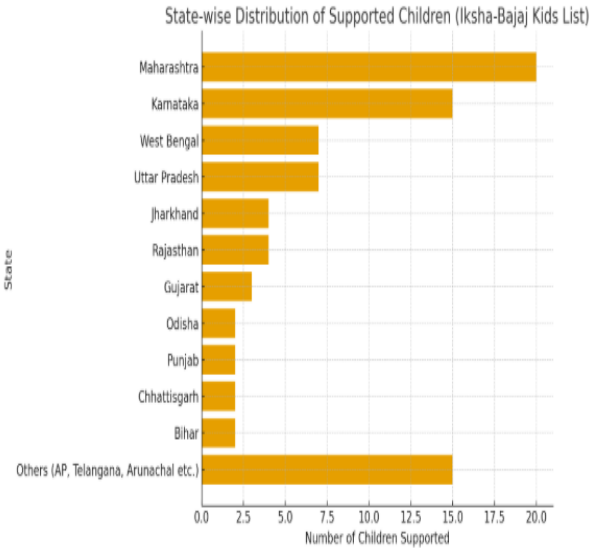


Figure 4: State wise distribution of Children supported by IKSHA

Geographically, **Maharashtra and Karnataka** had the largest number of beneficiaries, followed by **West Bengal, Uttar Pradesh, Jharkhand, and Rajasthan**. Children were also supported from **Odisha, Gujarat, Chhattisgarh, Arunachal Pradesh, Punjab, and Telangana**, confirming Iksha's reach into both metropolitan and rural/tribal areas.

4. 6 Outcomes and Challenges

The surge in children supported post-2022 illustrates the potential of **CSR-backed expansion**. In 2023 alone, Iksha supported **over 177 children within just eight months**, exceeding the total caseload managed in the first decade of its operations. Beyond financial aid, the foundation played a vital role

in **screening, assessment, treatment navigation, and follow-up**, enabling access to chemotherapy, laser therapy, enucleation, prosthetic rehabilitation, and supportive care.

Challenges persist, particularly in ensuring that families adhere to **regular follow-up visits**. Cultural barriers, travel distances, and financial constraints still cause attrition, with some families discontinuing treatment. Nevertheless, case stories of children completing chemotherapy cycles, undergoing successful surgeries, and being fitted with prosthetic eyes illustrate Iksha's life-changing impact.

India remains the **global epicentre of retinoblastoma**, with **1,000–2,000 new cases annually**, most detected at advanced stages. Children in rural and low-resource settings suffer disproportionately from late diagnosis, high rates of enucleation, poor globe salvage, and lower survival compared to their counterparts in high-income countries. Regional disparities remain stark, with better outcomes concentrated in southern and metropolitan hubs and worse prognosis in underserved states.

Against this backdrop, the Iksha Foundation has emerged as a **critical support system**, bridging socioeconomic and healthcare gaps for some of India's most vulnerable families. Its work demonstrates how targeted interventions—particularly when bolstered by sustained CSR funding—can transform care pathways. By supporting 227 children in just 18 months, compared to 264 in the previous 13 years, Iksha has proven that with adequate resources, RB care can be scaled dramatically. The foundation's impact illustrates a model for public–private partnerships in pediatric oncology, offering hope for improved survival and quality of life for children facing this devastating disease.

Quantitative Findings

1. Early Diagnosis & Protocol-Based Treatment

- **81.8%** (18/22) of children were diagnosed early and referred to tertiary care on time. These families reported that their child received structured treatment immediately after referral.
- **18.2%** were diagnosed late, often because frontline providers failed to recognize symptoms (white reflex, squint) or due to family-level delays.
- **90.9%** of children received treatment strictly according to standard protocols (chemotherapy, laser therapy, enucleation when needed).
- Only **9.1%** reported deviations, such as delayed initiation of one or the other procedures or incomplete cycles due to financial/logistical issues.

2. Timely & Uninterrupted Treatment

- **100%** were able to initiate treatment immediately after referral; no child was denied hospital admission due to inability to pay.
- **45.5%** described Iksha's support as *complete coverage*—all major clinical expenses were borne by the Foundation.
- **54.5%** said that despite hospital costs being waived, they faced **heavy indirect costs** (travel, accommodation, food, medicines not stocked in hospital).
- **18.2%** either discontinued or temporarily paused treatment because these residual costs became unmanageable.

3. Referral and Hospital Linkages

- **81.8%** reported smooth referrals from local clinics to Iksha-supported tertiary hospitals (Hyderabad, Bangalore, Pune).
- **18.2%** experienced delays or confusion, often due to poor communication from local providers.
- At the treatment centers, however, every referred child was admitted and supported.

4. Follow-Up & Monitoring

- Only **36.4%** families entered structured, long-term follow-up (scheduled visits every 6 months, scans, prosthesis care).
- **63.6%** either lacked clarity on the importance of follow-up, could not afford travel, or stopped after primary treatment.

5. Family Awareness on Follow-Up

- **36.4%** could clearly state follow-up schedules (e.g., “every 6 months” or “every 15 days”).
- **63.6%** were unaware, confused, or felt it was burdensome due to cost/logistics.

6. Financial Burden

- **100%** reported that direct hospital costs (surgeries, chemotherapy, laser, enucleation) were fully covered by Iksha.
- However:
    - **45.5%** achieved *complete relief* (no significant residual costs).
    - **54.5%** still bore partial costs, mainly travel, accommodation, and outside medicines.
    - **18.2%** dropped out due to these indirect costs.

7. Health-Seeking Behaviour & Adherence

- **81.8%** of families pursued treatment consistently, followed instructions, and actively sought follow-up.
- **18.2%** discontinued care, citing reasons like poverty, travel distance, or fear of surgery (e.g., eye removal).
- Families with counselling reported greater confidence and proactive engagement.

8. Outcomes: Survival and Vision Preservation

- **45%** achieved **vision preservation** in at least one eye.
- **91%** adhered to internationally accepted treatment protocols.

Chapter 5: Qualitative Findings and Analysis

This chapter presents the detailed analysis of qualitative data collected through in-depth interviews (IDIs) with caregivers of children diagnosed with retinoblastoma, conducted as part of the evaluation of the medical and financial support program implemented by Iksha Foundation. The findings are organized around the OECD DAC criteria—Relevance, Effectiveness, Efficiency, Impact, Sustainability, and Coherence—to provide a comprehensive understanding of the program's performance.

The analysis highlights caregivers lived experiences, demonstrating how the intervention effectively addressed critical medical needs, alleviated financial pressures, and enhanced child health outcomes. By promoting early detection of retinoblastoma and raising awareness among underprivileged families, the program has contributed to higher survival rates and an overall improvement in quality of life. Verbatim quotes further illuminate respondents' perspectives, showcasing both the program's impact and the ongoing challenges families face in sustaining long-term care.

