A Step-by-Step Guide to Operating an Ines Project

Health Bridges International

The Ines Project for Medically Fragile Children

The Commitment

Our Outcomes

THE INES PROJECT

Care Coordination for Medically Fragile Children

A Manual for Program Development and Implementation

Director's Forward

The process of developing, implementing and sustaining a model project can be overwhelming. From the challenges of resource allocation to the ever present need for sustainable financing, project development is a complicated undertaking. We, the staff and volunteers of Health Bridges International, have spent years building the infrastructure that is the Ines Project. We've learned just as much from the challenges and pitfalls as we have from the triumphs of our work. To aid and support the advancement of the model program we call the Ines Project, we have put together this manual. Our hope is that any organization – governmental, non-governmental, and faith-based – can take this manual and implement their own program to aid families with medically fragile children.

We recognize that any new endeavor requires support and to this end, HBI is available to help with technical assistance and training. We are committed to create better outcomes for families living in extreme poverty and challenged by the day-to-day efforts of advocating for medically fragile children.

We firmly believe, and our research is demonstrating, that the key to better health outcomes is better care coordination; and this is especially true for children with medically complex conditions living in extreme poverty. We have had the honor of working with a number of such families and their wisdom and leadership has helped to shape this manual and the Ines Project.

If you have any questions about how HBI can support efforts to plan for and implement a care coordination program for medically fragile children in your community – please feel free to contact us at: info@HBInt.org

Thank you for the work that you are doing to make the world a better place for people living in extreme poverty. Together I know we can change the world; and perhaps the best place to start is through better care coordination for medically fragile children.

Dr. Wayne A. Centrone
Executive Director, Health Bridges International

Acknowledgements
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A special thanks to the Anglican Church of Peru for their leadership, guidance, and support of this project – especially Ms. Fanny and Reverend Pat Blanchard. A very special thanks to all of the families and children who have participated in the Ines Project – they have shown us that true collaboration is a process that requires ongoing communication and considerable respect.

Finally, the Ines Project nor this manual would not be possible without the leadership and dedication of Dr. Townsend Cooper.

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Why this Manual?

The following manual is designed to be a "how to" roadmap for implementing and sustaining a care coordination program for medically fragile children. The manual is written for administrators and leaders in non-governmental organization, government agency or program and faith-based groups that work with children and their families living in poverty.

Over the past couple of years, HBI has received a growing number of requests for the "manual" for the Ines Project. Community based organizations have a strong interest in using the model to advance their own care coordination programs and projects for medically fragile children. With this in mind, we created this manual. We recognize that every organization will have cultural and economic challenges unique to your own with implementation of the model. As such, we've developed this manual with a number of resources and resources. We are also are available to help with the design and implementation of projects and invite requests for support.

The basic outline for developing and implementing an Ines Project in your community is referenced below –

Who is Health Bridges International?

Health Bridges International (http://hbint.org) works to build bridges of collaboration within extremely impoverished and marginalized communities. We are dedicated to sustainability and the development of projects that offer long-term change. To this end, Health Bridges International (HBI) connects resources to needs through programs and projects that build local level change agents. The work of HBI is grounded in our Four Pillars of service: training, consulting, connecting and serving. HBI is committed to changing the world through collaboration. The Mission of HBI is the facilitation of sustainable improvements in the health of underserved communities through collaboration.

Disclaimer

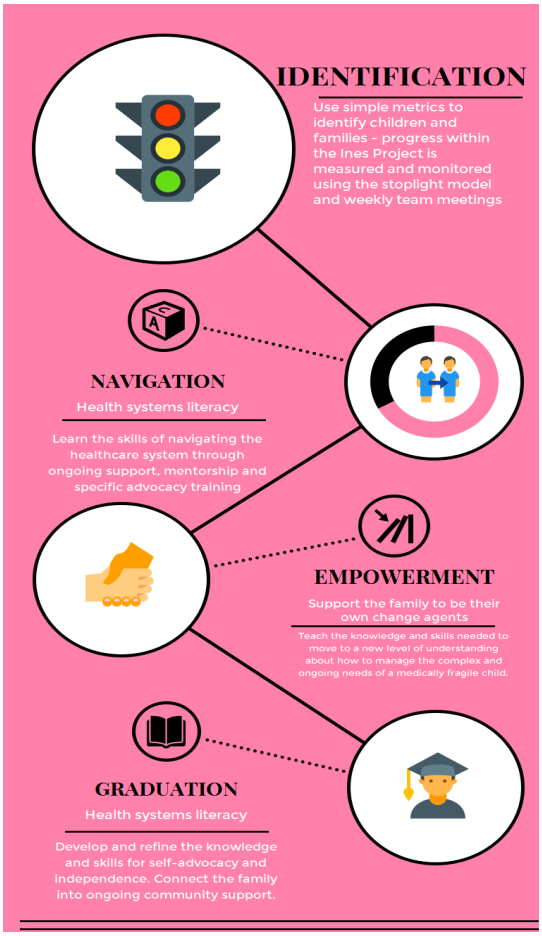
This manual represents Health Bridges International's (HBI) interpretations of the many steps required to implement an Ines Project model. The manual itself does not impose legally enforceable rights and obligations, but sets forth a standard operating guideline or agency practice that HBI staff and employees follow to be consistent, fair, and equitable in the implementation of the Ines Project.

HBI undertook substantial efforts to ensure that this manual incorporated all applicable policy and guidance. HBI will review changes to standard of care recommendations, World Health Organization other global agency guidance that impacts the implementation of the project and issue updates to this manual as warranted.

The Ines Project

A Step-by-Step Guide to Implementation

INTRODUCTION



Why this manual?

The following manual is designed to be a "how to" roadmap for implementing and sustaining a care coordination program for medically fragile children. The manual is written for administrators and leaders in non-governmental organizations, government agency or programs and faith-based groups that work with children and their families living in poverty and the staff that work on the day-to-day operations of an Ines Project.

The material in this manual provides a brief description of the Ines Project to better orient and help set the context for the model we've developed to help with care coordination for medically fragile children. The Ines Project, the name for the model care coordination program Health Bridges International (HBI) created, started with a *simple* question, "How do you care for medically fragile children in resource-poor environments where educational attainment and economic viability are very low?"

In response to this compelling question, we developed the Ines Project for Medically Fragile Children. Working in collaboration with the Anglican Church of Perú, HBI initiated a care coordination program in four urban slums of Lima in the spring of 2013. The project, drawing from the Patient-centered Medical Home model (https://www.pcpcc.org/about/medical-home), is a team-based approach that focuses on helping families learn to advocate for their needs. It creates individual health and advocacy plans for medically fragile children who live in low resource areas. The team provides care coordination, health education, healthcare advocacy, and daily planning to each family. These relationships contribute to the rapid improvement in the quality of life for each medically fragile child and their families, as well as increased economic efficiency for the family, community, and health care system as a whole. The primary objective of the Ines Project is not to provide care, but to advocate for services. The model works closely with local community leaders, our team pulls together resources, identifies opportunities, and supports families seeking the knowledge and skills they need to be self-advocates.

Over the past couple of years, HBI has received a growing number of requests for the "manual" for the Ines Project. Community based organizations have a strong interest in using the model to advance their own care coordination programs and projects for medically fragile children. With this in mind, we created this manual. We recognize that there will be subtle differences between how Ines Projects are organized and implemented. As such, we've developed this manual with a number of resources. We hope you find the material in this manual helpful to the work of planning, implementing and operating an Ines Project for Medically Fragile Children and their families.

General overview of the Ines Project

The Ines Project for Medically Fragile Children aims to improve the health and overall wellness of economically marginalized, medically complex children and their families. The project owes its name to Ines, a child with an incurable skin condition that inspired the idea that helping families to identify the resources and knowledge they need to best support their own futures is the most effective way of supporting people living in extreme poverty with medically fragile children. The project began in 2013 through collaboration with

healthcare providers experienced in low resource community healthcare delivery. Despite the existence of a Peruvian health care system that strives to cover the basic health needs of these children, the patient's overall care is often substandard due to a host of logistical, financial and cultural obstacles. Through targeted resource allocation, education and advocacy we seek to maximize patients' appropriate utilization of the existing state health care system and work with them to learn the skills they need to be their children's own best advocates. You can view a short video that explains the core concepts of the Ines Project online at: https://youtu.be/yWyDyApN0JU

How was the project developed?

