

LEARNING, INNOVATION AND RESEARCH AGENDA USAID CHILD BLINDNESS PROGRAM



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LEARNING, INNOVATION AND RESEARCH AGENDA

USAID CHILD BLINDNESS PROGRAM

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DISCLAIMER

The author's views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

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ACRONYMS

- AAPOS American Association of Pediatric Ophthalmology and Strabismus
- CBP Child Blindness Program
- CoC Continuum of Care
- IAPB International Agency for the Prevention of Blindness
- ICEH International Centre for Eye Health
- IEF International Eye Foundation
- PGRD Partners for Global Research and Development
- ROP Retinopathy of Prematurity
- RFA Request for Applications
- SES Socio-economic Status
- TAG Technical Advisory Group
- USAID United States Agency for International Development

INTRODUCTION

The United States Agency for International Development's (USAID) Child Blindness Program (CBP) is part of the global effort to reduce blindness and visual impairment in children. The primary goals of CBP are to:

- 1) Increase the number of children provided with quality eye care services in underserved communities around the world.
- 2) Expand global knowledge of pediatric eye care through innovation and the implementation of best practices.

CBP developed this Learning, Innovation and Research Agenda (Research Agenda) based on the latest scientific and programmatic information available in the field of pediatric eye care. The Research Agenda draws on data from published sources, evidence from field programs, information from key international organizations (such as the International Agency for the Prevention of Blindness, the International Centre for Eye Health and the American Association of Pediatric Ophthalmology and Strabismus), as well as the expert guidance of CBP's Senior Advisors and Technical Advisory Group (TAG).

The Research Agenda presents fundamental considerations in the delivery of pediatric eye care and highlights current knowledge gaps within the field. Addressing these gaps through further research, new partnerships and the development of potentially catalytic approaches will make significant and meaningful contributions towards the treatment of visual impairment and the reduction of childhood blindness.

BACKGROUND

Delivering pediatric eye care is complex in all settings, but it is essential to avoid preventable and treatable childhood blindness. Pediatric care is highly specialized and is especially challenging in the context of the developing world. CBP emphasizes the need to treat a child within a fully established referral network. The child must enter a comprehensive service delivery system that integrates the identification of visual impairment with referral, treatment and rehabilitation. Providing the full range of services in ophthalmology and optometry is an essential part of all CBP projects and activities.

A summary of the basic considerations and existing circumstances, as assessed by CBP in the delivery of pediatric eye care are noted below:

• The Continuum of Care (CoC) must be present.

The CoC is a best practice that ensures a child has access to all the services s/he may need for her/his care. Every point in the CoC is critical. Without the availability of all the services needed, the child is not likely to achieve maximum visual potential. Projects may provide all of these services in-house or document the linkages that exist with other service providers to maintain the continuum. Service elements that must be in place include: 1) identification; 2) referral; 3) appropriate management (medical, surgical, optical, low vision care); 4) follow up; and 5) rehabilitation and education.

- <u>Highly skilled sub-specialty trained pediatric ophthalmologists must be available.</u> The number of pediatric ophthalmologists in the world is very small. Most developing countries face a chronic shortage, or complete lack, of these sub-specialists. Availability of needed pediatric ophthalmologists requires that those ophthalmologists with the expressed commitment to this field are trained at an appropriate facility with the needed equipment and supplies. Reimbursements may be required to retain the specialists in the country requiring their services. Outreach and transport to a central facility are required to maintain patient volume and to ensure services are available to the children in most need.
- <u>A team of specialized clinical staff to support the ophthalmologist is needed.</u> The ophthalmologist cannot function on his/her own without specialty pediatric staff to achieve a child's best possible vision. Clinical staff include: a) orthoptists to measure strabismus (squint); b) specialized anesthetists and nurses to participate during surgery; and c) optometrists and low vision therapists to provide eyeglasses and/or low vision devices after surgery. Non-clinical staff such as screeners, counselors and equipment technicians, are also important members of the team.
- <u>Careful consideration to the high cost of services must be made.</u>
 Due to the specialized nature of pediatric eye care, treatment can be costly. Administrators must be creative and develop pricing structures that are attractive to the largest number of healthcare consumers in order to maximize the collection of funds. In many places this has meant the cross-subsidization of pediatric ophthalmic services through other services that generate surplus income, reimbursements from the government and/or revenue from philanthropic sources.
- Eyeglasses (refractive error) programs can only be successful with the understanding of the complexity of delivery and wear of spectacles.

