

Opportunities for Children with Disabilities: Community Based Rehabilitation in the Dominican Republic

International Child Care (ICC) respectfully requests that Alternative Gifts International consider selecting the Community Based Rehabilitation program in the Dominican Republic for its 2008-09 Alternative Gift Catalog.

A. Project Description

Although people with disabilities face challenges no matter where they live, it is especially difficult for the disabled to receive the rehabilitative assistance they need in developing countries like the Dominican Republic. Public access to health services is often limited by geographic and economic barriers, and social stigma toward the disabled means it is even less likely that those in need will receive adequate care. Making the most of the resources that do exist, Community Based Rehabilitation programs that train family members and friends in basic rehabilitation exercises have proven to be an effective way to reach many people with disabilities who otherwise would have no access to care.

International Child Care, a Christian health development organization that has worked in Haiti since 1967 and the Dominican Republic since 1988, has successfully improved the lives of more than 1200 children and families in the past fourteen years through its Community Based Rehabilitation program in Santiago, Dominican Republic. The program trains Community Rehabilitation Workers to visit families with disabled children and teach a caregiver in the home how to perform simple rehabilitation exercises with the disabled child to help the child progress toward appropriate developmental goals. This empowers the family to assist the child's growth and improves both the family dynamics and the community's attitude toward people with disabilities.

A recent study of 155 children who left the Community Based Rehabilitation program showed that 90% of them exhibited an increase in their development quotient, which is a measure of a disabled child's progress toward established development goals. International Child Care believes the program's high rate of effectiveness is due to directly involving parents, relatives, and neighbors—those who have the greatest investment in a child's life—in providing him or her with care.

The World Health Organization indicates: "Over the past decade, WHO has been promoting community based rehabilitation as a way to increase access to rehabilitation and promoting equalization of opportunities for the social integration of persons with disabilities into the community and society. This approach employs resources within the family and community, along with support from the referral system."¹

ICC was at the forefront of the movement to empower families in developing countries to improve the lives of their children with special needs.

¹ World Health Organization. "The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities: NGO Responses to the Implementation of the Rules on Medical Care, Rehabilitation, Support Services and Personnel Training—Regional Report AMRO." p15.

International Child Care's Community Based Rehabilitation program in Santiago, Dominican Republic began as a pilot in October 1993 and as a home-based program in July 1994. A staff of 56 (50 program and 6 shared support staff) carry out the program activities; all but one of them are local Dominicans. International Child Care works in partnership with other governmental and non-governmental agencies that provide services to the disabled. An Association of Mothers of disabled children (MANIDI) and a Cooperative of Family and Friends of disabled children (COFANIDI) are both organizations that have formed as a result of International Child Care's work in the Dominican Republic. The program also partners with several medical specialists who attend to the poor children at low cost and make referrals to local, private special education schools for the intellectually challenged and the hearing impaired.

For the past fourteen years, International Child Care's Community Based Rehabilitation program has succeeded in helping children with disabilities and their families to reclaim lost levels of developmental function and recapture a sense of self-respect, dignity, and hope for the future. Community Based Rehabilitation has a proven track record, providing employment in the local community and serving 420 children in 2006. With the support of AGI, ICC can continue and expand this work to serve even more children in need.

B. Verification of Project

ICC's Community Based Rehabilitation program is a legitimate, established project that has been in effect since 1993. There is no budgetary limit to the amount of funding the Community Based Rehabilitation program may receive, as it means that with more income more children will be served.

C. Project Goals, Objectives, Timeline, and Testing Plans

Despite the difficulties that Dominican children with disabilities face, their lives are not without hope. Through diagnostic and rehabilitation services a disabled person can reclaim a higher level of developmental function. With support and encouragement as well as community education and advocacy, the stigma associated with disability can be reduced. Both the disabled and their families can reclaim some of their lost dignity; shame and embarrassment can be replaced by newfound confidence, self-esteem and respect.

The goal of International Child Care's Community Based Rehabilitation program in Santiago, Dominican Republic is to provide the opportunity for children with disabilities and their families to enhance their levels of physical, mental, sensorial and emotional function and improve their quality of life through a grassroots, community-based rehabilitation approach.

