

A photograph of a man with a prosthetic leg, wearing a plaid shirt and a cap, using a wooden cane to walk on a paved street. A white van is parked in the background. The image is split horizontally by a green text box.

Community-Based Rehabilitation for People with Amputation in Guatemala: Situation Analysis and Recommendations

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Acknowledgments

A number of people were involved in the design, execution, analysis, and write up of this study, and the author would like to acknowledge and thank them for their role.

The following people provided input towards the development of the concept of CBR for people with amputation in Guatemala:

- Dr. Ricardo Bello - Johns Hopkins School of Medicine, United States
- Dr. Jorge Brown - ChileComunidad, Chile
- Dr. Bernadette de Jager - National Health Service, United Kingdom
- 1st Lt. Ian Gibson - United States Air Force, United States
- Dr. Hannah Kuper - London School of Hygiene and Tropical Medicine, United Kingdom
- Neha Lamech - Schizophrenia Research Foundation, India
- Dr. Lionel Nizigama - World Health Organization, Mozambique
- Alex Palmer - Freelance Writer, United States
- Dr. Sabeen Shah - The Indus Hospital, Pakistan
- David Shallcross - London School of Hygiene and Tropical Medicine, United Kingdom

Dr. Ricardo Bello (Johns Hopkins School of Medicine) translated the interview instrument into Spanish.

Manuel Colón (US Peace Corps) translated the participant information form and informed consent forms into Spanish.

The following people recruited and coordinated participants in their respective organizations:

- Norma de Leon, Eli Miranda - Centro de Atención al Discapacitado del Ejército de Guatemala (CADEG), Guatemala City
- Francisco Sojuel, Juan Francisco Chavajay Sisay - Asociación de Padres y Amigos de Personas con Discapacidad de Santiago Atitlán (ADISA), Santiago Atitlán
- Carmen Garcia - Senderos de Maíz, Panajachel
- Dr. Jorge Hurtarte, Dr. Gerardo Ferringo, Dra. Miriam Scheel - Trauma Heroes Association, Guatemala City
- Jorge Coy, Florie Bielsa, Hermalinda Macz - TrickleUp, Cobán

Fernanda Pinzon (Naturaceites, Guatemala) and Andrea Reyes (Cemaco, Guatemala) served as research coordinators and conducted participant interviews in Guatemala City.

David Shallcross (London School of Hygiene and Tropical Medicine, United Kingdom) provided input towards the analysis of the study.

Michael Bell (Fronterion Ventures, United States), Karen and David Hyman (University of Illinois at Urbana-Champaign, United States), and Jonathan Naber financed the study.

Philip Amoa (McCarter & English, LLP), Michael Bell (Fronterion Ventures, United States) and Alex Palmer (Freelance Writer, United States) provided organizational/strategic support to the study.

Carrie Weingart (Independent Graphic Designer) was responsible for the graphic design of the report.

David Krupa (ROMP-USA, United States) helped to develop the recommendations and edited the report.

The author acknowledges and thanks his colleagues at ROMP for their outstanding, ongoing support of the ROMP Program on CBR - past, present, and future.

ROMP USA:

- Sandy Dukat - Member of the Board of Directors, ROMP-USA
- Daniel Grant - Member of the Board of Directors, ROMP-USA
- Josh Kaplan - Member of the Board of Directors, ROMP-USA
- David Krupa - Founder and Chief Executive Officer, ROMP-USA
- Eric Neufeld - Founder and Member of the Board of Directors, ROMP-USA
- Lizzy Neufeld - Vice President of Strategy and Growth, ROMP-USA
- Lauren Panasewicz - Director of Events and Outreach, ROMP-USA
- Lindsay Senter - Member of the Board of Directors, ROMP-USA
- Shree Thaker - Operations Associate, ROMP-USA
- Hirshini von Kalm - Member of the Board of Directors, ROMP-USA
- Carrie Weingart - Member of the Board of Directors, ROMP-USA

ROMP-Guatemala:

- Luis Aragón - Prosthetist/Orthotist and Executive Director, ROMP-Guatemala
- Luis Antonio Aragón - Prosthetist/Orthotist, ROMP-Guatemala
- Vivian Aragón - Administrator, ROMP-Guatemala
- Rosa Hernandez - Auditor, ROMP-Guatemala
- Carlos Herrera - Prosthetic/Orthotic Technician, ROMP-Guatemala
- Elsa Orellana - Maintenance, ROMP-Guatemala
- Gever Vargas - Inventory, ROMP-Guatemala

ROMP-Ecuador:

- Felipe Chediak - Member of the Board of Directors, ROMP-Ecuador
- Dominic Hamilton - Member of the Board of Directors, ROMP-Ecuador
- Maria Luz Arellano - Member of the Board of Directors, ROMP-Ecuador
- Kathy Pico - Member of the Board of Directors, ROMP-Ecuador
- Fernando Rivera - Member of the Board of Directors, ROMP-Ecuador
- Liliana Romero - Member of the Board of Directors, ROMP-Ecuador"

Thank you to Olive Media/ROMP and Marc Altman for providing photos for this report.

The author apologizes for any individual or institution that was accidentally omitted from these acknowledgments.

Aim and Objectives

The aim of this study was to inform the development of a community-based rehabilitation (CBR) program for people with amputation in Guatemala, namely through two specific objectives:

1. Assess the needs and desires of people with amputation in Guatemala for a CBR program.
2. Make recommendations for action by the CBR program based on the assessment.

“...discrimination never, never will end. Never.”
- Participant 3

“When I suffered the accident more than anything it affected my mother a lot because I’m the oldest son.

...she felt it a lot because she never expected in life that she would be given this surprise that one of her sons was going to be a leg and arm amputee.”

- Participant 13

“if I didn’t have this amputation, it would be a different life... perhaps economically, perhaps socially, perhaps in the field... I could go to walk a bit on the hill, to do a little exercise... but now [I’m] not able and [I] won’t be able.”

- Participant 9

Community-Based Rehabilitation

According to the World Health Organization (WHO), the concept of community-based rehabilitation (CBR) arose from the international primary healthcare movement, sparked by the 1978 Declaration of Alma Ata. Since its conception, the CBR approach has transitioned from a strategy of public health systems for care and service delivery for people with disabilities in resource-limited settings to a strategy for community development that is inclusive of people with disabilities and involves a wide range of stakeholders. [1] According to the UN's Joint Position Paper 2004, "... the concepts of disability and rehabilitation, the emphasis placed on human rights and action to address inequalities and alleviate poverty, and on the expanding role of DPOs" were drivers behind this change. [2]

In 2004, CBR was given the following definition by the United Nations (UN): "... a strategy within general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities." [2] Today, the development and execution of CBR programs is guided by the WHO CBR Matrix, which "... consists of five key components – the health, education, livelihood, social and empowerment components." This framework is consistent with the revised definition of CBR, and in particular the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and it demonstrates the broad scope of intervention and involvement presented by CBR. [1] The CBR Matrix is exhibited in Figure 1 below.