5.1 Relevance

Relevance assesses the extent to which Iksha Foundation's intervention responded to the urgent needs of families affected by retinoblastoma. The program's focus on covering treatment costs, reducing financial hardship, and bridging communication barriers at tertiary hospitals was highly aligned with caregivers' priorities, ensuring timely and effective access to life-saving care for their children.

Alignment with urgent medical needs

The onset of retinoblastoma presented as a sudden medical emergency, with parents often failing to recognize the seriousness of early signs such as white spots or squinting eyes. Local doctors frequently gave vague advice or suggested extreme solutions, such as eye removal, without explaining the disease. Families described this stage as confusing, frightening, and marked by helplessness. In this context, Iksha Foundation's intervention was highly relevant—it bridged the gap between diagnosis and treatment by enabling access to specialized oncology care that families otherwise could not reach.

"When she was six months old, her eyes looked slightly squint. The doctor in Azamgarh just said, 'Show to a doctor in Hyderabad.' We did not understand it was such a big disease. Only after reaching there, with support, treatment started." (Caregiver 2, Jaunpur, Uttar Pradesh)

"My child's eye had a white spot, like a mustard seed. In Patna, they told us one eye must be removed. We were shocked. Only after reaching Hyderabad and connecting with the Foundation, proper treatment began." (Caregiver 5, Saran District, Bihar)

"Initially in our town they said nothing could be done. We were scared and thought it was the end. In Hyderabad, within one day treatment began. That gave us hope." (Caregiver 11, Jalna, Maharashtra)

"For my nephew, doctors only kept saying to go to Hyderabad, but nobody told us why. We wasted months before coming here. If the Foundation had not helped at the right time, things could have gotten worse." (Caregiver 15, Patna, Bihar)

Financial vulnerability of households

Households were uniformly fragile in terms of income, relying on small shops, agricultural labour, or daily wages averaging ₹15,000–20,000 per month. Such incomes were insufficient to meet the high recurring costs of chemotherapy, scans, and hospital stays. Many caregivers had already borrowed heavily from relatives or taken loans before Iksha's support. Families emphasized that without the Foundation, they would have had to discontinue treatment altogether. Thus, financial support was central to the relevance of Iksha's intervention.

"We run a small shop, earning around 15,000. We live daily—earn daily, eat daily. Nothing is left to save. Without their help, treatment was impossible." (Caregiver 2, Jaunpur, Uttar Pradesh)

"My monthly income is hardly 18,000 from labour work. The cost of chemo and scans was beyond us. Foundation's support came exactly when we had given up." (Caregiver 7, Nagpur, Maharashtra)

"I had two children affected. Imagine the expenses—impossible for us. Iksha took that burden, otherwise both lives would have been lost." (Caregiver 6, Pune, Maharashtra)

"We mortgaged some jewellery for the first visits. After that we had nothing left. Only with their support could we carry on." (Caregiver 12, Pune, Maharashtra)

"Judging by their profession and monthly income, that's how we apply for support. Because sometimes what happens is they don't have documents like ration cards, but actually they are eligible for that, right?" (Doctor KII)

"Most of the families... come from underprivileged backgrounds... daily wages or small work."
(Program Official KII)

Bridging communication barriers

Language emerged as a key barrier in accessing treatment. At Hyderabad hospitals, where doctors primarily spoke English or Telugu, caregivers from Hindi-speaking states struggled to understand medical instructions. This created confusion and fear. Iksha Foundation staff stepped in to explain medical terms in Hindi, reassure parents, and guide them through procedures. This linguistic and cultural mediation was repeatedly cited as a critical aspect of relevance.

"The main language there is English, which we don't understand. Our language is Hindi. Whatever we did not understand, madam explained to us clearly in Hindi. That guidance gave us confidence." (Caregiver 2, Jaunpur, Uttar Pradesh)

"Every time doctors spoke in English, we were lost. Madam explained things slowly in our language. Without that, we would not have understood what was happening." (Caregiver 8, Hyderabad, Telangana)

"They guided us in such a way that we felt less scared. Even during tests, they explained why it was needed. That built trust." (Caregiver 14, Nagpur, Maharashtra)

Addressing information and awareness gaps

Another dimension of relevance was Iksha's role in bridging awareness gaps. Many caregivers admitted they had never heard of retinoblastoma before diagnosis. Misconceptions were common, with families attributing symptoms to "normal squinting" or "white reflections." By providing clarity and continuous information, Iksha enabled families to recognize the disease and pursue the right treatment pathway.

"Before this, we had never heard of such a disease. We thought it was a normal eye problem. Only after Iksha told us did we realize it was cancer." (Caregiver 9, Saran District, Bihar)

"We thought it was some swelling. Nobody explained properly in our town. When Foundation explained, we understood the seriousness." (Caregiver 16, Bhopal, Madhya Pradesh)

"Even now, people in our village ask what disease it was. We tell them it is eye cancer and that treatment is possible. That awareness came to us only because of Iksha." (Caregiver 20, Pune, Maharashtra)

5.2 Effectiveness

Effectiveness examines the degree to which the intervention achieved its intended outcomes. Iksha Foundation enabled timely initiation of chemotherapy, laser therapy, and surgeries, resulting in improved child health outcomes, restored vision in many cases, and children's reintegration into schooling and daily activities. Regular follow-ups further ensured continuity of care.

Timely initiation of treatment

Caregivers consistently highlighted the speed with which treatment began once Iksha was involved. For many, local doctors had delayed treatment or only suggested extreme measures such as eye removal. In contrast, Iksha facilitated immediate initiation of chemotherapy, laser therapy, or surgery, reducing the risk of the disease spreading. This quick response was often described as life-saving.

"Treatment started the very next day after we reached Pune. Laser therapy and chemo were given right away." (Caregiver 6, Pune, Maharashtra)

"Earlier doctors only kept referring us from one place to another. But once Iksha came in, everything started quickly and properly." (Caregiver 11, Jalna, Maharashtra)

"For my nephew, the process had been dragging for months. Only after Foundation support did things move fast." (Caregiver 15, Patna, Bihar)

"Approval is given promptly… most of the time Iksha has been very prompt in providing the help." (Doctor KII)

"Our priority is mainly to focus that the child receives the treatment on time, rather than delaying it." (Program Official KII)

Improved child health outcomes

The most tangible sign of effectiveness was the dramatic improvement in children's health. Parents described how their children regained vision, became active again, and returned to school. These outcomes not only reassured families about survival but also allowed them to imagine a better future for their children.