HBI began care of Ines using the traditional direct service approach, assisting Ines to purchase medication and helping the family financially. Even though Ines's condition improved, we realized this approach was not sustainable or helping the family achieve independence. Through the program, the family gained the knowledge and skills to live independently with Ines's illness. In Peru there are adequate medical resources to address the needs of medically fragile children; however, families living in extreme poverty do not recognize their right to access this system; and, in many cases, people living in extreme poverty do not know how to access the system and the system fails to provide the appropriate means. This leads to a dramatic injustice for children living in poverty with a fragile medical condition.

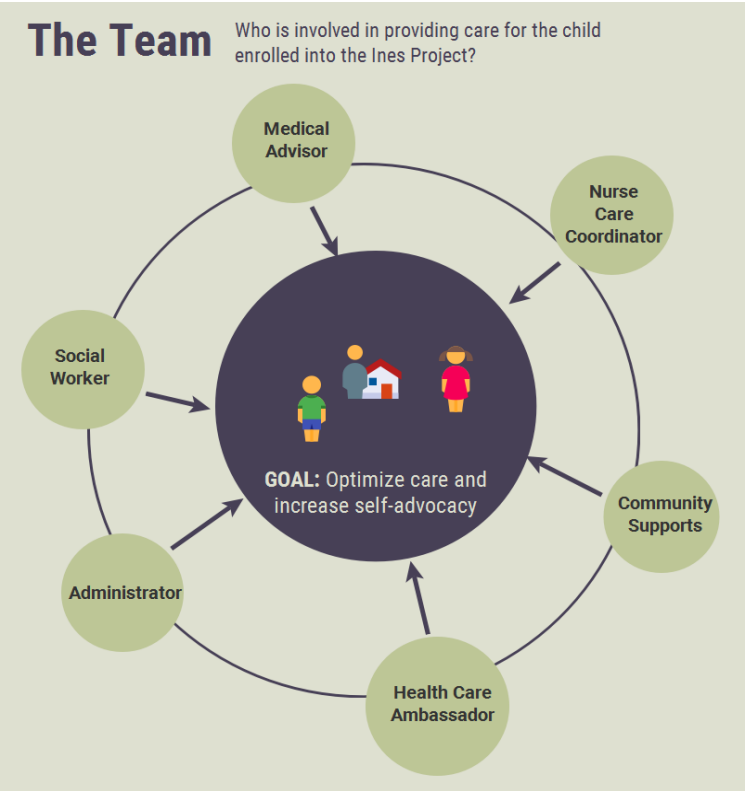
Who is enrolled in the Ines Project?

Children and families enrolled in the Ines Project have a medically fragile child and they live in extreme poverty. A medically fragile child is defined as having a chronic medical condition, an increased risk for potential medical complications, and requires ongoing support from general and specialized providers.

Why are children enrolled in the Ines Project?

The goal of the Ines Project is to help families gain the knowledge and skills they need to drive the care for their own children. Complex medical conditions require comprehensive care. Complicating factors for these children include:

- Limited access to basic support and services such as transportation, nutrition, and hygiene
- Challenges advocating in a complex health delivery system
- Geographic isolation from care delivery centers and/or programs



The following enrollment criteria (See appendix D) are used by the care coordination team, which includes a health care ambassador, a nursing care coordinator, a social worker, and a physician: **(1)** an inclusion diagnosis and/or diagnosis that interferes with independent living or grossly affects activities of daily living or age appropriate activities, **(2)** family is stratified to the 1st or 2nd lowest socioeconomic category, AND **(3)** the child is <18 years old at time of enrollment.

Who is involved in providing care for children?

In our experience, a team including a nursing care coordinator, a social worker, and a personal healthcare advocate or health ambassador (See appendix E for job descriptions of each team member) who lives in the same community, is the best mechanism for coordinating well-rounded care. The complete coordinated care team includes the following:

Project Administrator: The project administrator coordinates the logistical needs and medical record keeping for the project.

Medical Advisor: A pediatric or general medicine physician trained in the unique aspects of underserved care delivery. The medical advisor is the physician-in-charge on the Ines Project and is responsible for evaluating the medical needs of the child and training and supervising the nurse care coordinator and health ambassadors.

Nurse Care Coordinator: A nurse trained in advocacy for medically fragile children and charged with training the health ambassadors and families in the specific needs of the child.

Health Ambassador: A member of the community with a passion to help medically fragile children and their families.

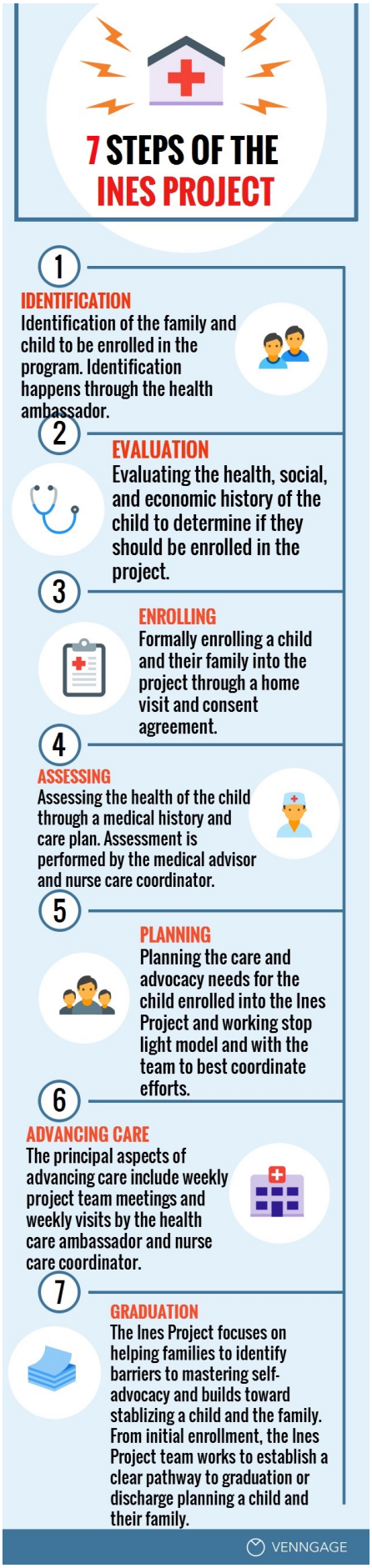
Social Worker: A licensed social worker with unique knowledge of the needs of people living in extreme poverty. The social worker evaluates the economic and social needs of the family.

How are children identified?

Initial identification of children who may benefit from enrollment in the Ines Project often comes through informal, word-of-mouth referrals. Once a child is identified, a health ambassador, working in their own community, will visit with the family and begin the assessment process. Identification of medically fragile children is completed after an initial consult with the family and an analysis of the well being of the child using a series of standardized inventories. A team, made up of the health ambassador, nurse care coordinator and medical advisor, then identify the specific deficits in the child's care and aid the family in finding the appropriate solutions, usually within the structure of the state sponsored health and social service systems. The health care ambassadors have contact with the patients through home visits and telephone check-in calls at least weekly. The nurse care coordinator attends to the patients enrolled in the project as determined by their particular needs. The medical advisor is available to work with the team around specific care issues or as a consultant to the family to support them in navigating the state sponsored health system. The goal is thus not to provide unsustainable direct medical intervention, but to provide the family with the tools to promote self-advocacy and effective navigation of the health system.

How is progress measured?

The Ines Project is a comprehensive model for helping families with medically fragile children access resources and identify the knowledge and skills to support them in moving toward greater advocacy. The Ines Project is a holistic, individualized model of care delivery utilizing a team-based approach that involves the community, the family, and the individual. The model pulls from the traditional Medical Home Model and the Individualized Health Plan and is uniquely tailored to medically fragile children in low-resource environments. To measure the impact of the project, HBI has set-up a formal evaluation that includes a number of measurable outcomes (See appendix F). Weekly data reporting from the nurse care coordinator and health ambassadors is critical to this plan.



The Ines Project utilizes the Child Status Index (See appendix A) and the stoplight tool (See appendix B) to help measure and monitor the child and families' progress as they access existing local health resources. These tools will help the team to best evaluate and monitor the health needs of the child enrolled into the project and their family. If successful, each child will graduate from the program and each family will leave with the skills and knowledge to sustain care for their medically fragile child and navigate the local health services.

PROJECT DESCRIPTION AND MEASUREMENT TOOLS

The following section provides a broad overview of the project, enrollment, instruments, and methods for monitoring and planning for discharge. It is important to correlate the information provided in this section with the additional resources provided in the Ines Project Manual.

How does the Ines project work?

There are seven steps in the identification and care of the child and family.