CBR MATRIX

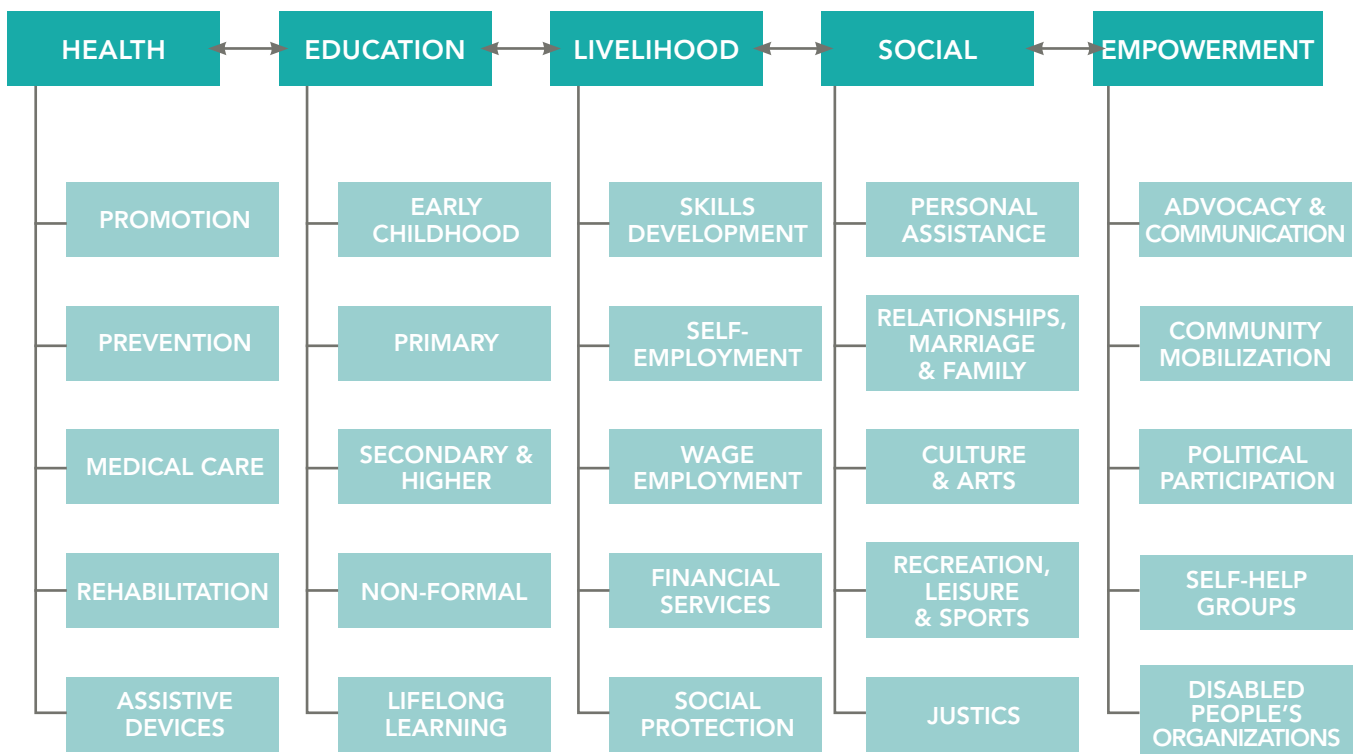


Figure 1: The CBR Matrix. [3]

The first step in the WHO management cycle of CBR is the situation analysis, which is the collection and study of information regarding the context and experiences of people with disabilities in the community of focus. It provides the intelligence upon which the program is designed to ensure it meets the needs and desires of its clients. The Situation Analysis consists of five “analytic modalities”:

1. “Collecting facts and figures.
2. Stakeholder analysis.
3. Problem analysis.
4. Objectives analysis.
5. Resource analysis.” [1]

Following the situation analysis, the WHO specifies that the management cycle of a CBR program moves through the following steps, on a continual basis:

2. “Planning and design (Stage 2)
3. Implementation and monitoring (Stage 3)
4. Evaluation (Stage 4)” [1]

In 2010, the WHO reported that “CBR is currently implemented in over 90 countries.” [1] Despite its widespread use, according to Lemmi et al, evidence on the effectiveness of CBR programs is extremely limited. However, in their systematic review of outcomes studies, some notable impacts of CBR programs were observed, in both people with physical disabilities and people with mental disabilities. Health-related outcomes of interest were generally improved in the CBR intervention group compared to the control group in a number of studies conducted primarily in Asia. There were almost no studies in the education, livelihood, social, and empowerment categories. [4]

Aim and Questions

The aim of this literature review is to analyze the statistics, policies, and stakeholders affecting people with amputation in Guatemala. The following questions guided the review:

- What is the etiology (cause) and burden of amputation in Guatemala?
- What does the policy landscape look like for people with amputation?
- What stakeholders engage people with amputation, and what elements of CBR are provided?
- What stakeholders provide CBR, and to what extent do they engage people with amputation?

“...at that moment many things happened in my mind... what will I do, from what will I live, how will my life be, who will love me without a leg... here in [town, redacted for privacy], it is not normal... it is not normal to see people without leg, without arms...”

- Participant 9

What is the etiology and burden of amputation in Guatemala?

Published data on the etiology and burden of amputation is extremely scarce for nearly all developing countries, and Guatemala is no exception. Searches of the Medline and Embase databases using the search criteria (incidence OR prevalence OR aetiolog* OR caus*) AND (amput* OR limb*) AND (Guatemala*) yielded no papers in English or Spanish that were epidemiological studies of amputation in Guatemala. Given the dearth of peer-reviewed literature on the epidemiology of amputation, it is necessary to rely upon information in publicly-available documents.

In 2016, the Government of Guatemala conducted a National Disability Survey, which included: “1. A population based survey to estimate the prevalence of disability 2. A case-control study to compare people with [cases] and without disability [controls] in terms of their socio-economic status and their use of education, health, water and sanitation and employment services.” While neither the prevalence, nor the etiology, of amputation were measured in this study, the prevalence of disability in the “mobility” domain was measured to be 8.0% in all adult participants - 6.5% in adult men and 9.1% in adult women. While amputation is among the causes of mobility-related disability, it is not the sole cause and thus this prevalence simply serves to illustrate the importance of mobility-related disability in the Guatemalan context. Furthermore, the prevalence of mobility-related disability varied significantly by geographic region of Guatemala: it was highest at 7.2% in the Central region and 6.4% in the Northwest region, compared to 1.9% in the Southeast region and 2.2% in the Northeast region. [5] This prevalence measure cannot specify the geographic variance of amputation, however it can give a general idea of how amputation might vary across the country as part of the larger mobility domain of disability.

Additionally, among cases, the leading “main cause of functional limitation” were “Illness” at 30%, “Aging” at 18%, “Trauma” at 15%, “From birth” at 12%, and “Unknown” at 10%. The leading “Age of onset of functional limitation” were “Older age (50+)” at 40%, “Adult (18-49 years)” at 27%, and “Child 5-17 years” at 17%. [5] These measures were taken for all cases and thus cannot be directly applied to understanding cause or age of amputation; however, they may indirectly and at a high-level shed some light onto the most important causes and ages of amputation in Guatemala.



“...if they are going to amputate me I won’t be able to see my foot again the way it is right now, I will only see a piece of... with a prosthesis it is not the same as seeing your foot as a prosthesis. I think it will affect me emotionally. I think I will feel bad.”

- Participant 12

What does the policy landscape look like for people with amputation?

In 2008, the Guatemalan Congress passed the National Policy on Disability with the overarching goal to “Create opportunities for integration and participation for people with disabilities in Guatemalan society.” The National Council for the Care of People with Disabilities (CONADI, per its acronym in Spanish), which conducted the situation analysis and writing leading to this Policy, was designated as the primary coordinator of the various governmental and nongovernmental stakeholders working to bring the Policy to fruition [6].

The Policy sets seven strategic objectives through which to accomplish its overarching goal:

1. “Prevention of disability, health, habilitation and rehabilitation of people with disabilities.
2. Education, culture, recreation and sport for people with disabilities.
3. Employment, income-generating activities and occupation for people with disabilities.
4. Access to physical spaces, housing and transportation for people with disabilities.
5. Information and communication for society and for people with disabilities.
6. Access to justice, citizen security and human rights.
7. Organizational development by and for people with disabilities.” [6]

These strategic objectives are further broken down into 25 operational objectives, which are then distributed among a number of governmental and nongovernmental stakeholders into a coordinated plan for implementing the Policy, which includes “objectively-verifiable indicators” and “forms of verification” for monitoring and evaluation. The stakeholders are grouped by the Policy into four key categories:

- **CONADI:** described above.
- **Governmental ministries:** Specific ministries include: “Education; Public Health and Social Assistance; Labor and Social Provision; Communications, Infrastructure, and Housing; Culture and Sport; Public Finances, through the Budget Administration; Agriculture, Livestock and Nutrition; Governance.”
- **Other governmental entities:** Specific entities include: “Secretariat of Social Wellbeing of the President of the Republic, SBS; Secretariat of Social Works of the Wife of the President, SOSEP; Secretariat of Planning and Programming of the President of the Republic, SEGEPLAN; Secretariat of Executive Coordination of the President of the Republic, SCEP; Secretariat of Social Communication of the President of the Republic; Presidential Secretariat of Women, SEPREM; National Institute of Statistics INE; departmental [state] governments; System of Development Councils, especially at the departmental, municipal and community levels.”
- **Other public entities:** Specific examples include: “Guatemalan Institute of Social Security; University of San Carlos in Guatemala; Autonomous Sport Confederation of Guatemala; the 334 municipalities of the country.”
- **Disabled persons organizations (DPOs):** “.... entities and organizations by and for people with disabilities and their families....” [6]