"Now my daughter goes to school regularly. Earlier we thought she would never study, but now she is in Class 3 and doing well." (Caregiver 3, Hyderabad, Telangana)

"Earlier our son was weak and always lying down. After treatment he became active, plays outside, and studies in Class 5 now." (Caregiver 14, Nagpur, Maharashtra)

"She helps with small household things and goes to tuition. We feel she has become a normal child again." (Caregiver 10, Pune, Maharashtra)

"Two of my children were affected. Both have improved so much that they now study and play like others." (Caregiver 6, Pune, Maharashtra)

Counselling and guidance

Alongside treatment, Iksha provided practical guidance to parents on childcare—such as maintaining hygiene, proper nutrition, and encouraging schooling. Parents said doctors and staff repeatedly told them to treat their children as "normal." This built confidence, though many caregivers still felt that emotional and psychosocial counselling was limited, leaving them to cope with anxiety and stigma largely on their own.

"Doctors and madam told us clearly how to take care—keep clean, give good food, and treat him like a normal child. That gave us courage." (Caregiver 4, Pune, Maharashtra)

"We were very emotionally weak. People around us gave negative feedback which made us scared. Only treatment guidance was given, not much counselling." (Caregiver 8, Hyderabad, Telangana)

*"They explained everything step by step in our language. That guidance helped us not to lose courage." (*Caregiver 2, Jaunpur, Uttar Pradesh)

"We got advice on what to feed and how to look after him after chemo. That was very useful." (Caregiver 19, Bhopal, Madhya Pradesh)

"Counselling is part of IKSHA's commitment... we always counsel the parents... Even after, for years all together, not just like okay you came, and we supported." (Program Official KII)

Continuity of care

Effectiveness was also evident in Iksha's emphasis on follow-up care. Parents described how they were called every six months for check-ups, tests, and scans, which reassured them about their child's

recovery and helped detect complications early. Families viewed this continuity as a safeguard against relapse.

"We must have gone 25–30 times over two years for check-ups. Because of that, now she is fine, and we are not worried." (Caregiver 6, Pune, Maharashtra)

"They keep reminding us of check-ups, otherwise with our financial situation we may have missed them." (Caregiver 13, Nagpur, Maharashtra)

"Follow-up support was there every time. Tests were completed within a few hours, and we returned the same day." (Caregiver 18, Jaunpur, Uttar Pradesh)

5.3. Efficiency

Efficiency considers how economically resources were used to achieve results. By covering the most expensive medical procedures, Iksha Foundation delivered high value for beneficiaries. While families continued to bear costs for medicines, travel, and lodging, the program was viewed as cost-effective and indispensable for sustaining treatment.

Coverage of core treatment costs

Iksha's full funding of chemotherapy, laser procedures, and surgery emerged as the most efficient aspect of the program. By removing the heaviest financial burden, the Foundation ensured that children could access specialized treatment uninterrupted, without families being forced to abandon care due to lack of funds.

"All the hospital expenses for chemo and surgery were covered. Without that, we could not have managed even a single cycle." (Caregiver 3, Hyderabad, Telangana)

Value for beneficiaries

Despite these financial pressures, all respondents considered the intervention highly cost-effective. They acknowledged that while they bore expenses for food, medicines, and travel, these were manageable compared to the prohibitive cost of hospital treatment that was fully covered by Iksha. The program's efficiency lay in ensuring that limited resources delivered the greatest possible benefit.

"Whatever we spent on travel or stay was nothing compared to lakhs of hospital treatment. That was fully covered by them." (Caregiver 4, Pune, Maharashtra)

"We somehow managed food and stay, but the real treatment cost was beyond our reach. Only Iksha made it possible." (Caregiver 9, Saran District, Bihar)

5.4 Impact

Impact assesses the broader and long-term effects of the intervention. Iksha's support saved lives, restored children's ability to study and play, and reduced stigma within families and communities.

Many caregivers described the program as giving their child a “second life,” with ripple effects of hope and awareness spreading to other families.

Life-saving interventions

For families, Iksha’s intervention marked the difference between continuing treatment and abandoning it due to costs. Some parents admitted that without Iksha they would have stopped treatment altogether. Several also emphasized how quickly chemotherapy or surgery began once they connected with the Foundation, preventing disease progression.

“If the help was not available, we would have stopped the treatment. What else could we do? We are poor people. We don’t have the money to afford it ourselves.” (Caregiver 2, Jaunpur, Uttar Pradesh)

“For both children, they did it. All the hospital expenses, everything they paid—because we couldn’t have managed it. Today they have given not just one but two children a new life.” (Caregiver 6, Pune, Maharashtra)

“Treatment started the next day after we reached Pune. That immediate start saved our child from worsening.” (Caregiver 11, Jalna, Maharashtra)

“Definitely the quality of life improves because compliance with the treatment schedules will ensure that they get treated faster… quality and productive days improve significantly.” (Doctor KII)

"Because Iksha was able to provide the financial aid and the support... the counselling and even now the educational support ...I really have a strong feeling that Iksha made a big impact on all those families." (Program Official KII)

Restoration of normalcy

Iksha’s support not only extended lives but also allowed children to resume daily routines. Parents frequently mentioned children going back to school, playing with friends, and even helping with household chores. This “return to normal” was one of the most powerful outcomes for families who had feared lifelong disability or isolation.

“Now my son is in Class 5 and studies regularly. Earlier we thought he would never be able to sit in a classroom.” (Caregiver 14, Nagpur, Maharashtra)

“Earlier, our daughter was just lying weak. After treatment she became active, started looking better, and now even helps in small household work.” (Caregiver 10, Pune, Maharashtra)

“He plays cricket with other children in the village; nobody treats him differently now.” (Caregiver 7, Nagpur, Maharashtra)

Psychosocial relief for families

Parents described a journey from hopelessness to relief. Many reported crying and anxiety before treatment, with fears about losing their child or their child's marriage prospects. Successful treatment restored dignity, reduced stigma, and gave families confidence in their children's futures.

"We were always crying and tense. Now, seeing our child healthy, we are relieved and happy." (Caregiver 5, Saran District, Bihar)

"We thought who will marry our daughter with this disease. Now she looks normal, and we are not worried anymore." (Caregiver 6, Aurangabad, Maharashtra)

"Earlier, neighbours used to say negative things. Now, after seeing improvement, they encourage us." (Caregiver 12, Pune, Maharashtra)

Some families, however, continue to carry emotional burdens and stress about recurrence.

"Of course I am worried. I am always in worry. Just yesterday, when I looked at him, tears came in my eyes. Sometimes he asks me, 'Why was my eye taken out?'" (Caregiver 1, Hyderabad, Telangana)

Community-level influence

Iksha's beneficiaries became advocates within their communities. Several parents shared that they guided other families who noticed symptoms like white spots or redness in children's eyes to seek treatment. This peer-to-peer influence is expanding awareness about retinoblastoma in rural areas where knowledge remains limited.