- **First: Identification**
  The child and family are brought to the attention of the health care ambassador, a leader in the community who has received special training in health and wellness. She/he refers the family to a nurse care coordinator who collects basic contact information and uses the Child Status Index as an evaluation tool.
- **Second: Evaluation**
  As part of the evaluation, the nurse care coordinator and the health care ambassador administer an inclusion assessment test, the Child Status Index. If after the assessment the child does not meet criteria for inclusion, the family is referred to other more appropriate health services.
- **Third: Enrolling**
  The nurse care coordinator and the health care ambassador meet with the family to explain the program and the role and expectations for the family in the Ines Project. After the enrollment checklists are completed, the child is enrolled in the program and the family is provided with a date and time for a health assessment visit from the medical advisor and nurse care coordinator.
- **Fourth: Assessing Health**
  The medical advisor and the nurse care coordinator meet with the family to take the child's comprehensive health history and perform the medical examination. As part of the initial assessment, the care team begins to formulate the steps necessary for the child's discharge from the program.
- **Fifth: Planning for Care**
  The entire care team collaborates to develop a comprehensive care plan once the child is enrolled. The comprehensive care plan includes: a complete and accurate medical diagnosis, clearly defined treatment plan including medications, supplies, equipment, and identified advocacy training for the family. The plan also includes strategies for connecting the child and family to appropriate health resources in their community.
- **Sixth: Advancing Care**
  To develop realistic next steps, the team meets weekly to assess and monitor progress using the stoplight tool. The medical advisor attends the weekly meeting and acts as the driver of the evaluation for each patient using the stoplight tool. The stoplight tool is scored each week and next steps for care, advocacy and training are defined based on the patient's classification in the stoplight tool. Between meetings, the health care ambassador visits or calls the family weekly; this may include attending the child's appointments to explain treatment plans and encourage family participation. At a minimum, the nurse care coordinator visits monthly to reinforce self-advocacy.
- **Seventh: Graduation of the Child**
  If and when the family exhibits an extended ability to advocate for the health of the child, the medical advisor and healthcare team may consider graduating the child from the program. Graduation or discharge planning includes the completion of an

inventory and meeting with the family to complete the exit interview. A patient is only considered for graduation after stabilizing as green on the stoplight tool for 12-weeks.

MEASUREMENT TOOLS: THE CHILD STATUS INDEX AND THE STOPLIGHT

The Child Status Index

We use the Child Status Index to determine whether a child meets original standards for inclusion in the Ines Project. The Child Status Index provides a framework for identifying the needs of children, creating individualized goal-directed service plans for use in monitoring the wellbeing of children and households, and program-level monitoring and planning at the local level. The Child Status Index enables assessment of a child's current needs, monitoring of changes in specific dimensions of child well being, and identification of areas of concern that may be addressed through program intervention. The Child Status Index enables the health ambassadors to gather information in the following areas:

- **Food/nutrition.** Does the child have sufficient and nutritious food at all times to grow well and to have an active and healthy life?
- **Shelter and care.** Does the child have shelter that is adequate, dry, and safe? Is there at least one adult who provides consistent love and support?
- **Protection.** Is the child safe from abuse, neglect, or exploitation? Is there adequate legal protection for the child?
- **Healthcare.** Is the child healthy? Does he/she have access to preventive and treatment health services?
- **Psychosocial.** Is the child happy and have hope for a good life? Does the child enjoy good relationships with other children and adults?
- **Education.** Is the child performing well at home, school, job training, or work and developing age appropriate knowledge and skills? Is the child receiving the education or training he/she needs to develop knowledge and skills?

The Stoplight Model

The stoplight model represents the core evaluation instrument for the Ines Project. Every week the Ines Project team fills out a stoplight metric for each child. Using the stoplight model as a measure to prioritize resource utilization on each child and understand the challenges and opportunities for best supporting the family. The stoplight model also helps to prioritize which areas of child health the team needs to focus. The stoplight model, developed through review of psychometric tools, is currently under evaluation for validation. You can watch a brief video that further explains the stoplight model online at: https://youtu.be/E8d5ah0LFbw

This model utilizes the color-coding of a stoplight (red, yellow, green) to represent the immediate and progressing health needs of the children enrolled in the Ines Project. These needs may change through time as the child progresses toward the health goals specific to diagnosis and management strategy. A critical component of the stoplight model is the weekly team meeting. The weekly meeting allows for a case review of the child and a quantitative assessment of the stoplight score. A child is ranked through objective measures and a score is calculated to designate the color of the individual patients "stoplight." Scoring is based on tabulated scores as: **Red** – a total score between 7 and 24 points, **Yellow** – a total score between 4 and 7 points, and **Green** – a total score of less that 4 points in all categories.

THE STEPS OF THE INES PROJECT

Chapter 1: Identification

Identification of the child is the first step in the series of events leading towards the coordination of care. The process of child identification occurs through the health care ambassador.

The health care ambassador may receive referrals or recommendations from another member of the community suggesting that a particular child could benefit from enrollment in the project. For example, a mother in the community or a friend or even a friend of a friend may suggest to the health care ambassador a particular child. Other times, the health care ambassador may directly observe a child in their community. For example, the health care ambassador might be at a community event or religious event and she may observe a child who appears to need special medical care. Regardless of the route of referral, children and families enrolled into the Ines Project are first identified as having health needs – and then the needs are evaluated using a structured interview and investigation process.

Chapter 2: Evaluation

Once a patient has been identified the next step is evaluating the health, social, and economic history of the child and family to determine if they should be enrolled in the project. This process includes two distinct aspects:

1. Investigation
2. Group evaluation

Investigation

When a child is identified for potential inclusion, the project administrator and the nurse care coordinator investigate the child's medical history and family history. The project administrator and the nurse care coordinator have three primary goals during the investigation: collect facts about the child, make observations about the home and family circumstances, and explain the project to the family and child. Almost always, the nurse care coordinator and the project administrator will make one or two home visits to best assess the suitability for enrolling the patient and their family into the project. To gather facts, the nurse care coordinator and project administrator use the Child Status Index. The Child Status Index is a questionnaire that guides the interview. Information gained from the Child Status Index help to guide the group evaluation, in which the team review and discuss potential patients for their suitability for inclusion in the project.

Group Evaluation

After the investigation is complete, the nurse care coordinator and project administrator present the results of the investigation – all the information they collected and observed -- to the care coordinating team. The presentation of the information may take place at a weekly care coordination meeting, at a separate meeting, or immediately in cases of an emergency. The medical advisor and the nurse care coordinator work together with the whole team including the health care ambassador, project administrator and social worker to make a judgment about whether to enroll the patient and their family into the project.

The team uses the following basic criteria to determine if the child is eligible to be enrolled in the project:

1. First, there must be a medical condition that interferes with independent living or grossly impacts activities of daily living and/or a medical diagnosis from the Ines Project's list of inclusion diagnosis.
2. Second, age appropriate activities must be clearly and markedly reduced or impeded.
3. Third, the child should come from a family ranked no higher than the two lowest socioeconomic categories as defined by the government economic listings.
4. Fourth, the child must be under 18 years of age at the time of enrollment.

Once a basic outline for project inclusion has been established, the child's age and the family's socioeconomic condition are reviewed according to the data collected through the Child Status Index. The doctor and the nurse care coordinator will decide if the child is a

medically fragile child and therefore is eligible for the project. If the child is evaluated as medically fragile as per the inclusion diagnosis of the Ines Project, and the team comes to a consensus agreement about the suitability of the patient for the project - the enrollment process begins. It is important to assure that a child eligible for enrollment has one of the inclusion diagnoses. If the diagnosis is not already established and verified in the patient's medical records, then an appointment should be established with the medical advisor to ascertain eligibility as per an inclusion diagnosis.

Chapter 3: Enrolling

The enrollment part of the project marks the moment when the Ines Project will begin providing support services. There are 2 steps the enrollment process:

1. Assuring the family understands the objectives and goals of the Ines Project and their child's enrollment into the project.
2. Conversing with the patients established caregivers (if appropriate and possible) about the project's role in the care process.
3. Formalizing the relationship with a consent document or agreement. Please see appendix F for a sample consent document.

Assuring the family understands the project and conversing with the patients established caregivers about the project's role in the care process.

The best way to enroll a child and complete the two steps in the enrollment process is to make a home visit. The enrollment process is a collaborative process focused on providing information. The health care ambassador may use the Enrollment Checklist (please see Appendix G for a sample Enrollment Checklist) to make sure that all of the important points are covered during the home visit.

First, the health care ambassador will describe the project in detail. The purpose of this conversation is to clearly describe what the project does and more importantly, what it does not. The project will collaborate with and support the family to advocate for the child and the child's health. It is important that the family knows what to expect from the project and what not to expect.