 High quality and effective acrossing for visual impairment (i.e. parting out these with an

High quality and effective screening for visual impairment (i.e. sorting out those with an actual problem without missing those who need care) is imperative. The delivery of eyeglasses for those with refractive error and the associated process to ensure that children with clinical conditions reach medical care can be problematic. It cannot be undertaken without the existence of a quality referral network along with systems that promote the use of eye care services. Children need to have access to refraction, clinical evaluation and care, as well as a source of spectacles.

DIMENSIONS OF THE CBP LEARNING, INNOVATION AND RESEARCH AGENDA

The following seven areas represent the considerations and suggestions as well as the questions and identified gaps in services that are of particular interest to CBP. Projects are <u>not</u> <u>limited</u> to these areas. Rather, this document is meant to complement CBP's goals as laid out in the Agenda's introduction. Neither is the information restricted to Innovation Projects. The areas noted below may be addressed independently as a stand-alone research project, operational research embedded within a larger project or a holistic approach with a mixture of the below integrated in the design of the proposed project.

1. Innovative Practices and Technologies

Recent technologies and the rethinking of mechanisms to deliver healthcare have created a paradigm shift in awareness, communications, data transfer, affordability, convenience and knowledge sharing. Current innovative practices and technologies include, but are not limited to: utilization of mobile devices and cell phones, application of telemedicine, creation and identification of new sources for equipment and supplies, development of new pricing structures, and the implementation of new screening approaches.

Considerations and Suggestions

• Applications providing innovative solutions to address current gaps in services, increase the quantity of children served, reduce costs, simplify training, or improve the quality of pediatric eye care are of interest.

Questions and Knowledge Gaps

- What innovation(s) can be applied to facilitate diagnosis?
- Are there innovations that would allow underserved populations to access care they otherwise would not receive?
- How can the innovation(s) be applied to facilitate the use of services?
- Is there a role for innovative strategies or technologies to increase the use of follow-on services such as the availability of low vision devices for children?

2. Retinopathy of Prematurity

As the survival of premature infants has increased, there has been a corresponding increase in visual loss from retinopathy of prematurity (ROP). CBP recognizes the importance and urgency of keeping pace with this growing problem to ensure children do not unnecessarily endure a lifetime of blindness. CBP aims to contribute to better prevention, early and timely diagnosis and effective treatment.

Considerations and Suggestions

- Telemedicine is emerging as a key strategy to address the lack of specialists required to screen preterm babies in developing countries. CBP has funded several innovative telemedicine projects that are expected to contribute to lessons learned and best practices in this emerging approach.
- National policies and guidelines that provide recommendations for ROP prevention, screening and treatment are an essential step in guiding the identification and care of at-risk infants. CBP encourages applications proposing the creation of national policies and guidelines. Applications may be from individual countries or from a group of countries across a region.
- National policies and guidelines are often not adequately disseminated to those who should implement them, nor are they adequately followed. CBP will support innovative approaches that address this gap and promote best practices, such as training "implementation teams" at neonatal intensive-care unit level.

3. Eyeglasses (Refractive Error Programs)

CBP has traditionally funded programs to screen, refer and provide eyeglasses to children. However, applications in this category have not always been clear about referral networks and how they are structured to carry out a project. Many applications missed opportunities to generate revenue through the delivery of eyeglasses and opportunities to increase the use of glasses by offering them at the time of the screening.

Considerations and Suggestions

- Detail a reliable CoC either independently through the applicant's eye care network or through partner organization(s).
- Examine the potential for cost recovery. While it will not always be achievable, the ability to recoup funds should always be carefully considered.
- Determine whether providing eyeglasses on-site will increase uptake and wear.