International Child Care accomplishes this goal through the following objectives:

- Recruiting and training Community Rehabilitation Workers to make home visits to families with disabled children
- Providing weekly visits to each child's home by a Rehabilitation Worker, who makes an initial assessment of the child using the Portage Guide to Early Education, teaches simple

rehabilitation exercises and techniques to a caregiver, and continuously evaluates the child's progress toward developmental goals

- Tracking the progress of children in the program is necessary to evaluate the program's effectiveness and identify areas for improvement
- Referring children who have completed the program or are not adequately served by the program to other available special-needs schools and programs

Community Based Rehabilitation brings rehabilitation techniques to families with disabled children living in marginal neighborhoods or rural areas who have no access to regular rehabilitation services. Through weekly education of a caregiver in the home, International Child Care provides a sustainable way for families to help their children develop to their fullest potential. Training involves teaching parents or other caregivers about simple rehabilitation techniques and tools in a way that is easy for them to understand. Following the grassroots model of primary health care, rehabilitation methods and techniques are presented in a manner that allows even an illiterate community member to carry out therapeutic exercises and to produce and use simple aids and devices.

The Portage Guide to Early Education is used as base method for the home visiting program. This method permits non-professionals to prepare adequate individual programs for each child in six developmental areas until the upper level of six years of normal child development. The Portage Guide was originally developed in rural areas of the USA and is adapted and used in many developed and developing countries. The essence of the Portage program lies in its involvement of the family in assessment, decision making and day-to-day teaching of the child in the home setting. The process begins with a joint assessment of the child by the parent and Community Rehabilitation Worker. The assessment results can then be linked to a specific activity card which makes concrete suggestions on how the child can be helped in the home to reach goals identified in the assessment. Additionally the program stimulates creativity in the workers to think of many alternative ways. The rehabilitation worker may demonstrate a teaching technique or activity but it is the parent who assumes the role of teacher, with the rehabilitation worker acting as support to the parent on weekly visits.

Based on the Portage Guide, International Child Care developed an instrument that allows calculation of the child's development quotient at various points in time. The development quotient provides a way to determine whether a child's progress is due to natural learning or due to progress from program impact. The quotient is calculated by dividing the child's developmental level by his or her chronological age (both expressed in months) and multiplying by 100. For example, a child who is 24 months old but has a developmental level equal to a twelve-month-old child would have a development quotient of 50. Comparing baseline quotients from the time a child entered the program with final quotients when they graduated or left for other reasons allows International Child Care to effectively track program effectiveness in five developmental areas. A Portage checklist will be and has been filled out for each of the children with special needs that pass through the program.

The staff of the Community Based Rehabilitation Program at the Dominican office of International Child Care includes: 35 Community Rehabilitation Workers, 7 supervisors, 3 coordinators, and 2 psychologist. Shared staff who also work with the Community Health

Development program include the National Director, Program Director, Administrative Coordinator, 2 Office Assistants, and a Janitor (56 people total). All staff except the National Director are Dominican.

Each family who participates in the program is in a way, also a member of the team, because the nature of Community Based Rehabilitation is to empower people to improve their own lives and those of their family members.

D. Expressed Need for the Project

According to a recent report from the World Health Organization's Disability and Rehabilitation Team, "WHO estimates that more than 300 million people worldwide are disabled, over 70 percent of whom live in developing countries. Only about one to two percent of persons with disabilities in the developing world have access to rehabilitation and the majority of them are relegated to the margin of society."²

As the World Health Organization report suggests, the combination of disability and poverty makes life especially difficult for the disabled living in developing countries like the Dominican Republic. Children with disabilities in the Dominican Republic are often seen as an embarrassment to their families or even as a curse from God. Many are hidden, deprived of food, or abandoned by parents who don't know how to care for them or don't want the stigma of having a disabled child. Only families with greater economic means can usually afford the limited services that do exist for the disabled in the Dominican Republic. Further compounding the problem is the fact that the country's health system infrastructure is still inadequate to meet the basic health needs of its population. Often, disability is at the forgotten end of the primary health care spectrum and, as such, fails to attract the level of financial and human resources required to even begin addressing some of the needs.

For the past fourteen years, International Child Care's Community Based Rehabilitation program has succeeded in helping children with disabilities and their families to reclaim lost levels of developmental function and recapture a sense of self-respect, dignity, and hope for the future. Community Based Rehabilitation has a proven track record, providing employment in the local community and serving 420 children in 2006.

E. Number of People Affected

The primary beneficiaries are the approximately 400-430 children with disabilities who are served each year who would not otherwise have access to rehabilitation services. In 2006, Community Based Rehabilitation celebrated the following accomplishments:

- Weekly Rehabilitation services provided to 420 children with disabilities
- 13,000 home visits by Rehabilitation Workers
- 10 weeks of training workshops and 8 self-growth training sessions provided as part of in-service training for Community Rehabilitation Workers

² World Health Organization. "The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities: NGO Responses to the Implementation of the Rules on Medical Care, Rehabilitation, Support Services and Personnel Training—Regional Report AMRO." p15.