The health care ambassador should explain the following critical points: (1) the project does not provide direct medical care; (2) the project supports the family in advocating for the child through formally working to increase knowledge, advance skills and create better care linkages; (3) the project creates a comprehensive care plan for the well-being of the child; (4) the project assigns a health care ambassador to support the family while the child is enrolled in the Ines Project; (5) a medical advisor, nurse care coordinator, and project administrator will work with the family to improve the health of the child and advance the knowledge of the family; (6) during the family's time in the project, the family will learn new skills about accessing the health care system and connecting with social services and supports.

The health care ambassador should also describe the family's role in the project. Remember this is a collaborative process to improve the health of the child. The family has the most critical role in the project. The family should expect to work openly and honestly with the care team, attend appointments, keep track of important documents, and stay in contact with their health care ambassador on a regular basis. It is very important that the family stay in contact. The family should let the care team know right away if the family moves or changes the telephone number.

The family may have many questions about the project. This is the best time to answer the questions about the project. The family is an equal collaborator in the project. The health care ambassador should be prepared to answer questions the family may have and work with the medical advisor, nurse care coordinator and project administrator to assure the family recognizes the team approach of the Ines Project.

Formalizing the relationship with a consent agreement

The health care ambassador should then explain the consent agreement. This is a formal agreement that can be signed as a document or discussed and agreed upon as a Memorandum of Understanding as in the case of illiterate families. The consent agreement highlights the key points of the conversation. The consent agreement allows the project to provide support to the family. The consent agreement also gives the project permission to use information about the child and the family to improve the project, to make decisions about the future of the project, to create reports about the project, the health of the children, and the overall success of the project. If the family member or caregiver cannot sign, the family member or caregiver can make a mark observed by the health care ambassador. After enrollment, the next step is for the nurse care coordinator and medical advisor to complete a comprehensive health assessment of the child.

Chapter 4: Assessing Health

After enrollment, the medical advisor and the nurse care coordinator assess the health of the child. The medical advisor may decide that a home-based examination isn't appropriate and may select a different location for the medical exam. The medical advisor completes a comprehensive physical examination. During the exam, the medical advisor uses the Medical History and Comprehensive Care Plan document to record his or her observations about the child's health history, health status, and other important information. The purpose of the health assessment is to establish a baseline understanding of the child's health status and answer questions that will help to develop a comprehensive understanding of the patient and their families needs. The health assessment is a holistic review of the child's needs and a review of their current care. It also includes a full evaluation of the physical, emotional, mental and social challenges and constraints that prevent the patient from reaching their fullest health potential. During the assessment, the medical advisor, nurse care coordinator and program administrator will being to formulate objectives for the child's enrollment in the Ines Project and collaborate on ways to best support the family in gaining the knowledge and skills they will need as they move toward graduation from the project and full, autonomous advocacy for their families care needs.

The medical advisor will use the Medical History and Comprehensive Care Plan as she/he conducts the health assessment or completes an expanded interview with the family. The document has several useful features to guide the health assessment. Demographic information such as the patients name, home address, and contact information should be recorded.

In the history section, the medical advisor can record medical history, surgical history, and social history of the child. The medical advisor can record the present course of treatment that the child is currently receiving, if any. This section includes a space for medications, therapies, upcoming clinical appointments, scheduled exams, and other observations. After the Health Assessment is completed, the next step is for the team to create a Comprehensive Care Plan.

Chapter 5: Planning for Care

In the development of the Comprehensive Care Plan - the entire care team discusses and deliberates, working to determine the best interventions and strategies to use in order to achieve the desired health outcomes. The team reviews and uses the Medical History and Comprehensive Care Plan at the meeting. The medical advisor leads the discussion. The team will strategize on the methods to implement the interventions. For example, a Comprehensive Care Plan may include obtaining an official medical diagnosis from the Peruvian health care system. The team will then strategize about how to obtain that diagnosis which may involve many steps and appointments with specialists, laboratories and clinics. Another example: the medical advisor may determine that a child needs specialty care equipment or supplies. The team strategizes how to obtain the equipment and/or supplies within the health care system

or other social support services or programs, how to teach the family how to use the equipment and/or supplies, and then how to monitor progress.

The Comprehensive Care Plan prioritizes the treatments the child needs. Some interventions are more important than others; in addition it may be critical for the team to discuss the order or sequence of interventions and prioritize their actions and next steps. The Comprehensive Care Plan includes the medications that are needed and how and when are to be administered. The Comprehensive Care Plan also includes information about how frequently medical advisor should be involved in the patients care and whether she/he needs to accompany the family to any visits, any specialist needed in the patients care and the purpose of each doctor's appointment. The Comprehensive Care Plan may change over time as a child progresses in his or her treatment. A critical component of the Comprehensive Care Plan is outlining all of the resources needed to best care for the patient and the team members that will be needed in the plan. Included is a plan for advancing the knowledge and skills of the family – this may include working with the family on transportation related challenges, time management, working on a budget, defining goals for managing their family needs and the complex challenges of managing their child's diagnosis, and working with parents on self-advocacy skills so they can more effectively meet the needs of their child as they navigating the health system.

Chapter 6: Advancing Care

The principal aspects of advancing care include weekly project team meetings and weekly visits by the health care ambassador and nurse care coordinator.

Weekly Meetings

The project uses a weekly meeting of the entire project team – the project administrator, medical advisor, nurse care coordinator, health care ambassadors, and social worker – to advance the care of the child. The team meetings are very powerful and very important because they allow all members of the team to talk about the child's care, share information with each other, and make collective decisions. The team will learn about the other children being supported by the project. This cross-disciplinary and collaborative approach gives the individual team members a chance to learn new techniques, teach new concepts and knowledge, and problem-solve together. This collaboration improves the care of the child.

At the meeting, the care team uses the Stoplight Tool as the foundation for the discussion about each child. The Stoplight Tool structures the conversation at the meeting. For each child, the team collectively evaluates the Stoplight domains and reaches agreement on the score to give the child (red, yellow or green). Scoring the child at every weekly meeting is critically important and helps to determine what resources are needed to support the patient and their families. Each patient should have a stoplight tool completed at each weekly meeting. The stoplight should provide a framework for outlining the next steps for the child and their family over the coming week and into the future. Health ambassadors are required to take notes based on the stoplight tool discussion for their patients and work with the project administrator to define the care plan of the week. The project administrator then works with the health ambassador to coordinate all of the next steps.

The team generally divides the meeting into 4 parts – financials, stoplight tool care conference, general check-in and the medical advisor weekly training (See appendix D). The Project administrator calls the meeting to order and writes down who is in attendance. An attendance list is important especially for large projects with many participants. The meeting starts with a review of the accounting for each health ambassador – including payments for transportation and care needs. The Project administrator facilitates the Stoplight Tool conference for every patient currently enrolled in the project. Here, the team will use the stoplight tool to evaluate the progress in the Comprehensive Care Plan for each child. The nursing care coordinator, the medical advisor, and the social worker provide updates, if any. A team member leads a brief discussion on the project in general. Each member of the team should have a chance to facilitate this part of the meeting. It encourages leadership skills and makes certain that everyone's voice is heard. This is a good time to ask each other if the project can be improved? Are there things that the health care ambassador or nurse care coordinator need that would expedite the work? Finally, the medical advisor provides a weekly training on a specific knowledge or skill area critical to the Ines Project. This may be a

formal presentation with PowerPoint slides and handouts or an informal discussion that helps to refine and hone the skills of the team.

Weekly Visits

Every member of the team starts the week with a work plan: what are the tasks and strategies that need to be done this week to get this child into a better state of care? Who needs to be called, what appointments have been scheduled, which home visits are necessary. Are there doctors' appointments? Does the family need transportation assistance? Are there skills that need to be taught? Is there insurance needed? What medical tests or procedures are needed to advance the care?

The health care ambassador is expected to conduct a home visit or communicate with the family once per week. The home visit allows the health care ambassador to build rapport with the family, observe the family's situation, and directly observe the child. The health care ambassador should troubleshoot issues with the family so that the family is actively involved in solving problems that arise in the care of the child.

Along with the health care ambassador visits, the nurse care coordinator will also visit the family according to the weekly work plan. Generally, the nurse care coordinator should visit each family at least once a month. If the child is showing poor progress, or is regressing with respect to the Comprehensive Care Plan and as based on the stoplight model. The work plan should think about the needed interventions that might include increasing the number of nurse care coordinator visits or, in some cases, revising the Comprehensive Care Plan.

