Supporting the Inclusion of “Invisible” Children and Youth with Disabilities and their Families in Rural El Salvador

Final Research Report

Submitted by

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This report focuses specifically on the impact of the project with a particular focus on informants’ perceptions of the program, components that were viewed as most beneficial, barriers to participation, and components they would like to carry forward into the future.

**Methods**

Primary data sources included interviews individuals with disabilities or families from the original target group. Additional information was obtained during focus groups conducted with facilitators in the “biblioteca” (community based informal education centers) and other members community members (e.g. members of the community governing council, Biblioteca Committee, and Circulos de Amigos). We also recorded information collected in working groups held during Encuentro II (e.g, NGO representatives, individuals with disabilities, families, and other community members).

**Interviews.** One-on-one interviews were conducted with 15 individuals with disabilities or family members who actively participated in the project (e.g.attending the biblioteca, participating in one or more community activities, and/or receiving support as part of the “Circulos de Amigos”) and who were available at the time the interview. Two were adults with disabilities; the remainder were family members (e.g. in one family both the mother and father participated, and the remainder were mothers). Interviews were not conducted with families of persons who died (n=3) during the study period (one of these families had two children with disabilities) or had moved away (n=1). Additionally we did not interview families who had
declined to participate after the initial interview. Two of these individuals were adults, one of whom was deaf but functioning as she always had within her home and one with intellectual disabilities who had dropped out after failing first grade 10 times. Another was the family of a child with autism whose family had never participated in community functions and were unresponsive when approached. Another was the family of a young child with Down Syndrome whose parents initially accepted an IP school scholarship and then dropped out, and despite repeated invitations did not bring her to the biblioteca or to community functions.

Focus Groups. In addition to individual interviews, focus groups were held with a total of 38 participants, representing the communities. Community focus groups ranged from 6-15 participants and included members of the community governing councils of each village as well as members of the Circulos de Amigos. A separate focus group was held with facilitators of the five bibliotecas and included seven participants. These focus groups were led by Dr. Beckman and Mr. Montagna. Two note-takers were present and groups were audio-recorded. Focus groups were asked to respond to the following lead questions:

1) Tell us about your experience with the “Comunidades Inclusivas” project;

2) Tell us about the most successful parts of the project;

3) Tell us about any challenges you had in implementing the project;

4) Describe families who participated and those who did not. [Follow-up prompt: What were the differences between those who participated and those who did not?];

5) What are your recommendations for the future? [Follow-up prompt: If you could carry this project forward into the future, what would you like to continue?]
Encuentro II Working Groups. In addition to specific community focus groups, four working groups were also held as part of Encuentro II. Participants were randomly assigned to one of four groups so that we could have a mix of individuals with disabilities, families, community members and participating professionals/NGO representatives. A total of 51 people participated in these groups. Groups included 12-15 persons; one person led the discussion; one was assigned to make lists of participant responses to each question, and two independent IP note-takers maintained ongoing notes of the discussion. Working groups were grounded in an “Appreciative Inquiry” format and asked to respond to the following questions:

1) What were the most positive aspects about the project?

2) What were the successes and challenges?

3) If we could continue the project into the future, what should we make sure to carry forward and what should we change?

Activity Logs. IP staff members in El Salvador, facilitators in the bibliotecas, and Circulos de Amigos maintained ongoing activity logs throughout the project. They recorded activities in each village designed to support individuals with disabilities in the community, (e.g. activities completed as part of Public Awareness Campaigns in each village, activities of each Circulos de Amigos, individual support to people with disabilities and their families, home visits, visits from specialists, training activities, specific ways of including individuals with disabilities in the communities, etc).

Observations/Field Notes. We maintained detailed notes of all activities in which either the principal investigator or IP staff were directly involved. This included observations during home visits, visits to the bibliotecas and community events. We took particular care to note the
activity in question, the involvement (or lack thereof) of individuals with disabilities as well as the nature and extent of support they received during the activity.

**Activity Log.** IP staff and facilitators in the biblioteca maintained an ongoing activity log which documented participation in the project including attendance at the biblioteca and community functions, home visits, activities of the Circulos de Amigos, trainings, etc.