"When other parents asked about the white spot in their child's eye, I told them to contact the Foundation. Two families have gone after hearing my story." (Caregiver 9, Saran District, Bihar)

"People in our village now know this disease can be treated. We guide them where to go." (Caregiver 13, Nagpur, Maharashtra)

"Neighbours who had never heard of this cancer now come to us for advice when they see similar symptoms in children." (Caregiver 17, Pune, Maharashtra)

"When it comes to awareness, when parent comes by reading the newspaper or online campaign that my child has a particular kind of symptoms. So, that is a success in awareness part." (Program Official KII)

Intergenerational hope

Grandparents and extended family members also expressed relief, underscoring the broader family-level impact. The sight of children recovering and returning to normal routines brought peace of mind to older generations who had felt powerless during the illness.

"We are old and could not see our granddaughter suffer. Now, seeing her play and study gives us peace in our last years." (Caregiver 10, Pune, Maharashtra)

"It is not only the parents—the whole family is living again after this support." (Caregiver 18, Jaunpur, Uttar Pradesh)

5.5 Sustainability

Sustainability considers the likelihood that benefits will continue after the intervention. Outcomes have been sustained through regular six-monthly check-ups and improved caregiving practices. However, families' ongoing financial vulnerability and dependence on external support highlight the need for stronger counselling, awareness, and systemic linkages for long-term resilience.

Medical follow-ups maintained

One of the strongest indicators of sustainability has been the continuity of medical care. Parents consistently reported being called every six months for check-ups, and many noted that doctors completed tests quickly to reduce their burden. Families recognized that this monitoring was critical in preventing relapse and expressed commitment to maintaining it as long as Iksha continued to provide support.

"Every six months they call us for check-ups. We go regularly and whatever test is needed, it is done. This has kept the child stable." (Caregiver 2, Jaunpur, Uttar Pradesh)

"They make sure everything happens in one or two hours, so we can return the same day. That has made us continue without stopping." (Caregiver 18, Jaunpur, Uttar Pradesh)

"Follow-up is important, and they never let us miss it. That routine has kept my son's eye safe." (Caregiver 14, Nagpur, Maharashtra)

Household economic fragility

Financial sustainability emerged as the weakest link. While hospital costs were covered, families had to spend substantial amounts on food, accommodation, and medicines not available in the hospital pharmacy. With fragile incomes from daily wages or petty shops, these recurring expenses placed families under constant financial pressure. Some mortgaged assets or borrowed repeatedly to continue attending follow-ups.

"We live on daily earnings. For travel and food, we borrow from relatives every time. Without Foundation's main support, we could not even think of continuing." (Caregiver 5, Saran District, Bihar)

"We run a shop with about 15,000 income. After rent and food, nothing is left. Every check-up means new borrowing." (Caregiver 1, Nagpur, Maharashtra)

"I mortgaged jewellery for the first trips. After that, we had nothing left. Still, we had to manage somehow for food and medicines." (Caregiver 12, Pune, Maharashtra)

"Our monthly income is 18,000. For two children's treatment, only with Iksha was it possible. Otherwise, we could not sustain." (Caregiver 6, Pune, Maharashtra)

Adherence challenges

In some cases, sustainability was threatened by fear of invasive treatment, particularly the removal of eyes. Parents admitted to stopping formal treatment temporarily or turning to alternative therapies, such as eye drops or home remedies. This points to a gap in sustained counselling and psychosocial support to build trust in the medical process.

"Doctors said the other eye also had to be removed. We could not accept that, so we stopped treatment and started using drops from outside." (Caregiver 7, Nagpur, Maharashtra)

"We became scared after hearing about surgery. We delayed and tried other medicines, but later we returned when the problem got worse." (Caregiver 4, Pune, Maharashtra)

"Sometimes the child asks, 'Why was my eye taken out?' We don't know how to answer. That emotional part is still not addressed." (Caregiver 1, Nagpur, Maharashtra)

Dependency on external support

Families repeatedly acknowledged that without Iksha's financial coverage, they would not be able to sustain treatment or follow-ups. While hospital treatment was secured, they lacked the resources to independently manage ancillary costs. This heavy dependency raises concerns about the long-term sustainability of outcomes if external support were reduced or withdrawn.

"If the Foundation was not there, treatment would have stopped long back. Even today we cannot manage without them." (Caregiver 3, Hyderabad, Telangana)

"For us, it is not possible to continue on our own. The Foundation is our only support for this treatment." (Caregiver 9, Saran District, Bihar)

"They gave us courage by saying don't worry about money, we will cover. Without that assurance, we would not have gone back for check-ups." (Caregiver 15, Patna, Bihar)

"Till today, we are dependent on them. If they stop, we don't know what will happen." (Caregiver 20, Pune, Maharashtra)

5.6 Coherence

Coherence examines the fit of the intervention within the wider policy and program environment. Iksha Foundation complemented tertiary hospitals by filling critical financial and navigational gaps, but linkages with government health schemes and social protection programs remain limited. Strengthening these connections would enhance alignment and systemic impact.

Complementing hospital care

Iksha Foundation's financial coverage enabled hospitals to provide treatment effectively. Doctors could focus on medical interventions while the Foundation ensured that families did not drop out due to inability to pay. This complementarity was appreciated by caregivers, who viewed Iksha and hospitals as partners working together for their children's recovery.

"Hospital did the treatment, but Foundation paid for it. Both together saved my child." (Caregiver 2, Jaunpur, Uttar Pradesh)

"Doctors guided us, and Iksha made sure we could continue. Without both, it was not possible." (Caregiver 6, Aurangabad, Maharashtra)

Limited integration with government schemes

While some families accessed government support—such as state-level cancer treatment schemes—these were not systematically facilitated by Iksha. Most respondents managed these linkages independently, highlighting a missed opportunity for greater coherence with public health systems.

"From Bihar government, we got eighty thousand once. That helped for travel. But it was separate, not through Iksha." (Caregiver 5, Saran District, Bihar)

"We tried to apply for a government scheme but did not get much help. Foundation only covered hospital treatment." (Caregiver 1, Nagpur, Maharashtra)

Coordination gaps in holistic support

While Iksha effectively funded treatment, non-medical needs—such as travel, accommodation, and daily meals—remained unsupported. This created a partial mismatch between what families required and what was offered, forcing parents to borrow money or cut household expenses.

"Treatment was covered, but for medicines outside, food, and room rent, we had to manage ourselves." (Caregiver 7, Hyderabad, Telangana)

"Every visit meant 10–12 thousand for stay and food. This was not included, so we struggled." (Caregiver 4, Pune, Maharashtra)

Potential for partnerships

Several respondents felt that stronger collaboration with other NGOs, CSR programs, or government welfare boards could ease the non-medical burden and create a more integrated support system. Beneficiaries expressed the need for such partnerships to reduce dependency on family borrowing.