The laws that underpin the implementation of the Policy are made by the Guatemalan government, and can be generally characterized into three categories:

- **Constitutional law:** The Constitution has a number of disability-specific provisions. Article 53, for example, states: “The medical-social interest [of people with disabilities] is declared as a national interest, through the promotion of policies and services that allow for their rehabilitation and integral reincorporation into society.” Furthermore, Article 102, part m states: “Protection and promotion of work for the blind, disabled and people with physical, psychiatric or sensorial impairments.”
- **Cross-sectoral laws:** These laws transcend multiple stakeholders as a coordinated, strategic policy of the national government. The Law for the Care of People with Disabilities, is a clear example of this type of law, as are the Law for Social Development and the Law for Rural and Urban Development Councils.
- **Sectoral laws:** These laws are implemented by specific ministries given their agency and expertise. Examples include the Health Code, implemented by the Ministry of Public Health and Social Assistance, the Work Code, implemented by the Ministry of Labor and Social Provision, and the General Law of Education, implemented by the Ministry of Education. [6]

Because of the general, blanketing design of the Policy, no specific mentions of people with amputation are made. Thus, the themes discussed should be viewed as inclusive of, but not unique to, people with amputation. On a high level, the inclusive nature of the policy is encouraging; that the implementation of the Policy does not discriminate upon type of disability is important. However, it is also important to note that key nuances of specific types of disabilities can be overlooked without sufficient in-depth engagement. For example, the situation analysis that CONADI conducted to inform the writing of the Policy, although very comprehensive in nature, appears to have engaged organizational stakeholders more than individuals with disabilities. [6] This reflects a common issue encountered in the creation of social policy: an institution-centric rather than an individual-centric approach.

CBR is specifically mentioned in the Policy, which indicates that the Ministry of Public Health and Social Assistance is pursuing CBR “as a model of care for disability in rural areas.” [6] That CBR is mentioned only as an activity of the Ministry of Public Health and Social Assistance shows the singularly medical focus of the Policy’s vision for CBR; the Ministry of Labor and the Ministry of Education are not implicated, which reveals either a limited vision or an inability to deliver services consistent with the principles of CBR, as it is defined in the preceding section of this literature review.

Although the Guatemalan government passed the Policy, developed an implementation plan, and charged CONADI with coordination, the results have been disappointing. Grech writes that nearly twenty years after Guatemala adopted the UNCRPD, the situation has not improved for the people with disabilities. He attributes this to “institutional practices” of the stakeholders involved in implementing the Policy. [7]

Some of these detrimental practices can be ascertained from the Policy document alone. The structure for coordination of the Policy is highly centralized, relying upon CONADI to liaise between the stakeholders that make law, and the stakeholders that actually implement it. This means that the implementation of the Policy can only be as strong as CONADI, which, given its limited funding and bandwidth, has indeed left much to be desired. [6]

Aside from structure, funding, and bandwidth issues, a major consideration is the corruption that permeates nearly every level of the Guatemalan government. In September 2015, Otto Perez Molina resigned as President of Guatemala due to ongoing controversy over his alleged involvement in a massive corruption case involving the Guatemalan customs agency. [8] Corruption in Guatemala is extremely prevalent, where the impunity rate is approximately 70%. [9] This corruption is commonly known to permeate nearly every level of the Guatemalan government.

Due to the historical failure of policy and institutions to meet the needs of its citizens with disabilities, and the ongoing upheaval in the government, it is clear that a solution outside of the government, although not exclusive of it, will be needed to realize the vision articulated in the Policy. It is also clear that this solution will need to be designed in a more individual-centric and comprehensive manner to avoid the current pitfalls plaguing the system.

What stakeholders engage people with amputation, and what elements of CBR are provided?

There are several organizations in Guatemala that work with people with amputation, either as their primary focus or via a specific program they implement:

- **Centro de Atención al Discapacitado del Ejército de Guatemala (CADEG)** – This governmental institution, located in Guatemala City, provides rehabilitation services to current and former members of the Guatemalan military and their families, of which there are a number of people with amputation. Specifically for people with amputation, the center features a prosthetics workshop providing prosthetic care. The center also provides medical, dental, psychological, and social work services to its patients. Through its military administration, this center is affiliated with the Military Hospital located in Guatemala City. [10] This center helped to recruit and coordinate participants for this study.
- **Hospital Nacional de Ortopedía y Rehabilitación** – This public hospital, located in Guatemala City, provides rehabilitation medicine to members of the public with cases of congenital or acquired disability, including people with amputation. Although the hospital offers clinical, surgical, therapeutic, psychological, and social services to patients, it does not provide prosthetic care, but instead refers patients with amputation to other prosthetics workshops in Guatemala City. As a part of the Ministry of Public Health, this hospital is loosely affiliated with a number of other public clinics and hospitals throughout the country of Guatemala. [11]
- **IGSS Hospital de la Rehabilitación** – This social security hospital, located in Guatemala City, provides rehabilitation services to people who work for employers paying into the Guatemalan Institute of Social Security (IGSS) system, and their families. The hospital features a prosthetics clinic providing prosthetic care for people with amputation. It also provides a wide spectrum of therapeutic, psychological, and social work services to its patients. This hospital serves as the flagship rehabilitation hospital in the national network of social security hospitals throughout Guatemala. [12]
- **Ortopedía Centroamericana** – This private clinic, with a primary office in Guatemala City and a satellite office in Quetzaltenango, provides prosthetic care to people with amputation that choose to receive private prosthetic care rather than receiving it through the public or social security systems. In order to reach individuals distant to these two urban centers, the company also has clinic days in the cities of Cobán, Jalapa, Jutiapa, Chiquimula, Puerto Barrios, Morales, and Salamá. The clinic also provides orthotic care to those with other musculoskeletal impairments. [13]

- **Range of Motion Project (ROMP)** – This nongovernmental organization, based in the city of Zacapa, provides prosthetic care to people with amputation that either cannot, or choose not to, access prosthetic care through other institutions like those described above and below. In order to reach patients facing a geographic or mobility barrier to traveling to Zacapa, the organization sends a mobile lab to patients in their communities. It also provides orthotic care to people with other musculoskeletal impairments, is involved in new product development and testing, and connects patients to physical therapy through partner Hearts in Motion (HIM) and the Universidad Mariano Gálvez network. [14] The author works for this organization, and this study will inform its development of a CBR program for people with amputation in Guatemala.
- **Teleton-Fundabiem** – Once per year, a nation-wide Teletón fundraising campaign raises funds to subsidize the services of the Fundabiem network of rehabilitation centers for the coming year. The Fundabiem centers, located throughout the country, provide rehabilitation services to people with disabilities. Specifically for people with amputation, some of the centers feature a prosthetics workshop; if they do not, they are able to refer the patient to a center with a workshop. Physical, occupational, and psychological therapy are also offered to patients. [15]
- **Transitions Foundation of Antigua** – This nongovernmental organization, based in the city of Antigua, provides a variety of services to people with disabilities from throughout Guatemala, especially those in the Western, majority-indigenous departments. Specifically for people with amputation, the organization features a prosthetics clinic. It also provides orthotic care, and operates a wheelchair workshop, and education, vocational training, and sports programs. One major focus of the organization is employing its participants at its wheelchair workshop as well as at its own print shop, and it is also active in disability advocacy work both within Guatemala and internationally. [16]

While there are a number of organizations that work with people with amputation in Guatemala, some of which provide certain elements of CBR to their patients, none yet provide a comprehensive, decentralized CBR program for patients with amputation. It is also worth noting that the majority of these organizations are based, or primarily operate, in Guatemala City.



“I don’t work since my operation. Since they operated on me, I stopped working, my economic situation has become more difficult everyday, right, because it is impossible for me to get a real job.”

- Participant 18

What stakeholders provide CBR, and to what extent do they engage people with amputation?

