

RESEARCH BRIEF

Understanding and Responding to the Needs of Individuals with Disabilities in Rural El Salvador: “Comunidades Inclusivas”

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In rural El Salvador, people with disabilities are often “invisible,” that is, they rarely leave home, attend school, or participate in village life. This action-research project used qualitative methods to 1) investigate the needs of individuals with disabilities and their families who live in economically impoverished, rural villages; and 2) identify barriers to their social and educational participation in the community. We then implemented a community-based intervention project aimed at promoting their participation and, at the end of the project, examined stakeholder perceptions of these interventions.

We began by conducting a series of focus groups designed to learn about barriers to educational and social participation in El Salvador and to generate ideas for ways that persons with disabilities might be more fully included. The first three focus groups included professionals and advocates from relevant disability rights groups and government organizations, persons with disabilities, and caregivers. We then conducted seven local focus groups with community leaders, educational facilitators and volunteers in the five rural villages where we conducted the intervention. These focus groups were designed to identify individuals with disabilities in each village as well as to understand local needs. We then conducted open-ended interviews with 24 families of children, youth and young adults with disabilities who were identified in five participating communities. We maintained field notes during home visits, community meetings and during observations in the informal education centers/ ‘bibliotecas’ operating in each village. After the intervention, we used a similar strategy to obtain participant perceptions of the project. Verbatim transcripts from interviews, notes from focus groups and field notes from observations were coded using an inductive, constant comparison process to identify themes and subthemes.

Based on initial data collection, we developed and implemented an intervention program called “Comunidades Inclusivas.” It was designed to serve persons with a range of disabilities who ranged from 18 months to 39 years of age. It included four components:

- 1) Community Based Public Awareness Campaigns. Local leaders in each village created materials (e.g. local presentations, inclusive videos, a logo contest, t-shirts, and community bulletin boards), designed to promote social and educational inclusion; inform villagers of the rights of individuals with disabilities; and promote the use of respectful, person-first language.
- 2) “Circuitos de Amigos.” Friends and neighbors formed teams to identify and support individual and family needs. Activities varied depending on individual circumstances but included home visits, helping families create accommodations at home (e.g. building a ramp), determining individual needs, and supporting participation in community activities and events. When a need emerged that required additional resources (e.g. funding, transportation, expert assistance), the “Circulo de Amigos” worked with the family and cooperating nongovernmental organizations to locate resources.
- 3) Training for local informal teachers (known as facilitators) and community volunteers. Training sessions were developed and implemented to enhance the ability of those working in local education centers to promote inclusion. Sessions focused on Universal Design for Learning, Positive Behavior Support, and Strategies for Alternative Communication. In addition, local disability rights groups offered training related to the rights of individuals with disabilities in El Salvador and ways to protect individuals with disabilities during natural disasters. Finally, in two villages, mothers of children who were deaf offered weekly sign language classes to community members to promote their children’s community participation.
- 4) Specialist Visits. Since accessing professional services was difficult, we arranged a series of visits from specialists (e.g., physical therapists, special education, experts in vision and hearing) who conducted assessments and recommended interventions. Visits were conducted in collaboration with the family member, the “Circulo de Amigos” and facilitators so that they could learn how they could support the individual in the village. When appropriate, specialists helped arrange additional supports (e.g. therapeutic equipment) for participants.

Key Findings

Multiple challenges to social and educational participation were identified at the *intersection of poverty, rurality and disability*. These challenges combined to exacerbate

barriers identified in other contexts (e.g. accessibility in schools; lack of teacher training) or create additional ones. These are briefly summarized below.

- 1) The ***adequacy and availability of public services*** was a significant challenge in poor, rural areas. Although basic public services (e.g., public hospitals & schools) are available at no cost in El Salvador, these systems are under-resourced, over-crowded and often distant for rural families. Thus, despite a good public children's hospital in San Salvador and a respected, national institution that provides physical, occupational, and speech therapy, these were difficult for families in this study to access. Services were sometimes available in private programs; however, most were located in cities, unavailable in rural areas, and cost-prohibitive for those living in poverty.