"If they also helped in travel or stay through some other NGO or scheme, it would be even better." (Caregiver 3, Hyderabad, Telangana)

"Partnership with government could make things easier. Then everything would not depend only on Iksha." (Caregiver 9, Saran District, Bihar)

5.7 Challenges and Implementation Gaps

Despite the strong progress achieved by Iksha Foundation, families and doctors consistently pointed to significant challenges that affected the overall experience of care. These challenges spanned financial, logistical, emotional, and systemic dimensions, and while the Foundation addressed treatment costs effectively, gaps remained in the surrounding ecosystem of care.

Financial Burden and Debt

The most pressing challenge reported by families was the heavy financial strain created by repeated hospital visits and prolonged treatment. Households earning ₹15,000–20,000 a month were unable to cope with additional expenses for medicines, food, and travel, and many fell into debt due to out-of-pocket expenditures.

- *"In the beginning, sir, during the treatment we had to go every 28 days, continuously for six months, because chemotherapy was going on for the child. So, a lot of money was spent on traveling back and forth. Our financial condition was not strong."* (Caregiver, IDI)
- *"Yes sir, now for the child we are already in so much debt. What to do, treatment for the child has to be done. We manage by borrowing money here and there."* (Caregiver, IDI)
- *"We borrowed ₹2,00,000 from others. Doctors used to say nothing works without money."* (Caregiver, IDI)

The Program Official highlighted that: *"Most families come from very poor backgrounds with limited income, some running small shops or working daily wages. Families sometimes borrow money or mortgage assets to pay for treatment and related expenses."*

Doctors reinforced that limited financial resources often disrupted follow-up care. Many parents skipped scheduled visits due to travel costs or the fear of losing daily wages. As one doctor explained, *"One thing is money because they don't have enough money to travel or because they will lose their daily wage… or the basic lack of understanding of the disease."*

Logistical Difficulties of Travel and Accommodation

Travel and lodging were recurrent challenges, particularly for families from rural or remote areas. Securing train tickets, long overnight journeys, and expensive accommodation added layers of hardship.

- *"Sometimes I didn't get a train ticket, so I had to adjust my dates."* (Caregiver, IDI)

- *"We had a lot of travel problems in the first year… sometimes we had to travel standing all night."* (Caregiver, IDI)
- *"First of all the problem was going there. The biggest issue was tickets. Our area is so backward that we have to first go out to Kota to catch a train."* (Caregiver, IDI)
- *"People who come from outside, they face a problem of renting a place. We had to rent for 8–10 days. Rooms are very costly—1000 rupees per day."* (Caregiver, IDI)

Doctors noted that the inability to afford repeated travel often meant families defaulted on check-ups, undermining continuity of care.

"Families have to spend a lot on accommodation near hospitals. Sometimes people travel overnight in unsafe conditions or stand in trains because of lack of reserved seats." (Program Official KII)

Emotional and Psychological Toll

The sudden diagnosis of retinoblastoma, often in very young children, caused severe psychological stress for families. Caregivers spoke of fear, despair, and stigma, worsened by limited awareness of the disease.

- *"Actually, we became emotionally weak… we didn't even know that this disease has treatment. So, we got very scared."* (Caregiver, IDI)
- *"The biggest thing was—after hearing about this illness… everything felt like it collapsed right there. I became blank, confused—what is this new thing that has come into my life?"* (Caregiver, IDI)
- *"There are three patients of retinoblastoma in the family—this child Ishwari, her mother, and Ishwari's brother."* (Caregiver, IDI)
- *"We counsel parents continuously, explaining treatment and prognosis, but emotional support remains limited."* (Program Official KII)

Doctors observed that low levels of parental education compounded this stress, as many struggled to fully grasp the nature of the illness and the importance of follow-up. *"Usually, it is the education level of parents that is the difficulty in making them understand what the problem is. It's not the language."* (Doctor, KII)

Medical Complexity and Side Effects

Families described the exhausting process of repeated chemotherapy, laser sessions, and surgeries that often stretched over years. Relapses, side effects, and uncertainty about outcomes heightened their distress.

- *"Again, the same tumour had come, in the other eye… immediately started chemo again."* (Caregiver, IDI)
- *"Yes, chemo started within a year… 14 chemotherapy sessions—it took one and a half years just for that."* (Caregiver, IDI)
- *"The child's hair fell; her body became very weak, white blood cells dropped. Then they gave blood transfusions."* (Caregiver, IDI)
- *"Some patients come late when disease is advanced, increasing need for enucleation or intensive chemotherapy."* (Program Official KII)

Doctors noted that when children presented late, treatment had to be more intensive. In contrast, early detection could reduce the need for chemotherapy or surgery altogether.

Information Gaps and Late Awareness

A major gap highlighted by both families and doctors was the lack of timely awareness about retinoblastoma and the availability of Iksha's support.

- *"When we went the first time, we didn't know about the foundation. If we had known earlier that money could have been saved."* (Caregiver, IDI)

Doctors stressed that early detection could prevent advanced cases, reduce treatment intensity, and save costs: *"If it's very small, we can avoid chemotherapy altogether or we can avoid surgery… awareness that this is a completely treatable disease is lacking."* (Doctor, KII)

Families affected by retinoblastoma faced a web of challenges—financial instability, exhausting travel, emotional trauma, medical uncertainty, and lack of timely awareness. While Iksha Foundation's support significantly reduced treatment costs, gaps persisted in travel support, psychosocial counselling, and community-level awareness. Doctors echoed these concerns, emphasizing that better parental education, continuity of follow-up, and early detection remain critical to bridging implementation gaps and strengthening program impact.

5.8 Suggestions from Respondents and Doctor

Financial Challenges and Suggested Solutions

As families described, the biggest obstacle was the sheer cost of travel, lodging, food, and medicines outside the scope of Iksha Foundation's support. While the Foundation took care of chemotherapy, laser, and surgical procedures, parents still struggled to survive in a new city while seeking treatment. Respondents suggested that financial support should go beyond hospital bills to include food, stay, medicines, and travel.

One parent clearly articulated this need: *"See sir, my suggestion is that any poor person, if he cannot travel far, cannot go far, then he should get facilities like ticket arrangements, facilities for travel, these things should be provided."*
Another father reinforced this point: *"Treatment is given anyway, but they should get medicine also, and some money should be given to poor people for food, stay, and travel – that's what you are saying, right? … Yes sir."*

Doctors echoed this concern, noting that while treatment costs were covered, *"one thing is money because they don't have enough money to travel or because they will lose their daily wage."* They recommended that flexibility be introduced for children who drop out and later return for treatment: *"There are certain kids who abandon treatment and come back. For them, we are not getting support from Iksha again. If you can ease off on that one clause, it will really help us."*

Some families also recommended spreading awareness about Iksha's existence early in the process to prevent unnecessary expenses: *"When we went the first time, we didn't know about the foundation. If we had known earlier that money could have been saved."* Doctors agreed, stressing that *"if you can help us with increasing the awareness, then that would really make a lot of difference."*

Travel and Accommodation Issues and Suggested Solutions

The long distances, lack of direct trains, and the high cost of staying in Hyderabad were constant pain points. Families often spent thousands per trip or rented expensive rooms while staying for weeks during treatment. Respondents felt that help with travel logistics and affordable lodging facilities near hospitals would ease their burden.