In addition to the children, their families, friends and neighbors also benefit from the program. Not only do parents and caregivers receive education specific to helping their disabled child, but they also learn about healthy child-rearing methods, so International Child Care's presence helps both the child with the disability and his or her entire family. By sending Rehabilitation Workers out into the community, Community Based Rehabilitation has a ripple effect, bringing knowledge and more widespread acceptance of people with disabilities into neighborhoods where a disabled child was once considered an embarrassment to the family.

The Community Rehabilitation Workers are being recruited from the same marginal urban and rural communities the program works in; all are women and very few are professionals. Most women have 6-8 years of primary school or some years of secondary or tertiary education, and around 50% are mothers or family members of a child with a disability. In-service training is provided to prepare the women to become able and knowledgeable trainers of the mothers of the children with disabilities during the weekly visits of the home based rehabilitation process. Although the main objectives of International Child Care's program are focused on helping disabled children, it is evident that the impact of Community Based Rehabilitation extends far beyond the people it initially set out to serve.

Because of this, the community of Santiago has come to embrace International Child Care's Community Based Rehabilitation program over the past fourteen years. Parents of disabled children in the program have joined together to form MANIDI, a support and awareness group for parents. The objective of MANIDI is to educate parents to ensure the development of their children while raising awareness of Community Based Rehabilitation and support for the extension of ongoing rehabilitation services in the future. Through this group, they are assisting their member families with micro-credit and have set up a multi-service cooperative in an attempt to raise their socio-economic level. MANIDI has recently started a job preparation and placement program for adolescents that have finished the Community Based Rehabilitation program and have no chance to be placed in a school.

With the help of AGI, International Child Care can continue to change lives for the children currently enrolled in the program and begin preparations to reach out to even more families in need of assistance with their disabled child.

F. Geographic, Demographic, and Political Background

The Dominican Republic occupies the eastern two-thirds of the island of Hispaniola. Originally colonized by the Spanish, the country has a long and fascinating history dating back to the first voyage of Columbus and to the native peoples who lived there for generations before.

Although Haiti and the Dominican Republic both share the same island—Hispaniola—the two countries have surprisingly different, but closely interwoven, histories. The island first became known to the western world when Columbus landed there in 1492, though it had been home to the native Arawak and Carib peoples for many years before that. Meanwhile, French and British buccaneers made use of the northern and western shores as ports (hence the infamous “pirates of the Caribbean”). As time passed and power changed hands many times, Haitians became bound

to the fortunes of the French, while the Dominican people were more heavily influenced by Spain. This divergence is most evident today in the countries' languages; Haitians primarily speak Creole and French, while most Dominicans speak Spanish. The colonizing countries took different approaches to their "prize," however, and while France enthusiastically took advantage of Haiti's abundant resources to create a booming export business, Spain was more focused on interests elsewhere and for the most part, left the settlers to their own devices.

The geography of Hispaniola also contributed to the evolution of two distinct cultures. The Dominican side, with its long valleys and wide plains, was better suited to vast sugar cane and tobacco plantations, while the more mountainous Haitian territory was valued for its forests and rich topsoil. Capitalizing on these natural resources, the French imported African slaves to work their sugar cane plantations. When the slaves organized themselves and revolted against the French in 1804, Haiti became the world's first black republic and the second nation in the western hemisphere (after the United States) to win its independence. This was not the end of Hispaniola's many power shifts, and throughout its colorful history, parts of the island have been variously controlled at one time or another by the native Arawak people, the Spanish, the French, the Haitian slaves, the Haitian elite, the Dominicans, and American and U.N. military forces.

Despite the many differences, there are a number of similarities. Both countries have had political and economic unrest over the years and have suffered under the rule of ruthless dictators. Poverty remains widespread among both peoples. The United States has invaded and occupied each country at least once in its history. Catholicism is the primary religion for Haitians and Dominicans, although people on both sides of the border have incorporated aspects of spirit faiths, like voodoo and santeria, into their Catholic practices. There is a long history of tension and struggle between the two neighbors, and wars and atrocities are unfortunately frequent throughout their shared history. In today's world, both are considered developing countries, though the Dominicans in recent years have been able to hold free and fair elections to form a stable, democratic government, an accomplishment Haiti still hopes and strives for.

G. Suggested Market Price

- \$32 brings one month of home rehabilitation to a special child in the program
- \$80 pays for training of one Community Rehabilitation Worker
- \$1000 pays for a team of one supervisor and her five Community Rehabilitation Workers to bring one month of rehabilitation services to 40 children with special needs in their homes.