Chapter 7: Graduation

The Ines Project is a model for helping families to gain the knowledge and skills to advocate for their own children and needs. The model focuses on helping families to identify barriers to mastering self-advocacy and builds toward stabilizing a child and the family. From initial enrollment, the Ines Project team works to establish a clear pathway to graduation or discharge planning a child and their family. The criteria for graduation includes securing stable permanent housing, identifying community connections, core services and secondary supports. After 12 weeks of "green" on the Stoplight model, the Health Care Team should evaluate a patient for discharge from the Ines Project (please see Appendix H for a sample Discharge Planning Document). Prior to discharge the team should review a broad list of concerns address next steps for leaving the project with the patient and family.

Through weekly health care ambassador team meetings, the care team identifies children who are suitable for graduation and works to build a long-term management plan to support the family throughout the life of their child. A family might be ready for graduation if they demonstrate the following characteristics:

1. The child demonstrates extended stability in health as evident by an extended green light ranking on the stoplight scale
2. The family demonstrates knowledge on how to care for their child and the ability to navigate the healthcare system effectively

These criteria should be discussed during a weekly team meeting to decide if the family is ready for graduation.

If the team decides the family is in fact ready to graduate, the following procedures should be followed:

1. The graduation of the family should be discussed with the family in a dedicated meeting that includes the health ambassador, nurse care coordinator, medical advisor and project administrator.
2. Extensive planning and pre-discharge preparation is necessary to assure the family and the child has the necessary and adequate support for the next phase of their advocacy plan. This includes creating linkages to community organizations, Church groups, social supports and other families with medically fragile children. In addition, the family should have a written plan that includes contact information for the Ines Project team, information for the Nurse Care Coordinator and the Medical Advisor and a listing of their medical care "vital information" (i.e. child's medications, medical providers [names, contact information, etc.] and schedule for care plan).

3. A formal graduation document should be signed by the Ines Project team and the family to assure a clear and transparent level of communication.

Final Thoughts

Remember, the function of the Ines Project is to empower families to be their own best advocates for their child's health. This means there is a constant and deliberate movement toward transitioning the family to the graduation period. However, every attempt must be made to move families toward discharge in a manner that assures they have the knowledge, skills and supports needed to maintain the health and wellbeing of their child and family. The biggest gift you can give a family is to be the advocates of their own health!

Appendices

What follows are pertinent supporting documents that will help with the implementation and ongoing facilitation of an Ines Project. Additional documents are available to help with the monitoring and evaluation of an Ines Project. For further supporting material and appendix, please contact Health Bridges International at: InesProject@HBInt.org

Appendix A: Child Status Index

Child Status Index

Child's Name:_____ **Age:**_____

DOB:_____ **Gender:**_____ **Diagnosis:**_____

Location:_____ **Caregiver Name/Relationship to child:**_____

Address:_____ **Phone #:**_____

CSI Scores	**Date:**	**Evaluators Name:**
Domains	**Scores (Circle ONE)**	**Comments**
1 – Food and Nutrition		
1a. Food Security	4 3 2 1	
1b. Nutrition and Growth	4 3 2 1	
2 – Shelter and Care		
2a. Shelter	4 3 2 1	
2b. Care	4 3 2 1	
3 – Child Protection		
3a. Abuse and Exploitation	4 3 2 1	
3b. Legal Protection	4 3 2 1	
4 – Health		
4a. Wellness	4 3 2 1	
4b. Health Care Services	4 3 2 1	
5 – Psychosocial		
5a. Emotional Health	4 3 2 1	
5b. Social Behavior	4 3 2 1	
6 – Education and Skill		
6a. Performance	4 3 2 1	
6b. Education and Work	4 3 2 1	

CHILD STATUS INDEX

Domain	1- Food and Nutrition		2- Shelter and Care		3- Protection	
	1A. Food Security	1B. Nutrition and Growth	2A. Shelter	2B. Care	3A. Abuse and Exploitation	3B. Legal Protection
Goal	Child has sufficient food to eat	Child is growing well compared to others of his/her age in the community	Child has stable shelter that is adequate, dry, and safe	Child has at least one adult (age 18 or over) who provides consistent care, attention, and support.	Child is safe from any abuse, neglect, or exploitation.	Child has access to legal protection services as needed.
Good=4	Child is well fed, eats regularly.	Child is well grown with good height, weight, and energy level for his/her age.	Child lives in a place that is adequate, dry, and safe.	Child has a primary adult caregiver who is involved in his/her life and who protects and nurtures him/her.	Child does not seem to be abused, neglected, do inappropriate work, or be exploited in other ways.	Child has access to legal protection as needed.
Fair=3	Child has enough to eat some of the time, depending on season or food supply.	Child seems to be growing well but is less active compared to others of same age in community.	Child lives in a place that needs major repairs, is overcrowded, inadequate and/or does not protect him/her from weather.	Child has an adult who provides care but who is limited by illness, age or seem indifferent to this child	There is some suspicion that child may be neglected, over-worked, not treated well, or otherwise maltreated.	Child has no access to legal protection services, but no protection is needed at this time.
Bad=2	Child frequently has less food to eat than needed, complains of hunger.	Child has lower weight, looks shorts and/or is less energetic compared to others of same age in community.	Child lives in a place that needs major repairs, is overcrowded, inadequate and/or does not protect him/her from weather.	Child has no consistent adult in his/her life that provides love, attention, and support	Child is neglected, given inappropriate work for his or her age, or is clearly not treated well in household or institution.	Child has no access to any legal protection services and may be at risk of exploitation.
Very Bad=1	Child rarely has food to eat and goes to bed hungry most nights.	Child has very low eight (wasted) or too short (stunted) for his/her age (malnourished).	Child has no stable, adequate, or safe place to live.	Child is completely without the care of an adult and must fend for him or herself or lives in child-headed household.	Child is abused, sexually or physically, and/or is being subjected to child labor otherwise exploited.	Child has no access to any legal protection services and is being legally exploited.
Domain	4-Health		5- Psychosocial		6- Education and Skills Training	
	4A. Wellness	4B. Health Care Services	5A. Emotional Health	5B. Social Behavior	6A. Performance	6B. Education and Work
GOAL	Child is physically healthy.	Child can access health care services, including medical treatment when ill and preventive care.	Child is happy and content with a generally positive mood and hopeful outlook.	Child is cooperative and enjoys participating in activities with adults and other children.	Child is progressing well in acquiring knowledge and life skills at home, school, job training, or an age-appropriate productive activity.	Child is enrolled and attends school or skills training or is engaged in age-appropriate play, learning activity, or job.
Good=4	In past months, child has been healthy and active, with no fever, diarrhea, or other illnesses.	Child has received all or almost all necessary health care treatment and preventive services.	Child seems happy, hopeful, and content.	Child likes to lay with peers and participates in group or family activities.	Child is learning well, developing life skills, and progressing as expected by caregivers, teachers, or other leaders.	Child is enrolled in and attending school/training regularly. Infants or preschoolers play with caregiver. Older child has appropriate job.
Fair=3	In past month,	Child received medical	Child is mostly happy but	Child has minor problems	Child is learning well and	Child enrolled in

	child was ill and less active for a few days (1 to 3 days), but he/she participated in some activities.	treatment when ill, but some health care services (e.g.) are not received.	occasionally he/she is anxious, or withdrawn. Infant may be crying, irritable, or not sleeping well some of the time.	getting along with others and argues or gets into fights sometimes.	developing life skills moderately well, but caregivers, teachers, or other leaders have some concerns about progress.	school/training but attends irregularly or shows up inconsistently for productive activity/job. Younger child played with sometimes but not daily.
Bad=2	In past month, child was often (more than 3 days) too ill for school, work, or play.	Child only sometimes or inconsistently receives needed health care services (treatment or preventive).	Child is often withdrawn, irritable, anxious, unhappy, or sad. Infant may cry frequently or often be inactive.	Child is disobedient to adults and frequently does not interact well with peers, guardian, or others at home or school.	Child is learning and gaining skills poorly or is falling behind. Infant or preschool child is gaining skills more slowly than peers.	Child enrolled in school or has a job but he/she rarely attends. Infant or preschool child is rarely played with.
Very Bad=1	In past month, child has been ill most of the time (chronically ill).	Child rarely or never receives the necessary health care services.	Child seems hopeless, sad, withdrawn, wishes could die or wants to be left alone. Infant may refuse to eat, sleep poorly, or cry a lot.	Child has behavioral problems including stealing, early sexual activity, and/or other risky or disruptive behavior.	Child has serious problems with learning and performing in life or developmental skills.	Child is not enrolled, not attending training or not involved in age-appropriate productive activity or job. Infant or preschooler is not played with.