**Data Analysis.**

As recommended by Creswell and Poth (2018) and Miles, Huberman, and Saldaña (2014), we used an inductive process to analyze the interview data, focus group data, and field notes obtained for the follow-up component of the study. We began coding procedures early by reading each piece of data multiple times and assigning codes to each meaningful unit of data. Also, along with the preliminary codes based on research questions (e.g. “barriers to participation,” “benefits”, etc), we allowed additional codes to emerge from the data. We then grouped initial codes into larger categories and further reduced categories into themes.

**Findings**

Participants across two or more research contexts (interviews, one or more focus groups, working groups) identified all major features of the program as important and as contributors to the benefits that they observed. In general, members of facilitator focus groups, community focus groups, and the Encuentro II working groups all identified the Public Awareness Campaign and the Circulos de Amigos program as particularly important. Parents and others, in communities where members with disabilities received scholarships, other forms of assistance,
and in those that had learned sign language, enthusiastically identified these components. All were outgrowths of the Circulos de Amigos program. Participants in the facilitators group also emphasized these same components as well highlighting the importance of professional specialist visits and the training activities. Four overarching themes emerged from this analysis. These included “Individual Benefits,” “Community Benefits,” “Barriers to Participation,” and “Recommendations.” Within two of the overarching themes, we identified subthemes.

**Individual Benefits**

During interviews, individuals with disabilities and their families reported many benefits from participating in this program. Participants in focus groups and Encuentro II working groups also described similar benefits and there is evidence in the activity logs maintained by Circulos de Amigos and IP staff as well. While some of these benefits came from participation in activities in the biblioteca, many additional benefits were the result of the work of the Circulos de Amigos and visits from professional specialists. Often during a home visit, it became clear that the individual or family needed some very specific support. Members of the Circulos de Amigos either worked to resolve this directly (e.g. accompanying a student with disabilities to school), or in the event they needed funds, submitted a proposal to IP. After receiving a proposal, IP staff and volunteers solicited donations from individual donors or local foundations. In this way, four students obtained scholarships to attend special schools and 15 families received support from International Partners for specific needs that the families would not have been able to obtain without the support. For example, some received support for transport them to and from medical and/or therapeutic services. Others received donations of
important equipment to facilitate their independence (e.g. 6 wheel chairs, 3 adapted exercise bicycles to promote the development of motor skills). Many also received other types of equipment that met particular needs (e.g. parallel bars, adapted toys, scooter boards to promote movement, a fence to prevent falls into a ravine outside of family’s house, a ramp at one home, vision examinations, glasses, individual communication boards, special shoes, access to sign language books and materials, medications and nutritional support). While resources such as these may be common in developed countries, for families in rural El Salvador without economic resources, they were important opportunities that would not have been available otherwise. For example, in the past, without a way to transport their children to therapy, many families had to forgo therapy services, which had detrimental outcomes to the long-term development and well-being of the individuals with disabilities.

**Community Benefits**

Multiple informants identified important benefits that accrued to communities as a whole as a result of participation in the project. Several sub-themes emerged within this overarching theme. These included: Community Awareness: “Now we see them;” Developing Practical Skills; Physical Changes; and Participation and Contribution.

*Community Awareness: “Now we see them.”* Participants in all focus groups, as well many of the individual interviews, emphasized changes in attitudes and awareness that they experienced themselves and observed in others as a result of the project. At the most basic level, this sentiment reflected an increased awareness of the presence of people with disabilities in the village. Most had thought little about the issue of disability prior to the project
and noted that they were unaware of the needs of those with disabilities in their village unless
the person was a member of their own family. One facilitator described this change, saying “I
feel it was a very good project, before [disability] was something that could not been seen,”
adding, “Now, we see them.” However, the sentiment often went deeper. Some participants
noted that now they were “not afraid” to approach individuals with disabilities and had a better
idea of how to communicate. One participant described the change in how she saw people with
disabilities by saying, “Now we treat them in a way that includes them in these spaces from a
perspective of their rights as a person, no longer as a ‘poor thing’ to pity.” Another
commented, “I had never stopped to think how great can be the capabilities of people [with
disabilities].” One mother of two children without disabilities who was part of the library
support committee in one village said, “I can see so many things that have happened in such a
short time”, adding “It is better than before.” Referring to individuals with disabilities, she
observed, “There is no reason to leave them aside. They are just like us, just like everyone else.”
Several participants also observed that anyone can become disabled after an accident, injury, or
illness and felt that this project made them aware of how they would want to be treated.