There are several organizations in Guatemala that provide CBR or CBR-type services, either as their primary focus or via a specific program they implement:

- **Asociación de Capacitación y Asistencia Técnica en Educación y Discapacidad (ASCATED)** – This Guatemalan, nonprofit organization takes a CBR approach to working with people with disabilities, with a focus on the education, social, and empowerment needs of its participants. Its largest program is a collaboration with Plan International, focusing on children with disabilities and their families in the Department of Izabal. The program utilizes community rehabilitation workers (CRWs) to reach the smaller, more-remote villages within its region of operation. [17] [18]
- **Asociación de Padres y Amigos de Personas con Discapacidad de Santiago Atitlán (ADISA)** – This grassroots, nonprofit organization provides CBR services to people with disabilities in the city of Santiago Atitlán in the Department of Sololá and the city of Chiquimula in the Department of Chiquimula. It provides multiple services and programs in each of the five CBR categories. Initiated by a local family, the organization has grown through the support of a wide range of domestic and foreign partnerships. This center helped to recruit and coordinate participants for this study. [19]
- **TrickleUp Guatemala** – This multinational nonprofit organization, with its national office in the city of Cobán, targets people “who are the most economically and socially excluded in their communities”, one segment of which is people with disabilities. Its primary intervention is the promotion of self-employment for participants, namely via a “graduation” program, which is currently focused on the communities of Lachuá and Tamahú in the Department of Alta Verapaz. This center also helped to recruit and coordinate participants for this study. [20]

While there are organizations that provide comprehensive, decentralized CBR or CBR-type services to the general population with disabilities, none is specifically focused on the population with amputation. The absence of this focus runs the risk of providing overly-generalized services to people with amputation, missing their specific needs and desires.

This major gap in the Guatemalan rehabilitation system for a CBR program that is focused on the needs and desires of people with amputation is the impetus for ROMP conducting this study.

“...because there are many people with disabilities, amputees...”
- Participant 7



Sampling

Participants were purposively sampled through several disability-focused organizations that agreed to participate in this study. These organizations included the following:

- Centro de Atención al Discapacitado del Ejército de Guatemala (CADEG), based in Guatemala City, Department of Guatemala
- Asociación de Padres y Amigos de Personas con Discapacidad de Santiago Atitlán (ADISA), based in Santiago Atitlán, Department of Sololá
- TrickleUp Guatemala, based in Cobán, Department of Alta Verapaz
- Trauma Heroes Association (THA), based in Guatemala City, Department of Guatemala

Inclusion criteria for participants served as a guide for participant sampling. The inclusion criteria for participants included the following:

- Participant has an amputation of either an upper or lower extremity. Neither the side or level, nor the date or the location of the amputation matter.
- Participant lives in one of the following departments (states) of Guatemala: Alta Verapaz, Baja Verapaz, Chimaltenango, Huehuetenango, Quetzaltenango, Quiché, Retalhuleu, San Marcos, Sololá, Suchitepéquez, or Totonicapán.
- Participant is adult (18+ years of age).
- Participant is willing to speak about their life as a person with amputation for 30-45 minutes.

“What I think my town needs is more options, and these options are what I want to create in this town. I want to create school-workshops of carpentry, school-workshops of ironwork, school-workshops of electricity, and school-workshops of confections. In which these school-workshops create their own product and go sell and this product serves to sustain these little businesses and these little businesses employ different people.”

- Participant 14



Data Collection

The participants were interviewed by two research coordinators and the author from December 2015 through February 2016. Some of the interviews were conducted in the office of the sampling organization, while others were conducted in the participants' homes or places of work. Each interview was audio-recorded.

The format of the interview was a structured interview with open-ended questions. Depending on the responses of the participant, the lengths of the interviews varied greatly upon the talkativeness of the participant. The interview was comprised of the following sections:

- I. Introduction
- II. General Information
- III. Amputation, Device, and Disability Information
- IV. Health Information
- V. Education Information
- VI. Livelihood Information
- VII. Social Information
- VIII. Empowerment Information
- IX. Additional information

The interview instrument was designed to cover the five pillars of CBR, as well as the analytical modalities of a CBR situation analysis. The instrument was adapted to the Guatemalan context, including translation into Spanish, from a similar study the author conducted in Tanzania. [21]

The English interview instrument is in **Appendix 1** of this report.

Informed consent was obtained from each participant prior to conducting the interview.

The Spanish participant information form is in **Appendix 2**, and the Spanish informed consent form is in **Appendix 3** of this report.

Each participant was given a modest cash remuneration of Q100 GTQ (approximately \$12 USD) to compensate them for travel and lost work-time costs.



Data Analysis

The audio recording was listened to and detailed notes were taken on a Microsoft Word copy of the interview instrument. The purpose of these notes was to capture as much of the meaning as possible from the participant's responses. Although some direct quotes were written down because of their significance, this process of detailed note taking was not a transcription of the interview.

An example of the detailed notes for a participant is in **Appendix 4** of this report. The detailed notes for all participants are available from the author upon request.

A Microsoft Excel worksheet structured by the analytical modalities of a CBR situation analysis was filled out with the individual pieces of meaning written down in the detailed note-taking. This arranged all of the meaning in the interview into an analytic framework. The analytical modalities and their respective prompts included the following:

- **Strengths, Weaknesses, Opportunities, Threats:** "Will this participant benefit from, contribute to, or influence a CBR program for people with amputation in Guatemala?"
- **Resources - Human, Resources - Material, Resources - Structures:** "What resources does this participant have that a CBR program for people with amputation in Guatemala could use or build upon?"
- **Problems:** "What problems are facing people with amputation/stakeholders that work with them?"
- **Objectives:** "What objectives do people with amputation/stakeholders that work with them have that could be consistent with a CBR program for people with amputation in Guatemala?"

These analytical modalities and their respective prompts were based on the WHO CBR situation analysis strategy. [1]

An example of the worksheet for a participant is in **Appendix 5** of this report. The worksheets for all participants are available from the author upon request.

For each of the analytical modalities, the individual pieces of meaning were grouped by similarity/connection in meaning, and the groups that resulted were given short codes. The coding framework was expanded and refined with each subsequent participant. A cumulative, updated list of codes was kept in a Microsoft Word document where the frequency of each code across all of the participants was determined, which allowed for filtering by frequency.

An example of the coding sheet for a participant is in **Appendix 6** of this report. The cumulative list of codes is in **Appendix 7**. The coding sheets for all participants are available from the author upon request.

"I have many dreams in life, in this life that I have. Even though it's with one leg, I'm always active, I'm always positive, always praying, thinking that I'm going to do everything that they can..."

- Participant 1

Description of Sample

Nineteen participants were interviewed in this study, 16 of which were male, 3 female. The ages of the participants ranged from 14 to 80, with a median age of 50. The amputations included 11 above-knee, five below-knee, one above-elbow, one-below elbow, and one unknown. One of the participants had both an above-knee and below-elbow amputation, and one of the participants was still pending his amputation.

Most Frequent Codes in Analytical Modalities:

The cumulative, updated list of codes across all 19 participants was filtered in order to determine the most frequent codes in each analytical modality. The threshold frequency in the filtering was set at $\geq 50\%$ (≥ 10 participants) for all analytical modalities with the exception of the objectives where the threshold frequency in filtering was set at $\geq 25\%$ (≥ 5 participants) due to the relatively smaller repetition of codes between participants.

