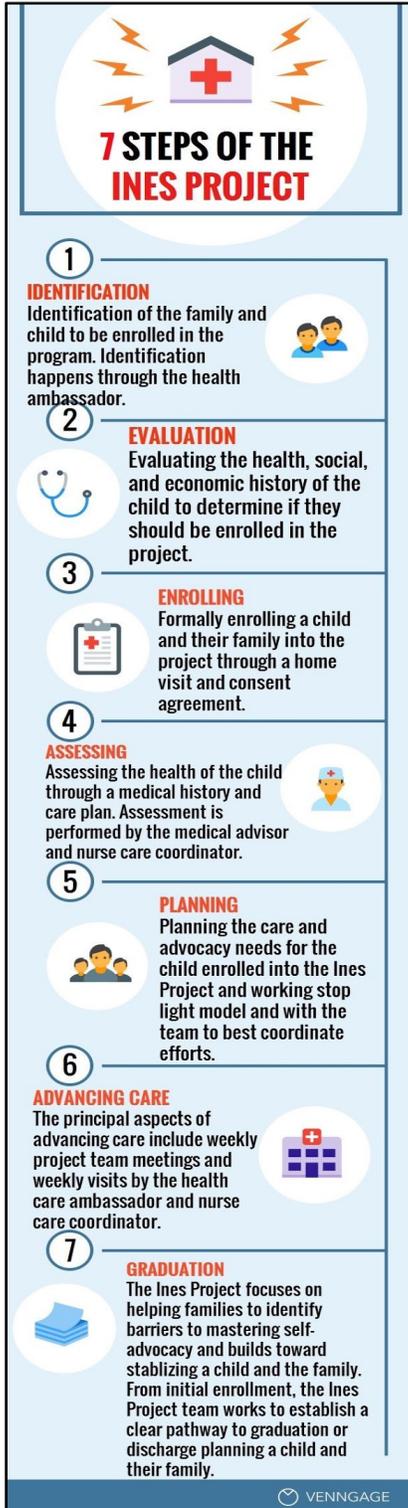


## **T**he Ines Project for Children Living with a Disability



**Health Bridges International:** Health Bridges International, Inc. (HBI) is a U.S. based non-governmental organization dedicated to building bridges of collaboration within extremely impoverished and marginalized communities. We are dedicated to sustainable development - grounded in Four Pillars: training, consulting, connecting, and serving. HBI connects resource to need through programs and projects that empower local change agents, in their own countries with their own ideas.

**Background:** The *Ines Project* began when the founder and Executive Director of HBI, met a little girl named Ines. Ines has an incurable, life-threatening skin disease. She lives in extreme poverty, and despite the best efforts of her mother, was previously unable to access adequate medical care. Ines is a disabled and medically fragile child with a complex medical condition that requires multiple health care providers, social services, and specialists - a complete care team to assist in daily living. This coordinated care can be lifesaving, but exponentially more difficult to access while living in the experience of extreme poverty. HBI has helped Ines and her family not only to manage her condition, but also to thrive in an adverse environment.

There are hundreds of thousands of children around the world with complex medical, developmental and disability challenges. In many parts of the developing and middle-income world, healthcare services are available to support medically fragile children, but sadly, many children are unable to access this system fully or not at all. Therefore, the overall care of these children is substandard due to a host of logistical, financial, and cultural obstacles. This is precisely where the *Ines Project* intervenes. The goal of the *Ines Project* is to improve the health and wellbeing of medically fragile children and their families living in poverty through educating and training families to better access health services and more comprehensive self-advocate for their long-term supportive service needs.