This awareness also extended to the understanding that individuals with disabilities have
rights (for example, to attend school, to participate in the community, to non-discrimination)
and that disability rights are human rights. In some cases, this translated to very specific
actions; for example, one family decided they wanted their 22 year old daughter with
disabilities to be recognized as a citizen of El Salvador, which she had never been. So they
worked with IP staff and the Circulos de Amigos group to get her an official residency card,
referred to in El Salvador as a DUI. Among other things, having a DUI entitled her to vote. Prior to the project, no one considered that this was an important thing to do.

Also noteworthy was that participants saw themselves as having developed more knowledge about the importance of being respectful in the language they used regarding disability. In this vein, many reported a better understanding of more appropriate, person-first language, with many and noted that they now found inappropriate language offensive. One participant described this change, saying “...now we are outraged when we hear people not say things correctly...” to describe people with disabilities and that other language was more appropriate. Another pointed out that this new respect was transmitted to their children, saying “When we go out she says.... she is a person with a disability....she does not say, look there is a crippled person.”

**Developing Practical Skills.** Facilitators and other community members also described a variety of practical skills that they had acquired and attributed these changes to training that they had received. One participant noted, “As my colleagues say, I really didn’t know anything about the subject ... for me I have learned to identify what kind of disability each person has...”

In two villages that included a child who was deaf, members of their respective Circulos de Amigos had advocated they receive scholarships to attend a public school for the deaf outside of their community because there were no opportunities at local schools to learn sign language and the local teachers did not have the training to teach them. Circulos de Amigos worked with each family to develop a budget and a proposal for a scholarship that they then presented to IP. IP then raised funds from individual donors to send them to school. To assure that this scholarship facilitated community participation, mothers of both boys offered weekly sign
language classes for members of Circulos de Amigos and other interested community members. These activities became extremely popular and now include 25 participants. One participant, referring to her experience of learning sign language, said, “It is very beautiful...such a beautiful experience to communicate with Diego, at first to understand him and how to communicate with him. Today he tells us something, and we can understand him. The beautiful thing is that we also live [in the community] with him.” One mother of several children who attended the biblioteca and were learning sign language spoke of how important it was for her children without disabilities. She noted that her children “infect her” with excitement after sign language classes, saying “Mommy, do you know what this means,” and then they show her signs.

In addition to sign language, facilitators emphasized the practical teaching skills they had learned, particularly as part of the training they received in Universal Design for Learning, Positive Behavior Support, and Strategies for Alternative Communication. One facilitator said, “At least in the biblioteca, the DUA [Universal Design for Learning] and positive behavior because it is not only used with people with disabilities...but the same has been used with the others [children] that attend. I have been practicing it with some children who have very difficult behavior. I feel that it has been quite good.” Another facilitator, whose adult sister has disabilities, noted that the communication board that had been developed as part of the training on alternative communication strategies had helped her sister, “…it is easier to communicate with her... she is using it.” Another facilitator agreed. She observed that the picture schedules and communication boards developed as part of the training had helped them communicate with an adult male who had dropped out of school after failing first grade three times without learning to read. She noted that by using these strategies in the biblioteca,
he had learned his colors, numbers and letters, could spell his name, and had even used his newfound skills to help another child in the biblioteca spell her name. He has recently begun to use the computer.

**Physical Changes.** All of the communities made a significant effort to modify the space in the bibliotecas to better accommodate individuals with physical disabilities. All five villages worked together to construct ramps; three villages installed bathrooms and/or adapted existing bathrooms so that individuals in wheelchairs could use them. Previously, lack of access to bathrooms had prevented participation of community members with physical disabilities since the only option was a latrine. (Latrines are typically set away from main buildings, often on inaccessible terrain, and require users to ascend three steep steps. The impact of these physical changes were especially striking in one village in which Miguel, a man who had been isolated and used a wheelchair as a result of a degenerative disease, became a very active part of the biblioteca. Once the ramp and bathroom were installed, he joined the “Committee of the Biblioteca,” a group of community volunteers charged with oversight and support of the biblioteca. He began attending regularly to support children with their homework, help them use computers, and to teach singing and drumming classes.