4. Primary Eye Care

Primary eye care for children is a neglected area that could be highly effective for early identification, initial treatment and referral of children with eye conditions. For example, newborns are routinely checked for conditions such as club foot, hip disorders, hearing impairment and heart defects, but the eyes are generally not a part of this initial examination. In addition, most primary health care for young children focuses on systemic conditions such as fever and diarrhea, yet eye conditions are not included.

Considerations and Suggestions

- Primary eye care for children needs to be integrated into policies and practices for newborn examination and into primary health care for children to be scalable and sustainable.
- CBP seeks applications that assess primary eye care for children.

Questions and Knowledge Gaps

- How effective is the integration of eye examination into existing practices for routine newborn examination?
- How effective is the integration of eye care into existing practices for primary health care for young children?
- How can primary eye care best be integrated within existing services for young children and their mothers?
- How might advocacy or other efforts bring about the necessary resources and support to ensure the long-term integration of this crucial assessment?

5. Capacity Building and Human Resources

Capacity building is critical throughout the healthcare field and is of particular importance in pediatric eye care. However, hiring, training and retaining a sub-speciality team can be challenging. Personnel need highly specialized skills, and once trained, strategies must be put in place to ensure on-going availability.

The reality of the local context does not always allow for the presence of pediatric ophthalmologists and expert staff even in sophisticated areas such as main cities. Human resources need to be appropriately organized to accommodate any given setting. For example, clinicians such as "pediatric oriented ophthalmologists" may take the place of their more highly trained counterparts, or technicians may be trained to fill gaps in services to provide linkages to doctors or tertiary care hospitals. Alternative staffing can be made available through proper training and has been shown to be effective.

Considerations and Suggestions

• CBP seeks applications that test approaches to attract, train and retain clinical personnel at all levels.

Questions and Knowledge Gaps

- What strategies best incentivize pediatric eye care clinicians to provide services to vulnerable populations?
- What strategies work best to ensure retention of qualified non-clinical staff?
- What are the most effective strategies for delivering and supervising pediatric eye care activities?

6. Sustainability and Cost Effectiveness

Understanding how to deliver pediatric eye care at a reasonable cost is critically important. Much of pediatric eye care is, by nature, costly. It is therefore important to understand costs for various strategies to ensure the greatest number of children receive eye care at an affordable cost.

Questions and Knowledge Gaps

- What strategies are most cost effective for identifying children with eye conditions when budgets are limited?
- Are there ways to lower the direct cost of eye care to the patient and his/her family?

- What is the population's willingness to pay for child eye care and what pricing maximizes participation?
- Are there models for the delivery of services that are completely financially self-sustainable?
- What models or strategies facilitate and promote cross-subsidization to ensure children with no financial resources have access to eye care?

7. Continuum of Care

As previously noted and as clearly detailed in the RFA, the CoC is considered essential to every project supported by CBP. Application grading criteria are based in part on demonstration of the CoC.

Questions and Knowledge Gaps

- How can implementing organizations find quality partners to ensure that the full array of services needed for the CoC in pediatric eye care is in place?
- If the CoC is already in place (either internally or with partners) how can organizations evaluate the quality and effectiveness of services provided by each of the partners and by the CoC as a whole?
- What strategies are most effective to ensure families take children in need of services for treatment? Do these strategies need to be different based on location, such as rural versus urban?
- Can counselors or other staff increase acceptance by families for eye care for their children?
- What is the role of Child Eye Health Tertiary Care Facilities and how can they best be organized and/or strategically placed for maximum value, including providing services for underserved populations?

For further information on the USAID Child Blindness Program and access to copies of this publication, please visit <u>www.usaid.gov/childblindness</u>.

USAID programs in global health represent the commitment and determination of the U.S. government to prevent suffering, save lives, and create a brighter future for families in the developing world. USAID's commitment to improving global health includes confronting global health challenges, such as child blindness, through improving the quality, availability, and use of essential health services.

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