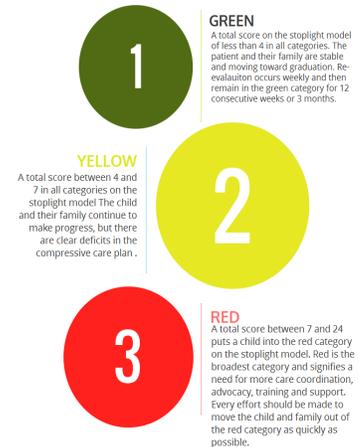
**Project Focus:** The *Ines Project* does not provide unsustainable direct care, but rather focuses on addressing the unique challenges and complex situations that prevent people to connect with the care services they need. The *Ines Project* helps a family gain the knowledge and skills they need to better self-advocate and effectively navigate health systems. The *Ines Project* achieves this success through advocacy, education, and targeted resource allocation facilitated by a team of well-trained care providers. The care team consists of Health Ambassadors (local community/church leaders), a supervising Nursing Care Coordinator, and a Consulting Physician. The holistic team identifies specific deficits in a family's knowledge in order to improve knowledge and advance skills.

**Holistic Care:** The *Ines Project* team works closely with each family living with a disabled child to create individual health plans and guide them towards appropriate solutions. Families are able to regain wholeness in the lives of their children and in the connections within their community. The *Ines Project* provides the knowledge and skills people need to build their own futures.

**T**racking Progress: To support ongoing project improvement, HBI developed a formative evaluation plan for the *Ines Project*. The plan includes easy-to-track project metrics, an integrated Microsoft Access database, and survey and focus group protocols. One of the key evaluation tools used to help quantify the impact of the *Ines Project*, is HBI's Child Crisis Indicator, represented by a "stoplight." The stoplight allows a project team to define the advocacy and care delivery needs of each child and family enrolled in the project. The stoplight helps teams determine the best strategies for effectively working with families to stabilize health needs and build long-term care plans. The goal for each family is improving their situation. The project relies on key Informant Interviews to gauge perception of progress and the development of self-advocacy knowledge and skills.

**Project Manual:** In the fall of 2015, HBI developed a comprehensive manual to assist in scaling the *Ines Project* to new locations and impoverished communities. The *Ines Project* manual provides a step-by-step roadmap to help churches, community-based organizations, and governments implement and operate an *Ines Project* themselves. The manual includes a training curriculum for teaching self-advocacy and health systems navigation and a number of helpful documents to support the ongoing operation of an *Ines Project*.

## Stoplight



**Economic Impact:** The cost of caring for a medically fragile child over their lifetime can run in excess of hundreds of thousands of dollars. In the developing and middle-income world, much of the cost burden is the responsibility of the family. Lost workdays, challenges coordinating appointments, and late-night visits to emergency care services place tremendous stress on parents and family members, as well as the child. Through care coordination, advancing self-advocacy skills, and health system navigation knowledge, the *Ines Project* has the potential to dramatically reduce costs. Evaluation data drawn from over 100 patients in the *Ines Project* demonstrate a marked reduction in unnecessary medical visits, missed work days, and hospitalizations. Therefore, stabilizing medical conditions and improving quality of life.

**Project Sustainability:** Through seed funding in 2012, HBI implemented the *Ines Project* in an impoverished community on the outskirts of Lima, Perú. The project recruited and trained Health Ambassadors from local communities. Within a few

months, the program enrolled 50 children – all with unique, complex medical conditions. After years of project implementation, formative evaluation and project improvement, HBI developed the program level materials need to expand the *Ines Project* to new areas. To support the development, implementation, and ongoing monitoring future *Ines Projects*, HBI has created a suite of technical assistance products, training materials, and a range of consulting services. The goal of the *Ines Project* is improving the lives of medically fragile children – and HBI has the tools and resources to help organizations, communities, and faith-based institutions implement their own projects.

**Starting an Ines Project:** Churches, community organizations, and government agencies are uniquely positioned to start their own *Ines Project*. HBI offers a roadmap for connecting the talents, skills and resources of the church or community-based organizations in order to better the lives of children living with complex medical, developmental or disability challenges. HBI can help churches, community organizations, and government agencies to create a comprehensive project to support families in learning the knowledge and skills they need to advance their own lives. To learn more about starting an *Ines Project*, including cost requirements and project details - contact Health Bridges International at [info@HBInt.org](mailto:info@HBInt.org)