Strengths Modality - Most Frequent Codes ($\geq 50\%$ Participants)	
Code	Frequency (n = 19)
[Device/rehabilitation]	16
[Ambition/will]	14
[Work experience/skills/attitude]	14
[Self-reliance/independence]	12
[Positivity/coping]	11
[Health management/wellness]	11

Weaknesses Modality- Most Frequent Codes ($\geq 50\%$ Participants)	
Code	Frequency (n = 19)
[Disempowered/mental barriers]	15
[Depression/psychological problems]	14
[Limited education/literacy]	13
[Unemployment/barriers to work]	13
[Pain/effects of amputation/accident]	11
[Financial hardship/limited earnings/costs]	10
[Activity/mobility limitations]	10

Opportunities Modality - Most Frequent Codes ($\geq 50\%$ Participants)	
Code	Frequency (n = 19)
[Family relationships/help/productivity/involvement]	18
[Medical care/medicines]	15
[Prosthetic/rehabilitation care]	11
[Community involvement]	10

Threats Modality - Most Frequent Codes ($\geq 50\%$ Participants)	
Code	Frequency (n = 19)
[Perception/treatment by others]	16
[Work climate/environment]	16
[Limited institutional help]	16
[Medical/prosthetic care gaps/insufficiencies]	14
[Educational climate/environment]	10
[Lack of connection/awareness]	10

Human Resources Modality - Most Frequent Codes ($\geq 50\%$ Participants)	
Code	Frequency (n = 19)
[Family relationships/resources/help]	18
[Vocational training/skills/experience]	15
[Ambition/will]	13
[Positivity/coping]	10
[Self-reliance/independence]	10
[Health/psychological wellbeing/management]	10

Material Resources Modality - Most Frequent Codes ($\geq 50\%$ Participants)

Code	Frequency (n = 19)
[Device/rehabilitation]	19
[Medicines/medical care]	16

Structure Resources Modality - Most Frequent Codes ($\geq 50\%$ Participants)

Code	Frequency (n = 19)
[Military health/CADEG]	10
[Church community]	10

Problems Modality - Most Frequent Codes ($\geq 50\%$ Participants)

Code	Frequency (n = 19)
[There is limited institutional help.]	17
[Participant faces difficult work climate/environment.]	15
[Participant faces adverse perceptions and treatment/lack of help from others.]	14
[There are gaps/insufficiencies in medical/prosthetic care.]	14
[Participant has depression/psychological problems.]	13
[Participant's work has been interrupted/made difficult.]	13
[Participant experiences disempowerment/general limitation/mental barriers.]	12
[Participant has limited education/literacy.]	11
[Participant has pain/other effects in his residual limb and other parts of his body.]	10
[Participant lacks an awareness of, and connection to, the disability community/services.]	10
[Participant has difficulty walking/mobilizing/exercising.]	10
[Participant faces financial hardship/limited income/high costs.]	10

Objectives Modality - Most Frequent Codes ($\geq 25\%$ Participants)	
Code	Frequency (n = 19)
[Participant wants to work.]	9
[Participant wants to restart studies/study for career development.]	8
[Participant wanted to accept his amputation and carry onwards.]	8
[Participant wants to diversify his livelihood/have greater economic capacity/improve economic situation.]	6
[Participant wants to connect with and support/help PWDs.]	5
[Participant wants to do activities/make the best of being at home.]	5

“What helped me was to stand in front of the mirror and cry for days... seeing my situation and seeing myself. It was a hard blow to see myself in the mirror and see myself mutilated, to see myself with stomach split and everything. It was hard at the time and remembering that moment I spoke of was difficult. It was really difficult. Later the moment came in which I said, ‘No, that’s how I am. There is no changing. I cannot change the situation. This is me.’”

- Participant 14



Introduction

The true situation of being a person with amputation in Guatemala can be better understood by examining the most frequent codes in the analytical modalities, as well as codes which are limited in frequency but significant. This understanding is most effectively reached by grouping “negative” and “positive” modalities, in order to accomplish the aim of this study, which is to inform the development of a CBR program for people with amputation in Guatemala.

Negative Modalities

The negative modalities include the weaknesses, threats, and problems faced by the person with amputation in Guatemala. Understanding these modalities in the context of the aim of this study, is guided by the following question: “What are the person with amputation and a potential CBR program for them up against?”

The most common weaknesses of the person with amputation in Guatemala span four of the CBR categories, demonstrating that multi-dimensional nature of weakness. Within the empowerment category is [Disempowered/mental barriers]. The health category includes mental health - [Depression/psychological problems], physical health - [Pain/effects of amputation/accident], and activity/mobility - [Activity/mobility limitations]. Within the education category is [Limited education/literacy], and within the livelihood category are both work - [Unemployment/barriers to work] - and finance - [Financial hardship/limited earnings/costs].

The most common threats come from all five CBR categories, illustrating a complex landscape of threats with which the person with amputation in Guatemala must contend. Within the social category is [Perception/treatment by others]. Within the livelihood category is [Work climate/environment]. The empowerment category includes [Limited institutional help] and [Lack of connection/awareness]. Within the health category is [Medical/prosthetic care gaps/insufficiencies]. Finally, in the education category is [Educational climate/environment].

The most common problems, similarly to the most common threats, come from all five CBR categories. Within the empowerment category are institutional-provident disempowerment - [There is limited institutional help.] and [Participant lacks an awareness of, and connection to, the disability community/services.] - and individual-provident disempowerment - [Participant experiences disempowerment/general limitation/mental barriers.]. The livelihood category includes work - [Participant faces difficult work climate/environment.] and [Participant’s work has been interrupted/made difficult.] - and finance - [Participant faces financial hardship/limited income/high costs.]. Within the social category is [Participant faces adverse perceptions and treatment/lack of help from others.]. The health category includes a systems problem - [There are gaps/insufficiencies in medical/prosthetic care.], a mental health problem - [Participant has depression/psychological problems.], a physical health problem - [Participant has pain/other effects in his residual limb and other parts of his body.], and a mobility problem - [Participant has difficulty walking/mobilizing/exercising.]. Finally, in the education category is [Participant has limited education/literacy.].

The quantitative results of the 2016 Guatemalan National Disability Survey provide a number of insights into the negatives of the CBR categories. [5] Additionally, the qualitative concerns and recommendations of the UN Committee on the Rights of People with Disabilities’ recent report on Guatemala’s compliance with the UNCRPD provides further qualitative insight. [22]

Within the health category, the prevalence of mental illness and lack of mental health infrastructure in Guatemala is alarming. Namely, 9.3% of adults surveyed self-reported “significant limitations” due to anxiety/depression; 8.0% of adults screened positive for “a moderate or severe impairment” from depression via the PHQ-9 clinical screen for depression. This high prevalence of mental illness is unfortunately met by a largely inadequate mental healthcare infrastructure, and a low awareness of, and access to, counseling services - within “cases” (people determined to have a disability), only 16.1% “have heard of” counseling, and only 3.1% “have received [counseling] services.” [5] These results underscore the importance of the recurring theme of mental health observed in this study.

There are significant deficits in “awareness, perceived need and access of rehabilitative services among people with disabilities.” Only 6.5% of cases “have heard of” CBR, and only 0.4% “have received [CBR] services.” Furthermore, only 25.0% of cases “have heard of” Medical Rehabilitation, and only 3.4% “have received [Medical Rehabilitation] services.” The proportions of cases aware of, and receiving, the other specific rehabilitation services were similarly low. Interestingly, 27% of cases “don’t know what device is” for a prosthesis. These numbers paint a drab picture of the rehabilitation of Guatemalans with disabilities. [5] These results are consistent with the recurring themes of the unavailability and inadequacy of care.

Finally, 47% of cases reported a “serious health problem past 12 months.” It is notable that the top three places that cases “sought [health] advice/treatment” were: “private clinic/hospital” (35%), “government health center” (28%), and “government/IGSS hospital” (23%). Significantly less important were: “community health worker/health post” (6%), “pharmacy” (5%), and “traditional healer/home remedy” (1%). [5] The UN report raised the issue of “the weakness of the state [public] health system and the obstacles that people with disabilities have in accessing the health services, especially in rural zones and indigenous communities.” It recommended community health services - both physical and mental in scope - to address this issue. [22]

Within the education category, for “highest education (adults only)”, 36% of people with disabilities had “no school” and 47% had “primary.” In terms of “literacy (adults only)”, 29% of people with disabilities “can read a little” and 37% “cannot read at all.” There was also a significant difference in school attendance between children with disabilities and children without disabilities in rural areas. [5] This data lines up with the issue raised by the UN: “the low [level of] schooling of boys and girls with disability, especially in rural zones and indigenous communities.” The committee recommended taking an inclusive education approach both in policy-making and implementation to address this issue. [22] These results and points resonate with the lack of, and problems with, education observed in this study.

Within the livelihood category, disability had a significant impact on work: only 34% of cases reported “working in the past week among adults”, compared to 47% of controls. Of cases, 30% reported as “works once in a while”, compared to 19% of controls. The top four “reasons for not working” in cases were: “childcare/household duties” (34%), “poor health” (27%), and “age-related” (18%), and “others will not allow” (14%). It was also determined that 44% of cases “work for own business”, 38% of cases “work for other’s business”, and 7% “work on own farm.” Reception of both “state support” and “non-state support” was extremely low in cases. [5] This situation is reinforced by the UN report: “...the majority of people with disabilities do not have a formal job, nor the real and effective possibility to receive reasonable adjustments necessary for their performance thereof. [...] lack of follow-up on the compliance of labor quotas in the public sector and affirmative action measures to accelerate the de facto equality of those people with disability with the most difficulty in accessing the job market....” The committee recommended that the existing labor inclusion law is applied, monitored, and enforced. [22] These results and points reinforce the themes surrounding the lack of, and problems with, livelihood and finance observed in this study.