Appendix B: Stoplight Tool

STOPLIGHT TOOL

How to Use: After the initial Child Status Index and Comprehensive Care Plan created by the physician is complete, use this tool to coordinate care. If any item in the box is **true**, use that higher number

Diagnosis A	Management B	Insurance C	Basic Necessities D	Family Help E	Logistical Obstacles F	Medicine & Ancillary Items G	Medically Necessary Treatment H	Confidence to navigate HCS I
There is no diagnosis or appropriate evaluation in order to create a care plan SCORE **Automatic Red** **7**	Symptoms are not controlled according to care plan SCORE **Automatic Red** **7**	There is no **active** insurance SCORE **2**	- Never enough food; - The child is below goal weight or not gaining weight -Inadequate housing** SCORE **2**	There is no adult willing/able to provide care, protection, consistent help (technical medical support) SCORE **2**	**Utilize 2 points if three or more of the following are present:** transport problem, need testing, health care strike, caretaker employment instability, secondary childcare, other SCORE **2**	Never can obtain medicine or ancillary items SCORE **2**	There is no medically defined treatment underway such as surgery, TB Tx or chemo SCORE **Automatic Red** **7**	Family not using the health care system SCORE **2**
Evaluation in process SCORE **1**	The symptoms are moderately to poorly controlled according to the care plan SCORE **1**	In process SCORE **1**	Sometimes sufficient food, gaining weight but still below goal weight; housing is rented but otherwise adequate** SCORE **1**	There is ONE adult willing/able to provide care, protection, consistent help SCORE **1**	Two or fewer are present SCORE **1**	Sometimes can get the medicine & items SCORE **1**	Waiting for or in process of getting treatment SCORE **4**	Inconsistent use of services *or* frequent use without success SCORE **1**
A valid diagnosis, tangible & effectively based in Peruvian HCS SCORE 0	Symptoms under control per the care plan SCORE 0	There is **active** insurance: SIS, EsSalud, Other SCORE 0	There is sufficient food; weight is adequate*; housing is adequate** SCORE 0	There are TWO adults willing/able to provide care, protection, consistent help SCORE 0	None are present SCORE 0	Always have medicine & ancillary items SCORE 0	No treatment is necessary SCORE 0	Navigating the system with much success SCORE 0

DEFINITIONS

***Adequate Weight** is defined by the medical doctor according to the care plan. ****Adequate housing** is not rented, not contested and has at least 2 of these: water, electricity, and/or cement floor.

NOTES

PATIENT NAME	DATE	COLOR
		RED (score 7-33) YELLOW (score 4-6) GREEN (score 3 or less)

Appendix C: Weekly Meeting Agenda

The Ines Project

Weekly Health Ambassadors Meeting

1) **Financials (20-minutes)**
    a. Receipts and Payments

2) **Stoplight Case Conference (1-hour)**
    a. Weekly review of all children
    b. Define stoplight quantitative value
    c. Assign qualitative category (stoplight color - Red, Yellow or Green)
    d. Plan for each child
    e. Set future appointments
    f. Meetings with Nursing Care Coordinator or Physician
    g. Transportation needs

3) **General Check-in (10-minutes)**
    a. What's working
    b. What's not
    c. How can it be better

4) **Medical Advisor Weekly Update (20-minutes)**
    a. Additions from Nursing Care Coordinator
    b. Question and Answer

Appendix D: Inclusion Information

Inclusion Criteria for "Vulnerability"

1. An inclusion diagnosis and/or diagnosis that interferes with independent living or grossly affects activities of daily living or age appropriate activities
2. Family is stratified to the 1st or 2nd lowest socioeconomic classification
3. Child is 18 years old or younger at time of enrollment

Inclusion Diagnosis

- Cerebral palsy
- Spina bifida and neural tube defects
- Muscular dystrophy
- HIV/AIDS
- Tuberculosis – pulmonary and disseminated
- Asthma or Reactive Airway Disease with history of hospitalization, intubation or profound poor control
- Seizure disorders (e.g. epilepsy)
- Congenital heart disease/disorder
- Autism spectrum disorder
- Diabetes (1 or 2)

Expected Health Outcomes

- Decreased severity of health problems
- Increase self care
- Better access to primary/continuity of care
- Disease specific measures (e.g. Diabetes – HgbA1C, fasting blood glucose, kidney function screening, etc.)

Cost Effective Measures and/or Milestones

- Decrease spending on healthcare services
- Decrease inappropriate health visits or hospitalizations (as measured in records review)

Expected Outcomes from Enrollment

- Decreased hospitalizations (maybe an initial increase in hospitalizations, but expect to see a plateau in usage and then a decrease do to stabilization and appropriate outpatient support)
- Decreased ED visits
- Increased appropriate specialty care
- Increased or decreased diagnostic testing
- Increased appropriateness of visits (e.g. Asthma patient is seen for periodic peak flow meter testing and spirometry testing and provided on-going health education and appropriate access to medications)
- Reduced family impacts (negative) and reduce societal costs related to entitlement expenditures
- Increased family wages due to an increase in the number of work days (secondary to a reduction in sick child days that require time off)
- Increased family relationships (as measured with family relationship model)
- Decrease stress or anxiety (as measured with a standardized instrument)

Appendix E: Job Descriptions

Project Administrator

Job Title: Project Administrator

Location: Lima/Peru

Description: The Project Administrator works with Health Ambassador, Medical Advisor, Nurse Care Coordinator, and Social Worker to ensure seamless team management and project administration. In addition, the Project Administrator works to ensure quality control and continuous project improvement. He/she will work with the HBI Director of Nursing to develop and institute a formative evaluation and assessment plan. The Project Administrator will also manage all staff involved in the project and be the key coordinator as the programs seeks to grow and expand to new communities.

Responsibilities - the Project Administrator will:

1. Supervise project personnel and aid in the development of a care plan for each patient in conjunction with the nurse care coordinator, medical advisor, and health ambassadors to maximize appropriate use of the Peruvian health care system. The Project Administrator will approve and adjust this plan as needed.
2. Meet with the Ines Project health care team weekly and be available for questions that may arise.
3. Utilize the *Stoplight* model in the weekly team meetings for each patient and coordinate utilization of the model within the Ines Project Team.
4. Arrange medical evaluation of new patients and existing patients enrolled in the Ines Project.
5. Oversee judicious use of the targeted resources allocated for each patient.
6. Grow and scale the project to other communities (with additional nursing and ambassador staff); the Project Administrator will collaborate with other government and non-government organizations and other stakeholders to identify geographic areas and existing structures in which the project could be useful.

Qualifications:

- Demonstrated leadership experience supervising, managing, and training others
- Excellent public speaking, writing, and editing skills
- Excellent organizational skills and can successfully manage detailed logistics
- Strong interpersonal and relationship-building skills
- Experience in managing diverse tasks, activities, and projects
- Flexible and willing to work non-traditional hours
- Self-starter with a positive attitude
- Persistent and comfortable problem solving in challenging circumstances
- Experience working with low-income families, ideally in Lima or similar urban areas

Appendix E: Job Descriptions

Nurse Care Coordinator

Project Title: Nurse Care Coordinator

Job Location: Lima, Peru

Description: The Ines Project utilizes the knowledge and skills of a licensed nurse to assist in the planning, coordination and advocacy of care for medically fragile children enrolled in the Ines Project. The position involves direct reporting to the Project Administrator. The position requires supervision of up to 7 Health Ambassadors.

Responsibilities: The nurse care coordinator is responsible for advocating medical care and social assistance for medically fragile children living in poverty in under resourced environments. These responsibilities include: program planning, working with families and children around medication adherence and treatment compliance, organizing the medical and social care delivery, directing family advocacy services, and working with the medical advisor to ensure families and children are enrolled into and aligned with the highest quality evidence based care. The nurse care coordinator reports to the Project Administrator. The Nurse Care Coordinator will be responsible for the following job tasks –

(1) Care Delivery: Coordinate care with Health Ambassadors, or by orders from medical advisor, to establish a care plan for identified patients.
- Ensure the care plan is reviewed and updated
- Oversee family involvement in home care
- Secure and monitor medication and care supplies
- Monitor appointments and transportation needs
- Help patients and families understand diagnosis and care needs
- Travel to clinic sites and patients homes
- Assure transfer of knowledge and skills to families for ongoing self-advocacy and care coordination

(2) Advocacy: Build alliances with other organizations to ensure sustainable levels of care delivery for medically fragile children.
- Meet with healthcare professionals and social service providers to coordinate care
- Assist health ambassadors in teaching families health system navigation and advocacy skills
- Identify resources for on-going care delivery

(3) Program Planning:
- Report status of program to Project Administrator
- Manage the health ambassador team for delivery of care

(4) Discharge planning:
- Work with health ambassador team to establish a discharge plan for patients
- Ensure child and family feel adequately prepared for management of chronic medical condition
- Work with the health care team to identify long term resources for child and family