One father explained: *"People who come from outside, they face a problem of renting a place. We had to rent for 8–10 days. Rooms are very costly—1000 rupees per day."*
Another respondent emphasized the need for structured support: *"To go from here to Hyderabad takes three days. That was the biggest problem."*

Doctors also highlighted that **follow-up ideally must be done at the treatment center** where the right equipment is available. However, they suggested that local health workers could play a supporting role in motivating families: *"ASHA or Anganwadi workers will not be able to follow up these patients because of the lack of equipment. But what they can do is motivate these people to come back, give reminders and motivate them to come for checkup."*

These experiences underline the necessity of providing low-cost or NGO-managed hostels, travel concessions, and guidance on transport facilities, while leveraging frontline workers to strengthen follow-up adherence.

Emotional and Psychological Stress and Suggested Solutions

Respondents spoke about the despair and shock that accompanied the diagnosis of retinoblastoma. Many said counselling sessions and emotional support systems could make the journey less overwhelming.

One parent shared: *"Actually we became emotionally weak… we didn't even know that this disease has treatment. So, we got very scared."*
While some received basic counselling at the hospital, they felt it was not enough. Another father recalled: *"Doctors said routine check-up every 6 months, so we go every 6 months. They explained all that. But my child doesn't have too many problems now, she's fine."*

Doctors suggested enhancing awareness and counselling to reassure families: *"Awareness that this is a completely treatable disease."* They also emphasized the role of sensitizing Anganwadi workers and local influencers to spread correct information at the community level.

From these accounts, families implied that consistent counselling, peer support groups, and interaction sessions with other parents could reduce the sense of isolation. Respondents also valued when doctors or Iksha staff explained things in simple language: *"Whatever we said in Hindi, they understood somewhat. They spoke a little and we could manage. Whatever was needed, madam explained to us clearly."* This suggests that language-appropriate counselling and awareness-building should be a priority.

Medical and Information-Related Issues and Suggested Solutions

Some families experienced relapses, multiple rounds of chemo, or were unsure about the disease's progression. Others did not fully understand the reports or treatment plan. A few parents even turned to herbal medicine out of fear when doctors suggested removing the second eye.

One respondent explained: *"When the doctor said to remove the other eye, my whole family became very angry. They said—what kind of hospital are you taking him to, that the doctor is saying to remove the second eye too."*

Doctors acknowledged this challenge and stressed that better communication is crucial: *"Usually it is the education level of parents that is the difficulty in making them understand what the problem is. It's not the language."* They recommended detailed counselling and clear communication to ensure parents grasp the severity and rationale of medical decisions.

Several participants also highlighted the importance of early awareness campaigns so that families don't spend lakhs before reaching Iksha: *"If someone is struggling a lot, has many difficulties, and cannot manage, then they should be told—brother, there is this foundation, take its support."* Doctors echoed this, urging systematic awareness efforts: *"Make them aware of where all these centers exist… awareness of where they can get treated."*

As families described, the biggest obstacle was the sheer cost of travel, lodging, food, and medicines outside the scope of Iksha Foundation's support. While the Foundation took care of chemotherapy, laser, and surgical procedures, parents still struggled to survive in a new city while seeking treatment.

Respondents suggested that financial support should go beyond hospital bills to include **food, stay, medicines, and travel**.

One parent clearly articulated this need: *"See sir, my suggestion is that any poor person, if he cannot travel far, cannot go far, then he should get facilities like ticket arrangements, facilities for travel, these things should be provided."*

Another father reinforced this point: *"Treatment is given anyway, but they should get medicine also, and some money should be given to poor people for food, stay, and travel – that's what you are saying, right? … Yes sir."*

Some also recommended **spreading awareness** about Iksha's existence early in the process to prevent unnecessary expenses*: "When we went the first time, we didn't know about the foundation. If we had known earlier that money could have been saved."*

Recommendations

The evaluation of Iksha Foundation's intervention highlights its critical role in enabling access to life-saving treatment for children with retinoblastoma, particularly among families facing severe financial and social vulnerabilities. While the program has successfully reduced the most prohibitive medical costs and ensured continuity of care, findings also point to persistent gaps around non-medical expenses, psychosocial support, awareness, and systemic integration. The following recommendations build on the voices of caregivers and insights from doctors, with the aim of strengthening program effectiveness, sustainability, and alignment with broader health and social protection systems.

Short-Term

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1. Extend Support for Medicines and Nutrition

- Many families had to purchase medicines and supplements separately, leading to additional debt. Iksha could:
    - Provide a monthly medicine kit for each child that includes commonly prescribed eye drops, syrups, and immunity boosters.
    - Offer nutritional support packages (milk powder, protein supplements, dry fruits) during the intensive treatment phase to counter weakness from chemotherapy.
- This would reduce out-of-pocket spending that most families described as unbearable.

2. Food Assistance During Hospital Visits

- Families traveling from villages spend ₹300–₹500 daily on food. Providing meal coupons or community kitchen tie-ups near hospitals could ease this burden.
- A simple arrangement with local canteens or NGOs can ensure affordable, hygienic food for caregivers and children.

3. Strengthen Counselling and Communication

- Parents often made drastic decisions (e.g., stopping hospital treatment, turning to herbal cures) due to fear or misunderstanding. Iksha should:
    - Institutionalize regular counselling sessions in Hindi and regional languages, focusing on disease awareness, treatment side effects, and long-term care.
    - Provide child-friendly counselling to reduce trauma for children undergoing repeated chemo.
    - Ensure simple progress reports are shared after each check-up (in local languages), so families feel informed and reassured.
- A second-opinion facility within Iksha's network should be offered before critical decisions like eye removal.

4. Awareness Through Local Networks

- Many families only learned about Iksha after exhausting savings. Early awareness is key:
    - Train ASHA workers, Anganwadi workers, and local doctors to recognize early symptoms like white spots in children's eyes.

- Distribute simple leaflets/posters at primary health centers in high-risk states (U.P., Bihar, Rajasthan, Chhattisgarh).
- Encourage recovered families to act as community advocates and refer new cases.

5. Emergency Support for Families in Crisis

- Create a small Emergency Assistance Fund (₹10,000–₹15,000 per family) to help with urgent needs like transport for critical surgeries, blood transfusions, or temporary shelter.
- This fund can be disbursed quickly on a case-by-case basis without heavy paperwork.