In terms of the social category, people with disabilities exhibited significantly lower participation in the “domestic”, “interpersonal”, and “community” categories than people without disabilities. Disability also made a significant difference on barriers experienced in the social realm, such as “Availability of assistance at home”, “Other people’s attitudes (at home)”, and “Prejudice and discrimination.” Furthermore, disability significantly lowered the quality of life (QoL) “social relationships” domain. [5] In this category, the UN raised the issue: “... that people with disability, especially boys and girls, women and indigenous communities, are submitted to grave forms of discrimination. Likewise [...] the lack of effective implementation of the National Disability Policy by all of the ministries and concerned public institutions.” The committee recommended improving the implementation of the National Disability Policy to address this issue. [22] These results are perhaps good measurement of, and the points good explanation for, the recurring theme of difficulty with others, in perception and treatment.

In terms of the empowerment category, disability made a significant difference on barriers in “Transport”, “Format of information”, “Policies and rules (Organizations)”, and “Government programs and policies.” Finally, disability significantly lowered the “Overall QoL Rating.” [5] Many of the UN concerns were focused on this category. One concern noted was “... the reduced number of complaints, records and pronouncements about cases of discrimination on the grounds of disability...” The committee recommended improving the availability of legal resources via the Guatemalan Human Rights Office. Yet another concern noted was that the component of the Law of the Attention of People with Disabilities that addresses “access to physical space and means of transportation” is left without the ability to punish those who do not obey it. They recommended that this issue is addressed on both the level of the law and the level of the community via “accessibility plans.” [22] Many of the themes observed in this study also fell within the empowerment category, particularly emphasizing the barriers to, and limitation of, services, as well as personal disempowerment.

The CBR program for people with amputation in Guatemala will need to utilize this new understanding of the negative modalities, designing the program to address the problems facing the participants, while accommodating for their weaknesses and being vigilant against threats.



Positive Modalities

The positive modalities include the strengths, opportunities, human resources, material resources, structure resources, and objectives of the person with amputation in Guatemala. Understanding these modalities in the context of the aim of the study, is guided by the following question: "What do the person with amputation and potential CBR program have going for us?"

The most frequent strengths of the person with amputation in Guatemala include some concrete, tangible strengths like [Device/rehabilitation], [Work experience/skills/attitude], and [Health management/wellness], alongside less tangible, more personality-related strengths like [Ambition/Will], [Self-reliance/independence], and [Positivity/coping]. It is encouraging to observe that so many of the participants have a device/rehabilitation, as well as health management/wellness, as the health of the participant is so fundamental to everything else the CBR program plans to achieve. Work experience/skills/attitude, as well as the personality-related strengths, are also advantages that can be harnessed in the CBR program.

The most frequent opportunities are health-related - [Medical care/medicines] and [Prosthetic/rehabilitation care] - and social-related - [Family relationships/help/productivity/involvement] and [Community involvement]. It is interesting that health-related opportunities were among the most frequently observed, considering the deficiencies with the health system illustrated in the negative modalities. It is less surprising that both family- and community-related opportunities are frequent among participants given their centrality to Guatemala society. The CBR program can help enable participants to take full advantage of the health- and social-related opportunities.

The most frequent human resources of the person with amputation in Guatemala, similar to the strengths, include concrete, tangible human resources like [Family relationships/resources/help], [Vocational training/skills/experience], and [Health/psychological wellbeing/management], alongside less-tangible, personality-related human resources like [Ambition/will], [Positivity/coping], and [Self-reliance/independence].

The most frequent material resources were both health-related: [Device/rehabilitation] and [Medicines/medical care].

The most frequent structure resources included a health structure - [Military/CADEG] - and a community structure - [Church community]. The relatively high frequency of the military/CADEG health structure in the participants is due to their sampling of participants for this study via CADEG; the majority of Guatemalans will not have served in the military, and thus this code will not be applicable to them. The church community, however, will be broadly applicable to Guatemalans due to the centrality of the church in Guatemalan society, like family and community.

Several of the most frequent objectives were focused on education- or livelihood-related productivity, including [Participant wants to work.], [Participant wants to restart studies/study for career development.], and [Participant wants to diversify his livelihood/have greater economic capacity/improve economic situation.]. Two of the most frequent objectives - [Participant wanted to accept his amputation and carry onwards.] and [Participant wants to do activities/make the best of being at home.] - were centered on the health and physical ability of the participant. Finally, one of the most frequent objectives was empowerment-related - [Participant wants to connect with and support/help PWDs.]. These objectives point the CBR program towards investment in the productivity, health, and empowerment of its participants.

The UN report on Guatemala's compliance with the UNCPRD highlighted some positive developments, particularly in the empowerment category. The report acknowledged Guatemala's progress in developing disability-centric laws, as well as "Municipal Offices on Disability and Departmental Commissions on Disability." [22] These laws, as well as the municipal offices, are potential conduits through which certain aspects of the CBR program can be realized.

The CBR program for people with amputation in Guatemala will also need to utilize this understanding of positive modalities, designing the program to address the objectives of its participants, while building upon their strengths and taking advantage of opportunities and resources.

Study Limitations

This study, like any other, had limitations.

Using a qualitative methodology, as this study did, reveals the phenomena occurring in the lives of the participants, ascertaining those phenomena from the meaning contained in structured interviews. While frequency counting of individual codes across the modalities of the situation analysis gives a rough approximation of their relative importance, the frequencies measured cannot be considered representative of the entire target population or statistically significant, due to the purposive sampling and small sample size. Corroborating and complementing the qualitative insights of this study with the quantitative insights from the 2016 Guatemalan National Disability Survey creates the most complete understanding of the situation.

Furthermore, the process of coding is, by nature, dependent upon and subject to, the perspectives of the author. Another researcher looking at the same set of data could interpret the data very differently, leading to different results and recommendations. Additionally, it is important to acknowledge that the development of a coding framework can result in some phenomena (i.e. higher-level codes with a broad scope) being over-assigned and thus overemphasized in frequency, while other phenomena (i.e. lower-level codes with a narrow scope) slip through the cracks; the model that results is a generalized view that does not include all nuances. For this reason, it is important to examine codes of small frequency in addition to those of a large frequency.

Finally, neither the element of timing relative to amputation, nor the element of attribution to amputation, can be consistently made from the data collected and the analysis conducted. Although timing or attribution was clear for some phenomena in some participants, it was not ascertained for many others. The results should be viewed as describing the situation of the life of the person with amputation in Guatemala - a snapshot. Some phenomena may have been caused by amputation and others may not. Some phenomena took place following the amputation while others took place prior to, or in parallel with, the amputation. A more specific interview protocol or questionnaire would be needed to measure timing relative, and attribution, to amputation, and such a study would be worthwhile in order to more fully understand the situation.

In spite of these limitations, this study represents one of the most comprehensive, in-depth studies on the situation of people with amputation in Guatemala, and it will be extremely valuable in the development of a CBR program targeting this population.

Short-Term Plan - Pilot Study

ROMP will stand-up a CBR program targeting its patients in one department of Guatemala. The pilot will be conducted during a period of six months, starting with the development of a field protocol and the training of one field coordinator and two community rehabilitation workers (CRWs) who are native to the department and will be responsible for covering ROMP patients in their respective coverage area. A tablet-based app will be developed to facilitate the work of the CRWs, including a small survey using validated instruments that will be administered at $t = 0$, $t = 3$, and $t = 6$ months to detect signals of improvement across a variety of indicators consistent with the most frequent themes. Where possible, ROMP will partner with already-existing institutions to leverage their expertise and resources. The actions listed in the table below are meant to address the problems and objectives ascertained through this study, and uphold the rights of the participants in accordance with the UNCRPD, in the context of the ROMP CBR program.