Qualifications:
- Current and active nursing license in Peru
- Demonstrated leadership experience supervising, managing, and training others
- Excellent public speaking, writing, and editing skills

- Excellent organizational skills and can successfully manage detailed logistics
- Strong interpersonal and relationship-building skills
- Experience in managing diverse tasks, activities, and projects
- Flexible and willing to work non-traditional hours
- Self-starter with a positive attitude
- Persistent and comfortable problem solving in challenging circumstances
- Experience working with low-income families, ideally in Lima or similar urban areas

The ideal candidate should:

- Demonstrate cultural competence and the ability to translate that competence into all program management practices
- Be a dynamic and open-minded individual who values input and collaboration from colleagues
- Exercise excellent judgment in decision-making and explain own perspective to others
- Be able to ask questions, communicate challenges, and seek assistance proactively to ensure alignment of priorities and to identify solution options
- Strive to constantly learn, grow, and reflect on his or her work
- Have experience working with medically fragile children

Appendix E: Job Descriptions

Health Ambassador

Job Title: Health Ambassador

Job Location: Lima, Peru

Description: Health Ambassadors assist in the planning, coordination and advocacy of care for the medically fragile children in the Ines Project. The position involves working with families and their children to help stabilize care, advance health and increase self-advocacy knowledge and skills. Health Ambassadors report to the Project Administrator and work closely with the Nurse Care Coordinator.

Responsibilities: The *Health Ambassador* is responsible for advocating medical care and social assistance for medically fragile children and their families living in extreme poverty. These responsibilities include: working with families to define their needs, supporting families as their grown in their knowledge and understanding of navigating the health system, organizing the medical and social care delivery, teaching families advocacy strategies and skills, and working in collaboration with the nurse care coordinator and the program administrator to refine the Ines Project to better meet the needs of medically fragile children and their families. The Health Ambassador is responsible for the following job tasks –

Advocacy and Coordination:

- Coordinate care with Nurse Care Coordinator, or by orders from medical advisor, to establish a care plan for identified patients.
- Provide weekly home visits to every patient and family enrolled into their group
- Ensure the care plan and stoplight model are reviewed and updated every week at the Team Meeting
- Oversee family involvement in home care
- Secure and monitor medication and care supplies
- Monitor appointments and transportation needs
- Help patients and families understand medical condition and care needs
- Travel to clinic sites and patients' homes
- Build alliances with other organizations to ensure sustainable levels of care delivery for medically fragile children
- Meet with healthcare professionals and social service providers to coordinate care
- Identify resources for on-going care delivery

Programmatic:

- Report status of families of medically fragile children to Nurse Care Coordinator and Medical Advisor
- Provide weekly reports to Program Administrator
- Participate in development and delivery of care plans
- Participate in weekly health care team meetings

Discharge planning:

- Work with health care team to establish a discharge plan for patients.
- Ensure child and family feel adequately prepared for management of chronic medical condition
- Work with the health care team to identify long term resources for child and family

Qualifications:

- Lives in community where Ines Project is operating or seeks to grow a new project

- Demonstrated leadership experience educating, managing, and training families
- Excellent public speaking, writing, and editing skills
- Excellent organizational skills and can successfully manage detailed logistics
- Strong interpersonal and relationship-building skills
- Experience in managing diverse tasks, activities, and projects
- Flexible and willing to work non-traditional hours
- Self-starter with a positive attitude
- Persistent and comfortable problem solving in challenging circumstances
- Experience working with low-income families, ideally in Lima or similar urban areas

The ideal candidate should:

- Demonstrate cultural competence and the ability to translate that competence into all program management practices
- Be a dynamic and open-minded individual who values input and collaboration from colleagues
- Dedicated and commitment to continuous self-improvement – including the acquisition of new knowledge and skills
- Exercise excellent judgment in decision-making and explain own perspective to others
- Be able to ask questions, communicate challenges, and seek assistance proactively to ensure alignment of priorities and to identify solution options
- Have experience working with medically fragile children

Appendix E: Job Descriptions

Medical Advisor

Job Title: Medical Advisor

Job Location: Lima, Peru

Description: The Medical Advisor will report to the Executive Director (ED) of Health Bridges International. The medical advisor will be responsible for the operational success of the Program. They will work with the Director of Nursing and Evaluation and the HBI staff to ensure seamless team management and project development. In addition, the medical advisor will work to ensure quality control and continuous project improvement. They will work with the health ambassadors and nurse care coordinator to develop and institute a formative evaluation and comprehensive care plan. The medical advisor will also manage all staff involved in the project and be the key coordinator as the programs seeks to grow and expand to new communities.

Responsibilities - the Medical Advisor will:

1. Supervise project personnel and aid in the development of a comprehensive care plan for each child in conjunction with the nurse care coordinator and health ambassadors to maximize appropriate use of the respective health care system. The medical advisor will approve and adjust this plan as needed.
2. Meet with the project health care team weekly and be available for questions that may arise.
3. Utilize the *Stoplight Model* for each child and coordinate utilization of the model within the Project Team.
4. Conduct an initial health assessment of each new child and existing children enrolled in the Project as per request of the nurse care coordinator and program administrator.
5. Provide monthly health education and care coordination training to the other team members involved in the Ines Project.
6. Meet with healthcare professionals and social service providers to coordinate care
7. Assist health ambassadors in teaching families health system navigation and advocacy skills
8. Identify resources for on-going care delivery

Qualifications:

- Current and active license to practice medicine in Peru
- Clinical training in pediatrics or general/family medicine
- Demonstrated leadership experience supervising, managing, and training others
- Excellent public speaking, writing, and editing skills
- Excellent organizational skills and can successfully manage detailed logistics
- Dedicated and commitment to continuous self-improvement – including the acquisition of new knowledge and skills
- Exercise excellent judgment in decision-making and explain own perspective to others
- Ability to ask questions, communicate challenges, and seek assistance proactively to ensure alignment of priorities and to identify solution options
- Experience working with medically fragile children

Appendix E: Job Descriptions

Social Worker

Job Title: Social Worker

Job Location: Lima, Peru

Description: The Social Worker will work to ensure that the child is covered by health insurance. In addition the Social Worker will be well versed in the respective country's health care system. The Social Worker will know how to obtain legal documents including: Peruvian Identification Card (DNI), birth certificate, custodial rights, and identification paperwork respective to government requirements. The Social Worker will also meet weekly with the health care team to discuss the comprehensive care plan and the needs of the children and families enrolled in the Ines Project.

Responsibilities – The Social Worker will:

1. Provide support for the family and child in navigating the health care system.
2. Obtain legal documents required for the health care of the child.
3. Advocate for and protect the human rights of the child and family.
4. Coordinate with the project administrator and health ambassador to conduct home visits with patients and their families to assist with care coordination and define advocacy needs.
5. Meet with other social service professionals and social service providers to coordinate care
6. Assist health ambassadors in teaching families health system navigation and advocacy skills Identify resources for on-going care delivery
7. Attend weekly meetings with health care team.

Qualifications:

- Current and active license to practice social work in Peru
- Excellent organizational skills and can successfully manage detailed logistics
- Dedicated and commitment to continuous self-improvement – including the acquisition of new knowledge and skills
- Exercise excellent judgment in decision-making and explain own perspective to others
- Ability to ask questions, communicate challenges, and seek assistance proactively to ensure alignment of priorities and to identify solution options
- Persistent and comfortable problem solving in challenging circumstances
- Experience working with low-income families, ideally in Lima or similar urban areas

Appendix F: Consent Document

This consent form authorizes the Ines Project to share pertinent information with the health care team* and provides consent for the health care team to share relevant patient information with Ines Project staff.

The purpose of this disclosure is to share information concerning _____ (print name of patient) with the patient's health care team. I, _____ (print name of parent/guardian if the patient is under 18), give my permission for the referral source contact, _____ (print name of referral source contact), to share pertinent information about _____ (print name of patient), regarding specified reason(s) for contact as defined in the patient care plan.

I understand that I may withdraw this consent by written request to the referral source contact, except to the extent it has already been acted upon.

The purpose of this disclosure is to release information from the health care team about_____(print name of patient) including name, date of birth, relevant referrals made, and relevant medical information as requested by the referral source. I understand that I may withdraw this consent by written request to my primary health care provider, except to the extent it has already been acted upon.

This consent allows the Referral Source to share pertinent information with the assigned primary care provider (doctor) and treating doctors within the group, for care coordination. Care coordination allows the Referral Source to receive relevant medical information concerning the named patient from the assigned primary care provider (doctor) and treating doctors within the group

I certify that this Authorization to Release Information has been given freely and voluntarily. Information collected hereunder may not be re-disclosed unless the person who consented to this disclosure specifically consents to such re-disclosure and or the re-disclosure is allowed by law. I understand I have a right to inspect and copy the information to be disclosed.