Long-Term

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1. Travel and Transport Support

- Distance and ticketing remain the biggest obstacles. Iksha can:
  - Create a patient travel desk in coordination with hospitals to help families secure tickets and provide travel guidance.
  - Explore bus/ambulance tie-ups for nearby districts where trains are unavailable.

2. Affordable Accommodation Near Hospitals

- Lodging costs of ₹500–₹1,000/day were widely reported. Iksha could:
  - Partner with low-cost patient hostels near treatment centers.
  - Leverage support from NGOs, religious trusts, or CSR partners to subsidize accommodation.
  - Provide family dormitory-style rooms with basic facilities (beds, clean water, kitchen access).

3. Education Support for Children

- Many children miss school during long treatment phases. Iksha can:
  - Link children with NGOs offering bridge education for hospitalised kids.
  - Provide learning kits (books, tablets with educational content) so children can continue studies during treatment breaks.

4. Livelihood Support for Parents

- Parents often leave jobs or cancel overseas work due to treatment needs. Iksha can:
  - Provide livelihood linkages with local NGOs or CSR programs offering short-term jobs (packing, tailoring, driving, small shop support).
  - Offer small income-support stipends for parents during long hospital stays.
  - Facilitate skill-building workshops for caregivers staying near hospitals, so they can earn while accompanying their child.

5. Partnerships and Systemic Integration

- To scale impact, Iksha should:
  - Align with government health schemes (like Ayushman Bharat, state cancer support programs) for cost-sharing.

- Build partnerships with corporate CSR donors to fund travel, hostels, and scholarships.
- Collaborate with NGOs that specialize in nutrition, counselling, and community awareness to provide wraparound services.

In the short term, Iksha Foundation can make immediate improvements by covering medicine and food costs, strengthening counselling, and building early awareness through health workers. These measures require relatively modest investments but will significantly reduce the daily struggles of families.

In the long term, travel tie-ups, patient hostels, educational scholarships, and livelihood support can create a holistic support ecosystem around treatment. With CSR and government partnerships, these initiatives are achievable and will prevent families from falling into debt, despair, or misinformation-driven treatment dropouts.

Conclusion

The evaluation of Iksha Foundation's intervention for children affected by retinoblastoma highlights the depth of its contribution to saving lives, preserving vision, and restoring dignity among some of the most vulnerable families in India. The program's ability to combine financial assistance with timely medical access has proven to be transformative, particularly for households living on daily wages or modest incomes who would otherwise have been unable to sustain the prohibitive costs of advanced oncology treatment. For these families, Iksha's support was not simply an aid mechanism but the decisive factor that enabled them to choose life-saving care over hopelessness and abandonment of treatment.

What emerges clearly from the analysis is that the intervention was not only relevant to the immediate crisis families faced but also responsive to their long-term needs. Parents often entered the health system with little to no awareness of retinoblastoma, confused by vague diagnoses and terrified by the prospect of losing their child's eyesight or life. The Foundation stepped into this critical juncture to provide clarity, reassurance, and the financial security necessary to pursue specialized treatment. In doing so, it filled gaps left by both public health services and private medical systems, acting as a bridge between families and tertiary-level oncology care.

The program's impact extended beyond survival to the restoration of normalcy in children's lives. Stories of children returning to school, playing with peers, and regaining the energy of childhood illustrate how Iksha's intervention redefined the trajectories of families who once feared permanent disability or loss. For caregivers, the relief was equally profound. They spoke of moving from despair and debt to cautious optimism, of finding courage in the guidance offered by Foundation staff, and of gaining a renewed sense of dignity when their children were no longer viewed with pity or stigma. These testimonies underscore that the true impact of the program lies not only in the medical outcomes it achieved but also in the hope and confidence it instilled within entire families and communities.

At the same time, the evaluation reveals that the struggle against retinoblastoma is not confined to the hospital walls. Families continued to bear heavy burdens related to travel, accommodation, food, and non-hospital medicines—expenses that repeatedly pushed them into debt despite the full coverage of core treatment costs. The journey to specialized centers often meant long nights in trains, costly rentals near hospitals, and weeks away from home, further eroding already fragile livelihoods. Emotional distress compounded these material difficulties, with parents describing feelings of helplessness, fear of relapse, and anxiety over their children's futures. In some cases, misinformation, fear of invasive procedures, or limited counselling led to delays or interruptions in treatment. These realities highlight that while Iksha has addressed the medical dimension of retinoblastoma with remarkable effectiveness, the broader socio-economic and psychological dimensions require continued and integrated attention.

The evaluation also points to the coherence of Iksha's role in complementing hospitals by ensuring that families could access and sustain treatment, but it brings into focus the need for deeper partnerships with government programs, NGOs, and CSR donors. Greater integration with existing welfare schemes and support networks would allow for a more holistic approach—one that

encompasses travel, lodging, nutrition, counselling, education, and livelihood support alongside medical treatment. Such convergence would not only enhance the sustainability of outcomes but also reduce the overdependence of families on a single source of external aid.

Ultimately, the intervention stands as evidence that well-designed, targeted support can overcome barriers of poverty, distance, and systemic neglect that too often decide the fate of children born into underprivileged families. The fact that the Foundation, with the support of CSR funding, was able to reach more than four times its original target and provide assistance to 227 children within just 18 months demonstrates both the urgency of the need and the scalability of the solution. It shows that when resources are strategically directed, lives can be saved at scale, awareness can spread through communities, and families once burdened by despair can envision a future of possibility for their children.

Iksha Foundation's intervention has gone beyond the provision of financial aid—it has created a safety net where none existed, given voice to families who once felt powerless, and generated ripple effects of awareness and resilience across multiple states. Yet, the findings also remind us that the fight against retinoblastoma cannot be won by medical treatment alone. It requires holistic, sustained, and collaborative support systems that recognize the socio-economic realities of families and address the full spectrum of challenges they face. By building on its achievements and forging stronger partnerships, Iksha Foundation has the opportunity not only to continue saving lives but also to create a comprehensive model of care that ensures no child is denied survival or a dignified future because of where they are born or how much their family earns.

Annexures – Case Stories

Case Story: 1

Location: Talegaon Dabhade, Pune
Child's Age: 8 years
Respondent: Mother

Before the Program

When her son was just two months old, his mother noticed a strange reflection in his eye — "like a cat's eye" whenever she fed him. Concerned, she rushed to a local retina specialist, who quickly referred them to Hyderabad. For the family, earning barely ₹10,000–15,000 a month from small, irregular work, the news was devastating.

The cost of chemotherapy, laser treatment, and scans was beyond their imagination. "Our economic condition was not such that every time we could pay fifteen thousand, twenty thousand, twenty-five thousand rupees—that much the bills used to be," the mother recalled. Local doctors only added to the anxiety by warning of the need for eye removal. The family was terrified, uncertain, and unable to see how their child could survive.