Similarly, ***a lack of resources in public schools*** had major implications for families. Although the Ministry of Education (MINED) had established a special school in each department and had at least one trained teacher in each department to serve in public schools, most worked in larger schools and even they often had few materials and limited training. Several families of students reported that their child had begun school, failed repeatedly, received little or no additional help, and finally dropped out. One student with intellectual disabilities failed first grade ten times before finally dropping out without being able to read. Smaller villages often did not have public schools. When they did, staff and resources were limited. One village had a school that served students from preschool to sixth grade, but only had two teachers for 60 children. Neither had training to address the needs of students with disabilities.

- 2) ***Distance and cost of transportation*** emerged consistently as an issue in this context. Most services for persons with disabilities were located in San Salvador. For families in this study, accessing such services required a complicated all-day trip, that included walking a long distance (or if lucky, catching a ride in the back of a truck) to get to a bus stop; then taking multiple buses. One mother began walking at 3 A.M. to take her six-year-old with cerebral palsy to a weekly therapy appointment. Some parents could make trips like this when their children were younger, but with age, their children became too heavy to carry.

The cost of accessing such services was also prohibitive for families. One single mother of five began taking her daughter, who had cerebral palsy, to therapy in the city, which required her to miss work. She depended on temporary farm labor for survival. At one point, she did not have money for bus fare and so her daughter missed several sessions. Although she eventually earned enough to return, they had missed too many sessions and could no longer attend. Her daughter received no further physical therapy.

- 3) In these villages, **accessibility** took on a different meaning than in most discussions of inclusion. For families in this study, accessibility in schools was only relevant when students could get to school in the first place. More importantly, all five villages lacked basic infrastructure and had poorly maintained, unpaved roads full of rocks and holes. Many homes could only be accessed by walking on narrow trails, across fields, or wading through streams and many had latrines that required users to walk up three steep steps. Thus, for participants with mobility impairments, simply leaving home became a major barrier.
- 4) **Lack of economic resources prevented families from following through on professional recommendations.** Some participants with disabilities had medical and nutritional needs requiring expensive supplements or medications. Although public hospitals sometimes provided medications at no cost, they often were out of supplies. One seven-year old had multiple disabilities including Down Syndrome, hearing loss, and vision impairment. He also had numerous health problems including hyperactivity, a missing kidney and gastric reflux disease. His parents could not afford the prescribed medications and so when the hospital did not have them, he went without. Another child was premature and diagnosed with failure to thrive. The prescribed food supplement cost half of the family's total income each month (when they had work) and they could not afford to purchase it. By age three, she was the size of child half her age. As part of this project the "Circulo de Amigos" helped her mother with funds to purchase the supplement and, over time, she was able to attend the education center, and eventually school.
- 5) **Beliefs and Attitudes** were barriers to inclusion when teachers or parents doubted the capacity of the person with disabilities to participate and/or learn. Some parents feared their son or daughter would be rejected or bullied and tried to protect them by limiting their

participation. Families also varied considerably in the extent they believed they could influence the trajectory of their child's development. Some believed that their child could not learn and thought the best course of action was to keep them at home where they would be protected. For some this was grounded in a religious belief that the disability was God's will and that their task was to protect and care for their child. Others tried to involve their son or daughter in school or other activities, but stopped when they found the challenges of participation outweighed benefits.

In contrast, other families went to great lengths to identify and access services. One mother spent the week in San Salvador so that her child could learn sign language. She then returned to the village where she taught sign language to community members so that they could communicate with him in the informal education center and during community events.