Name of Parent/Legal Guardian

_____

_____

Signature or thumb print of Parent/Legal Guardian (if patient is under 18)*

_____

Name of Witness

_____

_____

Signature of Witness

_____

_____

Date: _____/_____/_____

*Medical and health providers working with the patient enrolled in the Ines Project.

Appendix G: Enrollment Checklist

At the first family visit with the health ambassador, project administrator and the nursing care coordinator – the following checklist should be completed to assure enrollment into the Ines Project.

Enrollment Checklist				
Measure	**Date Completed**	**Person Completing**	**Verified By**	**Outcome (e.g. Inclusion diagnosis, CSI score)**
Inclusion Diagnosis				
Economic status				
Age of youth				
Health Ambassador assigned				
Consent form completed				
Verify contact information for family				
Copies of required documentation (i.e. SIS enrollment, DNI, intake application)				
Review Ines Project goals with family				
Child Status Index completed				
Initial stoplight model completed				
Appointment set for Medical Advisor to meet with family and take comprehensive health history and perform medical examination				
Comprehensive care plan completed				

Appendix H: Discharge Planning Document

Ines Project Discharge Planning

The following document should be used as an interview guide and completed at the time of discharge planning. After 12 weeks of "green" on the Stoplight model, the Health Care Team should evaluate patient for discharge from the program. Prior to discharge the following concerns should be addressed with the patient and family.

1. Follow up Care Plan: a. Care plan ☐ b. Appointments ☐ c. Therapies ☐ d. Medical equipment/supplies ☐ e. Nutrition ☐	• Where will continued care be received? • Does the patient/family have resources/financial ability to continue care plan? If not, who will assist family? • Does patient/family feel empowered to continue seeking care without the nurse care coordinator or health care ambassador? • Does patient/family know where to obtain additional equipment/supplies? • Are there any special diets or nutritional needs?
2. Knowledge of Health Condition: a. Understanding ☐ b. Signs and Problems ☐ c. Medications ☐	• Is patient/family able to verbalize diagnosis? • Is patient/family aware of what they are capable of doing to improve patient's well being? • Does patient/family know what problems to watch for and what to do about them? • Does patient/family now the purpose of medicines, how much to take and potential side effects? • Is patient able to access medications and supplies?
3. Documents: a. Insurance ☐ b. DNI/Birth Certificate ☐	• Has the Care Coordination Team worked with patient/family to ensure that the family will have adequate insurance? • Does the child have their birth certificate and identification?

4. **Coping and Confidence ☐**	• Is patient/family able to cope with illness? • Does the family know what to do in the case of new issues and complications? (i.e. contacting their health care ambassador)
5. **Other Concerns ☐**	• Does patient/family have any other questions or concerns?

Project Staff Signature: _____ Date: _____

Family Member Signature: _____ Date: _____

Appendix I: Support for a Grieving Family

Working with medically fragile children can be complex and challenging. The health needs of the children enrolled in an Ines Project are often very high and children can sometimes die prematurely while enrolled in the program. Helping families to deal with their loss and support them in their transition is critically important to the Ines Project. A death in a family leaves a huge impact on everyone. A death of a child, however, can be an entirely more devastating event. As someone who wants to help a family going through grief, it can be difficult to relate and give advice to someone who is experiencing something you have not. The best way to support the family is to first inform oneself about what they are experiencing.

1. **Many aspects of life are affected by a loss of a child.** There are psychological, emotional, physical and social changes that the family will experience.
    a. **Psychological**. People often have issues with remembering details and can fixate on what the days leading up to the death. Many people also struggle with their faith, trying to understand how such a thing could happen to them.
    b. **Mental.** For some people, in times of great emotional duress and stress their ”thinking” brain can shut down and they find themselves operating on an almost autopilot mode. This can be a vulnerable time when making simple decisions can feel overwhelming. This can be particularly challenging for parents who have multiple children that require the care and attention of an adult in their lives.
    c. **Emotional.** People can feel anger at themselves, their partner, a person they believe responsible to the loss, God, and even at their child for dying. There can also be a feeling of injustice and guilt when they can blame themselves for their child’s death. Finally, the family can feel a great amount of sadness and depression that can last years.
    d. **Physical.** After a death, people can have difficulty taking care of their own health. They can have irregular sleeping schedules and difficulty eating correctly. As a result, they can start to feel anxious and out of control of their emotions.
    e. **Social.** The family can have difficulty maintaining relationships with old friends and can feel disconnected from the community. Normal activities and hobbies stop seeming as important, serving to isolate the family more. Parents can also become overprotective of their surviving children and feel like they are bad parents.
2. **People react differently to grief.** A parent’s reaction to their child’s death can be extreme and can look very different between mother and father. This does not mean that any one behavior makes more sense or is “right.” It is important to allow the family time to process, but also stay alert for dangerous thoughts or behaviors like considering self-harm or suicide. Turning times of great grief, its important for us to continue working as safety nets in the lives of the people enrolled in the Ines Project – and sometimes the best safety nets are those that can’t be overtly seen.
3. **They are not alone.** They have the support of the Ines Ambassadors, the church, and the community. For a family who has just lost a child, it can be extremely difficult to continue to engage with others. They can often feel like their pain is so deep that others cannot relate to them, and can even feel ostracized by their friends and family. Support from those who understand that
4. **There is no time limit for grief.** Grief after the loss of a child can last a long time, often years. It is common for friends and family to tell them the need to “get over it,” but this mentality is never helpful for the family. Studies haves shown that instead, by talking about their grief in an accepting environment, families are able to resolve their feelings much easier.
5. **There are support groups available.** It is important to look for resources that exist in the area and share these with the family. This is a great way to not only stay informed about groups that exist in your community, you also show the family that they are not alone.
6. **Listening is very important.** In times of great change, our systems (psychological, mental emotional and physical) can become overwhelmed. It’s almost as if we are trying to process too much information and stimulation. In such circumstances, it can often be very healing to have someone who you can confide in and talk about your challenge and grief without getting advice or being told, “everything will be okay.” In these circumstances, the role of a care advocate and ambassador is more of a compassionate listener. Sometimes the most important thing we can provide people suffering through times of great grief is a listening ear and a compassionate heart.

References:

The Compassionate Friends. “To the Recently Bereaved.” *The Compassionate Friends: Supporting Family After a Child Dies.* Idea Marketing Group. 2016.
Wender, Esther, M.D. “Supporting the Family After the Death of a Child. *AAP News and Journals Gateway.* American Academy of Pediatrics, 30 Nov. 2012.

Appendix J: Evaluation Plan

Ines Project Monitoring and Evaluation Plan			
Objectives	**Indicators**	**Source of Data**	**Frequency of Collection**
Increased coordinated care delivery and support as evidenced by:			
• Decreased number of unplanned/emergency visits to clinic/hospital from enrollment to discharge from program	• # of visits to primary care physician/clinic (e.g. unplanned/emergency visits vs. routine maintenance visits)	Program Manager Tally Sheet	Weekly
• Increased visits to appropriate and planned specialty services from enrollment to discharge from program	• # of visits to specialist • # of visits to therapy (e.g. PT, OT, Speech pathology, etc.)	Program Manager Tally Sheet	Weekly
• Increased competence of Health Care Team as measured by annual examinations (around specific knowledge and skills)	• # Increase of 25% on pre- and post-test skills and competency scores	Pre- and Post-test scores	Annual
Improved advocacy for the family of special needs children as evidenced by:			
• Increased knowledge regarding disease and treatment for children and family to work effectively with Health Care Team from enrollment to discharge	• # of individualized care plans with high quality, evidence base care delivery • # of child/family ability to effectively communicate plan of care, treatment and medications	• Care plan records • Progression on Stoplight Model	Weekly
• Increased communication between children, family and Health Care Team	• # of home visits by nurse care coordinator • # of home visits by health care ambassadors • # of home visits by medical advisor • # of home visits by social worker • # of weekly meetings of Health Care Team	Program Manager Tally Sheet	Weekly
Appropriate health care utilization as evidenced by:			
• Improving access and appropriate use of services as determined by annual record review	• # of visits of planned health care services	Program Manager Tally Sheet	Weekly
• Decreased number of unplanned hospitalizations as determined by annual record review	• # of planned vs. unplanned hospitalizations	Program Manager Tally Sheet	Annual
Improved health outcomes as evidenced by:			
• Decreased Stoplight model scoring within one year of program enrollment	• Decreased Stoplight Model score (review scoring determine % decrease in score)	Stoplight Model Score	Weekly