After the Program

Through hospital referrals, the family connected with Iksha Foundation and Pramita madam (name changed), who assured them that financial support would be available. Soon, their child began treatment in Hyderabad and later in Pune. The Foundation covered all hospital expenses for chemotherapy and laser procedures — six rounds of chemotherapy and multiple laser sessions were completed without interruption.

"We did it at zero payment. Without Iksha, it would have been impossible," the mother said. Although the family still bore costs for medicines, food, and accommodation, the heaviest burden — hospital treatment — was lifted.

Beyond treatment, the Foundation's humane touch made a difference. "Every year on his birthday, they also sent gifts. It may look small, but it meant a lot for us," she shared, remembering how the gesture made her feel supported even far from home.

Change

Today, the child is eight years old, healthy, and attends regular six-monthly follow-ups. His vision in one eye is blurred, but he attends school and plays like other children. The family feels reassured that no complications have arisen since treatment began.

Emotionally, the journey has been transformative. From nights of fear and uncertainty — "we were always worried what will happen now" — the mother now feels confident and hopeful. She has become an advocate for others, encouraging parents in the hospital: *"Don't worry, go to Pramila madam, your work will be done."*

Looking to the future, the family still worries about the genetic risks, since their child tested positive, and they cannot afford further genetic testing. Yet they express deep gratitude for the chance their son has been given - survival, dignity, and a second chance at childhood.

"Iksha Foundation gave my son his life back. Without them, we would not be here today."

Case Story: 2

Location: Tanhaji Nagar, Pimpri Chinchwad, Pune
Child's Age: 8 years (female)
Respondent: Mother

Before the Program

The first sign of trouble appeared when the child was 11 months old. While playing, a spoon accidentally hit her eye — and soon the entire eye turned white. At first, her mother thought it might be the result of the injury, but further consultation revealed something more serious.

The family, earning about ₹15,000 per month through both parents' jobs, was unprepared for the reality of a cancer diagnosis. They first went to Birla Hospital and were referred to Desai Hospital in Pune. Treatment began there, but the family worried about how they would sustain the costs of chemotherapy, laser therapy, and follow-up tests over many years. *"Anyway, we are a middle-class family, so from where could we bring so much money? One salary of fifteen thousand—how do we run the house and also pay hospital bills?"* the mother explained.

At this stage, borrowing money from relatives and small loans became unavoidable. The stress of treatment expenses and lost wages from taking hospital leave weighed heavily on the household.

After the Program

The family came into contact with **Iksha Foundation** during chemotherapy sessions at Bharati Hospital. At first, the mother believed Iksha only provided gifts for children to keep their spirits high. But she later learned that all hospital costs — chemotherapy, surgery, tests, and even food during hospital stays — were being fully covered through Iksha's support.

Her daughter underwent **18 rounds of chemotherapy** (15 initially, followed by 3 more), after which laser treatment was continued. "**Earlier we had to spend, but now we don't have to spend anything. Everything is free,**" she said with relief. Only some outside medicines during laser treatment had to be paid by the family.

The support went beyond money. Iksha's presence in the hospital gave families reassurance that they were not alone. The mother recalled, *"When we were admitted, sir from Iksha told us they give gifts to children, so they feel happy. That encouragement meant a lot to us."*

Change

Today, the child is 8 years old. The tumors have reduced, and her health has improved significantly. She continues with regular follow-up check-ups, and her parents ensure that no appointment is missed. The mother explained proudly: *"We go to Chinchwad in the morning and return by evening. On that day we take leave from work, but we never miss it."*

The financial relief provided by Iksha Foundation transformed the family's outlook. From being anxious about survival and treatment costs, they now feel hopeful about their daughter's future. While they still worry about her education and long-term opportunities, they are determined to provide her with the best possible life.

Reflecting on their journey, the mother expressed her gratitude: *"If we had not got the help, then maybe we could not have managed so much expense. Whatever we got was very good. Iksha Foundation has supported us in ways we never imagined."*

Case Story: 3

Location: Narhe Dhayari Road, Pune, Maharashtra
Child's Age: 9 years (female, one of triplets)
Respondent: Father

Before the Program

When their daughter turned one year old, her parents noticed a strange white reflection in her eye during her birthday celebrations. At first, they assumed it was harmless, but photographs showed a red-and-white glow that alarmed them. They rushed to Navle Hospital in Pune, where doctors immediately referred them to Hyderabad's Centre for Sight.

The diagnosis was devastating — retinoblastoma at stage four. Doctors warned that treatment would be expensive and difficult, and that there was no guarantee of vision recovery. The father recalled, *"They told us this is fourth stage, it won't recover quickly. We got very scared. In our family, such a thing had never happened before."*

As a farmer earning ₹15,000–20,000 a month and the sole breadwinner for a family of five, he could not imagine how to bear such expenses. He borrowed nearly ₹1 lakh from relatives to make the first trip to Hyderabad. Emotional stress compounded the financial burden: *"Actually, we became emotionally weak. People kept saying 'this happens, that happens' and we got even more scared."*

After the Program

At Hyderabad, the family was connected to Iksha Foundation, who stepped in to cover the full cost of hospital treatment. This included chemotherapy, laser procedures, and diagnostic tests. The father said, *"From the heart, I am very thankful, because I had lost all hope. I didn't even have the capacity to do this, but a lot of help happened."*

Iksha also guided them on travel support through railway concessions, although arranging tickets remained challenging due to time off work. Still, the father emphasized that without Iksha's financial coverage, his daughter's treatment would not have been possible. *"Only the travel was mine, rest everything Iksha Foundation managed for me."*

His daughter underwent 6–7 cycles of chemotherapy and laser treatment. Unlike many cases, she did not require surgery or eye removal, which was a huge relief for the family. Follow-up visits, initially every month and now every six months, continue to be covered, ensuring continuity of care. Even during the COVID-19 pandemic, when travel was disrupted, the Foundation helped the family manage delayed appointments.

Change

Today, the girl is 9 years old, studying in Class 3, and living a normal childhood. Her vision remains limited — she cannot see far, but she can recognize objects nearby. The father explained proudly, *"When we show her something nearby, if she closes one eye, then with the other she can see lightly. She understands whether it is a mobile or a book."*

The family's journey has been one of resilience and gratitude. From the fear of losing their child's eye and life, they now have hope and stability. The father had to leave work for 6–7 months during treatment, but with Iksha's intervention, he managed to restart his livelihood while ensuring his daughter's care.

Looking back, he sees Iksha's role as life-changing: *"If the Foundation had not supported us, maybe we could not have managed so much expense. My daughter has started seeing a little, and for us, that is everything."*

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