	Problems	Objectives	Actions
I. Health	<p>[There are gaps/insufficiencies in medical/prosthetic care.] - 14</p> <p>[Participant has depression/psychological problems.] - 13</p> <p>[Participant has pain/other effects in his residual limb and other parts of his body.] - 10</p> <p>[Participant has difficulty walking/mobilizing/exercising.] - 10</p>	<p>[Participant wanted to accept his amputation and carry onwards.] - 8</p> <p>[Participant wants to do activities/make the best of being at home.] - 5</p>	<p>Physical Health - Facilitate/verify prescriptions; regular lay check-ins on physical health and referrals; subsidies for prescription medicines/nutrition.</p> <p>Mental Health - Screening for depression/psychological problems (PHQ-9/other clinical screens); regular lay check-ins on mental health and referrals; subsidies for psychological/psychiatric care.</p> <p>Physical Rehabilitation - New case finding and referral to ROMP; regular P&O/OT/PT technician check-ins and interventions/referrals; subsidies for transportation to ROMP, and for OT/PT care.</p>

Recommendations

	Problems	Objectives	Actions
II. Education	[Participant has limited education/literacy.] - 11	[Participant wants to restart studies/study for career development.] - 8	Education - Educational counseling; referral to educational institutions/ funding sources; subsidies (scholarships) for education; PWA day/group within educational system.
III. Livelihood	<p>[Participant faces difficult work climate/environment.] - 15</p> <p>[Participant's work has been interrupted/made difficult.] - 13</p> <p>[Participant faces financial hardship/limited income/ high costs.] - 10</p>	<p>[Participant wants to work.] - 9</p> <p>[Participant wants to diversify his livelihood/ have greater economic capacity/improve economic situation.] - 6</p>	<p>Wage Employment Track - Job counseling/professional skills development/ paperwork support; referral to employer; sensitization/ check-ins with local employers; subsidies for accessibility accommodations at employer; conflict arbitration with employer/ employees.</p> <p>Self-Employment Track - Business plan development/ business skills development/ paperwork support; seed funding for upstart/ expansion of business.</p>
IV. Social	[Participant faces adverse perceptions and treatment/ lack of help from others.] - 14	N/A at 25% threshold.	Social: Municipal-/school-based awareness/ sensitization; facilitating connections with other PWAs, especially for support group formation; conflict arbitration within family/community.
V. Empowerment	<p>[There is limited institutional help.] - 17</p> <p>[Participant experiences disempowerment/general limitation/mental barriers.] - 12</p> <p>[Participant lacks an awareness of, and connection to, the disability community/ services.] - 10</p>	[Participant wants to connect with and support/ help PWDs.] - 5	Empowerment: Outdoors, mobility-celebrating events/ support of athletics for PWAs; referral for legal support; development of PWA leaders through events, training, etc.; regular check-ins and referrals to services listed in directory.

Long-Term Plan - Systems Strengthening, Research, and Advocacy

The lessons learned through the execution of the proposed pilot will inform improvements to the field protocol. ROMP will seek to ensure the continuity of its CBR services for the pilot participants, and growth to new participants. In time, ROMP will utilize its field supervisor, CRWs, field protocol, training module, and funding resources to train and equip community health workers in already existing networks, both NGO and governmental in nature. This will allow ROMP to implement its proven model for CBR through existing systems and increase CBR coverage to its patients across Guatemala. ROMP will conduct intervention studies on the various components of its model of CBR in order to disseminate lessons learned to other stakeholders in the region, and to advocate on the national, regional, and international level in support of evidence-based CBR policies and programs for people with amputation. Advocacy efforts in Guatemala will be focused on the following governmental institutions: the Ministry of Public Health and Social Assistance (MSPAS, per its acronym in Spanish), the Ministry of Education (MINEDUC), the Ministry of Work and Social Prevision (MINTRAB), and the National Council for the Care of People with Disabilities (CONADI).

The recommendations made in this report are meant to be as practical as possible, enabling ROMP to stand-up a CBR program for people with amputation in Guatemala. Thus, although the recommendations are directed towards ROMP patients, the author encourages other institutions to develop recommendations for their patients, based on the results of this study. Furthermore, it would be valuable to conduct this study across different types of disabilities and various countries to enable positive developments for other people and countries. The author welcomes correspondence from institutions interested in conducting this or similar studies.

“I felt very... I felt like an invalid person,
that I am nothing.”

- Participant 17

“...I have the same rights and obligations that
everyone has.”

- Participant 13

Citations

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Appendices

Interview for Person with Amputation

PART 1: INTRODUCTION

Note to Interviewer:

Please note that the emotional wellbeing of the participant is the top priority during the interview. The questions you ask and the probing that you do should be as gentle and as compassionate as possible. Start slowly, and slow down if it is in the participant's best interest. Also be on the lookout for signs of emotional disturbance, even if the participant does not say anything about it. If the participant becomes emotionally unwell, you should immediately ask them how they are doing, and depending on their response, either offer to pause the interview and talk about their feelings or to take a break from the interview and come back when they are feeling better. If neither of these options is appropriate for the situation, you should offer to terminate the interview so that the participant can be finished and go home.

When ready, please greet the participant, invite them to enter the interview room and have a seat, and allow them to read the information sheet and answer their questions. If the participant cannot or does not prefer to read, please read them the information sheet out loud slowly and answer their questions. Once the participant has signed or thumb-printed the consent form, the interview may begin. If the participant gave their consent to audio-record the interview, please hit the record button now. Please record the participant number and interview start time on the cover sheet. During the interview, please make notes about important insights that come to you during the conversation, but do not worry about writing down every detail. Remember to not write down the participant's name. Please read the following message to the participant:

Interviewer to Participant:

"Thank you for doing this interview. It will help us to improve rehabilitation for people with amputation in Guatemala, like yourself. During the interview I am going to ask you some questions about your health, school, work, family, and community so that we can better understand what it is like to be a person with amputation in Guatemala.

Since we are talking about your amputation and your life, you may have some bad memories come back and these might make you have some bad feelings. It is normal to have some bad feelings about your amputation. If you want to talk about these feelings at any point during the interview, just let me know and we can pause the interview and talk about [other] things. Or if you feel like you need to take a break from the interview, just let me know and you can go out for a walk, have something to eat, or whatever you need to do to feel better, and you can come back when you are feeling good. If you feel really bad and you just want to be done with the interview and not come back, just let me know and you can leave right away. We want to make sure you are as comfortable as possible during the interview, so that is why we give you these options.

Remember that no one will ever know that it was you that said what we record during this interview. And remember that there is no right or wrong answer. So please be as honest and open as you are comfortable being, even if you want to say something that you think sounds negative. We just want to hear what you have to say. This interview will take about one hour. Do you have any questions before we get started?"

PART 2: GENERAL INFORMATION

Interviewer to Participant:

"We are going to start out with a couple of basic questions."

"What is your gender?" M / F or N/A

"What is your age?" _____ (Years)

"What city or village are you from?" _____ (City/village)

PART 3: AMPUTATION, DEVICE, AND DISABILITY INFORMATION

Interviewer to Participant:

"Thank you. Now I am going to ask you about your amputation(s)."

"Where is/are your amputation(s)?" *Record response below.*

"What was the cause of your amputation(s)?" *Record response below.*

"Are you using an aid for your amputation(s)?" *Record response below.*

"Do you have any other disabilities?"

Participant's right side (interviewer's left side):

Below-knee / above-knee / below-elbow / above-elbow / other _____

Cause: Diabetes / trauma / vascular disease / tumor / other _____

Currently using assistive device: no / yes (prosthesis / wheelchair / crutches / other _____)

Below-knee / above-knee / below-elbow / above-elbow / other _____

Cause: Diabetes / trauma / vascular disease / tumor / other _____

Currently using assistive device: no / yes (prosthesis / wheelchair / crutches / other _____)

Participant's left side (interviewer's right side):

Below-knee / above-knee / below-elbow / above-elbow / other _____

Cause: Diabetes / trauma / vascular disease / tumor / other _____

Currently using assistive device: no / yes (prosthesis / wheelchair / crutches / other _____)

Below-knee / above-knee / below-elbow / above-elbow / other _____

Cause: Diabetes / trauma / vascular disease / tumor / other _____

Currently using assistive device: no / yes (prosthesis / wheelchair / crutches / other _____)

PART 4: HEALTH INFORMATION

Interviewer to Participant:

"Thank you. Before we go any further, I just want to make sure you are feeling ok? [If the participant is emotionally unwell, offer to pause the interview to talk about their feelings or offer a break to cool-down. If these options are not appropriate, offer the chance to terminate the interview.]