**Participation and Contribution.** The physical and attitudinal changes described above had an almost immediate impact on communities. As in the example of Miguel described above, these changes promoted participation and facilitated the ability of individuals with disabilities to make their own contributions. In another community, a young woman who used a wheelchair and had never gone to school, began coming to some community events in the biblioteca. Although very difficult terrain around her house prevented daily participation in the biblioteca,
community members found ways to carry her to special events when they could. In two
villages, two young women with intellectual disabilities and who had never completed school,
became active, daily participants in the bibliotecas. One volunteered to assist the facilitator in
the biblioteca and became an active participant in the Circulos de Amigos for other individuals
with disabilities in her village. In another community, a young woman, who had dropped out of
school after failing first grade multiple times, had become afraid to leave her house for fear of
being rejected and bullied. Indeed, during an early home visit, she hid behind the family’s
refrigerator. Despite several invitations to come to the library she initially refused to participate.
She eventually began engaging during home visits and members of the Circulos de Amigos
eventually persuaded her to assist the facilitator in the preschool program at the library. She
now attends everyday where she helps the facilitator. In the process, she has begun learning to
read and write.

And, as described previously, in two different villages where the Circulos de Amigos for two
young boys made an appeal for scholarship funds so that each child could receive scholarships
to attend schools for the deaf in other towns. Their mothers accompanied them, and attended
sign language classes taught to parents. In both cases, their mothers returned to their villages
and began teaching sign language to anyone in the community who was interested. In total, 25
individuals from the two communities have been learning sign language so that they could
communicate with the boys and so that the boys could participate actively in the bibliotecas.
Both boys now attend school, are fully included in the bibliotecas in their respective
communities where they are active, happy participants.
In addition to these specific examples, building ramps and accessible bathrooms had several unintended consequences. In one village, better access to the biblioteca led them to form an “elders” group in which older individuals in the community gathered for weekly meetings – something that would not have been possible without a ramp and an accessible bathroom. And a man with physical disabilities began making trips to other villages to talk about his experiences during El Salvador’s 12 year civil war in which he had lost his leg to gunfire.

These experiences led community members who began to see that individuals with disabilities could make important contributions to village life. Indeed, a facilitator described the role of a young woman with intellectual disabilities who assisted her in the biblioteca and participated in the Círculos de Amigos program, “...she always feels part of the Círculos de Amigos, she does not feel like a person with a disability because she is helping. She supports me a lot.” Another said that she had learned that “people [with disabilities] have many capacities,” noting that some had capacities that she did not have.

**Barriers to Participation**

Despite the benefits reported by all of the communities, a number of barriers remained for some individual participants and their families. Focus group members noted that these barriers often made the difference between participation and lack of participation. The following subthemes are described in more detail below and include: “Barriers at the Intersection of Age, Mobility and Community Accessibility,” “Previous Experiences,” and “Family Barriers: Isolation, Priorities and Fears.”
Barriers at Intersection of Age, Mobility and Community Accessibility. As reported above, our efforts to make community buildings accessible and provide interventions that promote accessibility were successful in many cases. However, the reality of living conditions in remote communities with few economic and educational resources continued to make it difficult for families whose sons or daughters were older (and therefore larger so not easily carried) and who also had more severe physical disabilities that affected their mobility. The situation was particularly challenging for families who lived in the most remote and difficult to access areas of their communities. For example, one seven year old boy with microcephalus and exposed cerebral tissue lived in a remote adobe house at the outskirts of his village. Access to the home required walking up a steep cobblestone road near the top of a mountain and then going for another quarter mile up and down on a narrow path that wound through trees. Although the IP staff and the Circulos de Amigos made numerous home visits to his family, obtained a wheelchair, built a ramp for his home and brought several specialists to the home (PT, vision specialist, special educators), his size and weight made him difficult to lift and move – often taking two or three people. The wheelchair could be used to take him outside, but could not be navigated on the narrow trail or the rocky, cobblestone road. With help from IP, he left his house three or four times so his mother could take him to San Salvador to be seen by specialists in the one public hospital that had the ability to treat medical conditions as serious as his. However, he never went to school or attended the biblioteca as it was too difficult for his family and members of the Círculos de Amigos to get him there. He died of complications from his exposed cerebral tissue early this year.
This case was one of several in which distance, severe physical disabilities combined with size were barriers that could not be overcome with the resources available through this project or IP. Giving him the ability to participate more fully would have literally required road construction and a transportation system that could help his family move him more easily. A few other participants were in similarly difficult situations. While we were able to obtain supports for them, including home visits by IP staff, specialists and Círculos de Amigos, efforts to facilitate their participation were limited by roads, terrain near and around individual homes, mobility challenges and transportation limitations (for example, the need to walk over an hour to get to a public bus). While communities found ways to get some participants to the biblioteca for occasional special events and in one case enabled a four year old with severe, quadriplegic cerebral palsy to make weekly visits to the biblioteca, it prevented more regular participation by other participants.