- 6) Families also varied in the extent to which they were **engaged in the community** in general. Some were very active, participating in the community governing council or related committees and, as a result, very **socially connected**. Many had deep kinship networks and friendships that extended over multiple generations. These social connections often influenced participation of those with disabilities. For example, one mother was part of a large family network, worked as the "facilitator" in the informal education center, and had multiple family members who had long been active in the community. Her daughter (who had cerebral palsy) was included in the education center from age three. By the time she was old enough for school, many already knew her, accepted her disability and helped her when she needed it. In contrast, a few families had always been isolated and had limited interactions with others for reasons that had nothing to do with disability (e.g. personal disagreements, distance from the center of the community). Despite repeated invitations, neither they nor their children participated in community activities. For still others, the disability made it more difficult to leave home and participate in community functions, leaving them isolated.

The program was successful in facilitating engagement for many families. For example, one young woman with intellectual disabilities who had dropped out of elementary school was invited to assist in the education center. She became a popular participant, learned how

to use the computer and became a member of another child's "Circulo de Amigos." Similarly, the mothers of two young boys with hearing impairments (from two different communities) began teaching sign language to other participants so that they could communicate with their sons.

- 7) **Knowledge gaps** were common among stakeholders and included families, teachers, and community members. Many participants had limited information as to the nature of the disability, and even some parents had difficulty when we asked about their child's diagnosis. At the outset of the study, there was little knowledge about the rights of persons with disabilities; few families knew they had any rights and none knew what to do if their rights were violated. Community members did not know how to approach, communicate with, or assist members of their community with disabilities. Most teachers had little training as to how to facilitate learning for students with disabilities, leading students to fail repeatedly before finally dropping out. Parents were often unsure if additional services were available and did not know how to access those services. For example, one mother walked her six-year old twins to school to enroll them. When she explained that one of her sons was deaf, she was told that he had the right to come to school, but warned that no one at the school knew sign language and they did not believe he would learn.
- 8) In small remote villages we studied, **there was wide variation in the ages and types of disabilities**. The number of persons with disabilities who met the age criteria ranged from two to eight. For example, one village had an 18-month-old boy with cerebral palsy, a six-year old boy who was deaf, and a young woman in her 20s with intellectual disabilities. They had varied and distinct needs, which made it essential to create a program that was inclusive and appropriate to the individual needs of all participants.
- 9) Stakeholders described **multiple benefits from having participated in the program**. Most school age participants with disabilities either attended public school or the informal education center (or both) by the end of the project. Families had positive perceptions of the "Circulos de Amigos" component of the program whose members supported their individual needs and helped them access concrete assistance (e.g., obtaining a wheel chair, ramp construction at home) and provided social support during home visits and community

activities. For some, the program helped change the belief that their child needed to stay home, particularly when they sensed that there was more acceptance within the community. All villagers we talked to were delighted with the construction of accessible bathrooms and ramps in the education centers noting that they helped others in the community as well. For example, these additions in one community helped a group of community elders gather for regular meetings. Focus group participants cited social changes that came from the public awareness activities, training and "Circulos de Amigos" activities. One community member, explained by saying, "now we see them," a reference to the previous invisibility of this population in the community. Another said, "Of course, we want to help, we just never thought about them [individuals with disabilities]." Many appreciated new skills that they developed, such as learning how to approach someone with a disability "without fear," how to communicate more effectively, and how to create activities in which everyone could participate. Facilitators and volunteers in the education centers were grateful for the practical strategies (e.g. universal design for learning, creating communication boards, supporting positive behaviors) they learned as part of the training.

Conclusion and Recommendations

These findings suggest the need to develop and implement practical, community-based strategies for promoting acceptance and inclusion of persons with disabilities in rural villages. Local strategies such as the "*Circulos de Amigos*" program were especially important in a country where resources are so limited and the impact of poverty was so pervasive. Similarly, these findings argue for local training and public awareness activities to disseminate information about disability rights. In addition, there is a need for more systemic improvements that would permit inclusion. This includes better mechanisms for persons with disabilities to access services (e.g. systems of transportation), more awareness of the rights of individuals with disabilities, and practical training for teachers and professionals so that they can better accommodate individuals with disabilities into their classrooms.

This collaborative project between The University of Maryland College Park and International Partners Cassie Stern Memorial was supported by a grant from the International Foundation of Applied Disability Research (FIRAH).



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