*Previous Experiences.* Several participants who had gone to school at one point had difficult previous experiences (e.g. repeated failures, bullying, little help from teachers in dealing with learning and behavioral challenges). This made them and their families reluctant to expose themselves to the same disappointments again. As a result, our efforts to include them in the biblioteca had varying outcomes. For instance a 15 year old girl with autism attended school, had made little progress, and was often bullied. After the Círculos de Amigos group made home visits and arranged for IP to raise scholarship funds on her behalf, she reluctantly started coming to the biblioteca, afraid that people would make fun of her. She now comes once a week and both the facilitator and the Círculos de Amigos have worked hard to make sure she engages (rather than sitting apart from the group) and that she is welcomed by the group.
Similarly, in another village, a young man who failed first grade ten times and finally quit after becoming discouraged and angry. After more than two years and many invitations, he hesitantly began showing up occasionally in the biblioteca and attending some community events. Although we consider both of these examples “successes,” they illustrate how previous experiences made it difficult for some participants and presented a barrier to participation that persisted despite considerable effort to promote social and educational inclusion.

**Family Barriers: Isolation, Priorities and Fears.** During focus groups community leaders, members of the Circulos de Amigos, and facilitators in the biblioteca differentiated between families who participated and those who did not. In some cases, the families themselves had long been isolated within their communities and had never participated in community events, even prior to having a child with a disability. For them, the project did not generally alter their inclination not to participate. As one community leader told us, “…there are different families that maintain their own autonomy and they do not break this. They do not want to work with others.” Although IP staff and members of the Circulos de Amigos initially made visits, they felt their efforts were not welcome and began feeling uncomfortable continuing to visit. In other instances, families welcomed visits from the Circulos de Amigos, but would not or could not bring their child to the biblioteca.

For some, previous experience led families to fear that their son or daughter would be mistreated. Some feared their child would be bullied or rejected and so they were reluctant to put their child in situations in which they would have such experiences. In other cases, parents still feared their child would be taken advantage of if they could not be there to protect them.
In several instances, families had competing priorities and complications that kept their son or daughter from attending school and/or the biblioteca (e.g., needing to work, child care responsibilities for other children). For example, one young girl with Down syndrome initially participated in the preschool in the biblioteca. Because the local school did not have teachers trained to work with her, her mother was unwilling to send her to that school. After several discussions, IP raised funds to provide her with a transportation scholarship to attend a school in a town about 20 minutes away but which required her to go on a public bus which she was too young to attend on her own. Her mother and sister began taking her, but stopped after several weeks and took her out of school because they could not commit the time to take her every day due to other responsibilities (e.g., need to work, care for other children). Scenarios similar to this were not uncommon, particularly when a child had started to attend school, began failing repeatedly and did not receive help from local teachers.

**Recommendations for the Future**

Without exception, families and community members who participated in this study emphasized the importance of continuing the project beyond the funding period, although they focused on different aspects of the program. For example, families whose children had received scholarships as well as members of their Círculos de Amigos groups all talked about the importance of those scholarships in assuring that their children could continue in school. The facilitators in the education centers focused on the importance of the training they had received and expanding that training to others – other schools and communities. All focus groups described the value of the training and the importance of expanding it. All groups
described the value of the Círculos de Amigos program and the Public Awareness Campaign and expressed a desire to continue this even after the project period officially ended. IP staff and volunteers are now evaluating the possibility of continuing these interventions and seeking funds to address recommendations for expansion as well as continuation of key components.
References


Appendices A: Photos

Training
Implementing UDL, PBS and Alt Communication
Physical Changes
Círculos de Amigos
Home Visits and Specialist Visits
Community Based Public Awareness
Encuentro II
II ENCUENTRO DE PROGRAMA DISCAPACIDAD
"COMUNIDADES INCLUSIVAS"

PROCESOS EJECUTADOS

- Círculos de Amigos/ás
- Beneficios Directos
- Campañas de Sensibilización
- Visitas con Especialistas
- Capacitaciones
- Espacios Accesibles

Capacidades diferentes. Corazones iguales!

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