Are you ready to answer some more questions? Now we are going to talk about your health."

"Tell me a little about your health?" (5 minutes)

Probes: "How do you feel your body is?" "How do you feel your mind is?"

"Do you have any health problems?"

"Tell me about how you handle problems with your health?" (5 minutes)

Probes: "Where do you get help?" "Who helps you?" "Do you pay?" "What is the cost like?"

"Any examples?"

PART 5: EDUCATION INFORMATION

Interviewer to Participant:

"Thank you – you are doing great! Still feeling ok? [If the participant is emotionally unwell, offer to pause the interview to talk about their feelings or offer a break to cool-down. If these options are not appropriate, offer the chance to terminate the interview.]

Are you ready to answer some more questions? Now we are going to talk about your education."

"Tell me a little about your school or training?" (5 minutes)

Probes: "What level did you study?" "What subject(s) did you study?" "What did you like about school?" "What was difficult about school?" "Did you need any help at school?" "Do you have plans for the future?"

"What is education like in your community?" (3 minutes)

Probes: "What do people think about going to school?" "Where can people study?" "What do people study?" "Opportunities for people with disabilities?" "Any examples?"

PART 6: LIVELIHOOD INFORMATION

Interviewer to Participant:

"Thank you. Again, before we go any further, I just want to make sure you are feeling ok? [If the participant is emotionally unwell, offer to pause the interview to talk about their feelings or offer a break to cool-down. If these options are not appropriate, offer the chance to terminate the interview.]

Are you ready to answer some more questions? Now we are going to talk about your work."

"Tell me a little about your work?" (5 minutes)

Probes: "What is your role?" "How much do you work per week?" "What do you like about work?"
"What is difficult about work?" "Do you need any help at work?" "Do you have plans for the future?"

"What is work like in your community?" (3 minutes)

Probes: "What do people think about work?" "Where do people work?" "What do people do for work?"
"Opportunities for people with disabilities?" "Any examples?"

PART 7: SOCIAL INFORMATION

Interviewer to Participant:

"Thank you – we are almost half way done! Still feeling ok? [If the participant is emotionally unwell, offer to pause the interview to talk about their feelings or offer a break to cool-down. If these options are not appropriate, offer the chance to terminate the interview.]

Are you ready to answer some more questions? Now we are going to talk about your family and your community."

"Tell me a little about your family life?" (5 minutes)

Probes: "Who are the people in your family?" "How do you get along with people in your family?" "What activities do you do with your family?" "Do you have any difficulties with your family?" "Do you get any help from your family?" "Family members with disabilities?" "How does your disability affect your family?"

"Tell me a little bit about your participation in your community?" (5 minutes)

Probes: "How do you get along with people in your community?" "What activities does your community do?" "Do you have any difficulties with your community?" "Do you get any help from your community?" "Community members with disabilities?" "How does your disability affect your community?"

PART 8: EMPOWERMENT INFORMATION

Interviewer to Participant:

"Thank you – now we are pretty close to finishing! Again, before we go any further, I just want to make sure you are feeling ok? [If the participant is emotionally unwell, offer to pause the interview to talk about their feelings or offer a break to cool-down. If these options are not appropriate, offer the chance to terminate the interview.]

Are you ready to answer some more questions? Now we are going to talk about how you live your life."

"Are you in control of your own life?" (3 minutes)

Probes: "Do you feel like you make your own decisions?" "Do you feel like you do what you want to do?" "Do you know your rights as a person with disability?" "Are your rights respected?" "Any examples?"

"What things limit you from living the way you want to live?" (5 minutes)

Probes: "Any limits from your age?" "Any limits from your gender?" "Any limits from other people?" "Any limits from transportation and accessibility?" "Any limits from money?" "Any problems with the laws or government?" "Any examples?"

"Tell me about any special support you receive?" (3 minutes)

Probes: "Any special support from the government?" "Any special support from NGOs?" "Any special support from other places?" "Are you aware of services and opportunities for people with disabilities?"

PART 9: ADDITIONAL INFORMATION

Interviewer to Participant:

"Thank you – these are our last questions! Still feeling ok? [If the participant is emotionally unwell, offer to pause the interview to talk about their feelings or offer a break to cool-down. If these options are not appropriate, offer the chance to terminate the interview.]

Are you ready to answer these last questions? Now we are going to talk about problems from your amputation and how to solve those problems."

"Are there any problems that you face because of your amputation?" (6 minutes)

Probes: "Any health problems?" "Any problems at school?" "Any problems at work?" "Any problems in your family?" "Any problems in your community?" "Any other problems?" "Any examples?"

"Do you have any ideas on how to solve the problems that you and other people with amputation face?" (6 minutes)

Probes: "Ideas for improving projects or programs that are already there to help people with amputation?" "Ideas for new projects and programs to help people with amputation?" "Within your community?" "Within your region?" "What does rehabilitation mean to you?" "Any examples?"

"Is there anything else you would like to share?" (1 minute)

PART 10: CLOSING

Interviewer to Participant:

"We are finished with the interview! Thank you so much for your participation – we have learned a lot from talking with you.

Before you go, I just want to make sure you are feeling ok? [If the participant is emotionally unwell, talk about their feelings. If this option is not appropriate, offer the chance to leave.]

On your way out please see the receptionist and they will give you a copy of the consent form that you signed/thumb-printed before we started the interview and they will give you the cash for your time and travel. Do you have any questions before you go?"

Note to Interviewer:

Please stop audio-recording now and organize the papers. Please then escort the participant to the receptionist and ensure that the participant is given a copy of the consent form that they signed before the interview and their per diem and travel money. Please bid them farewell and return to the interview room and make any relevant notes about insights that you had during the interview. Feel free to take a break before conducting the next interview and let Jonathan know if you have any questions or concerns.

Información para los Participantes¹

Titulo del estudio: Rehabilitación comunitaria en Guatemala

Gracias por venir hoy. Por favor lea la siguiente información, o si le guste, nosotros podemos leerla a usted. Haga cualquiera preguntas que usted tenga.

Usted decidirá si quiere participar o no. Nosotros le informamos sobre lo que involucra si usted decida participar. Si usted quiere participar, hay que firmar el formulario de consentimiento después de leer esta información. Si no quiere participar, puede salir y no afectará el cuidado que recibe de esta clínica.

¿Qué es el propósito del estudio, y en especifica esta entrevista?

Estamos construyendo un programa sin fines de lucro para ayudar a gente discapacitada en Guatemala. Estamos entrevistando a personas discapacitadas, como usted, para aprender sobre lo que necesitan y lo que quieren que el programa sea.

¿Por qué yo fui elegido para esta entrevista?

Esta clínica lo recomendó a usted para la entrevista porque creen que usted puede compartir sus experiencias, opiniones, e ideas. En total, entrevistaremos a diez (10) personas discapacitadas para este estudio.

¿Qué pasará a mi si participo?

Si usted participa, la entrevista durara a una hora. El entrevistador le haga preguntas a usted sobre su salud, escuela, trabajo, vida social, y comunidad. Cuando termine la entrevista, ya no hay mas que hacer y puede ir a su casa.

Si nos da su permiso, el entrevistador grabará la entrevista. Así que podemos revisar lo que nos ha compartido en adelante que solo hoy. Si no, la persona haciendo la entrevista tomará notas en hoja durante que usted hable.

¹Note: this patient information sheet was adapted from the author's past study in Tanzania, which was adapted from a template from the London School of Hygiene and Tropical Medicine (LSHTM). [21]

¿Qué son posibles desventajas y riesgo en participar?

No hay peligros físicos ni biológicos que usted enfrentará en participar.

Pero, como usted puede tener experiencias duras y dificultades atribuido a su discapacidad, hay que saber que esta entrevista puede manifestar cosas negativas así en su mente. Aquí hay unas cosas que le puede ayudar con cualquier daño mental: Si usted tiene daño, puede hablar de sus experiencias y sentimientos con el entrevistador porque hemos trabajado con personas con discapacidades antes y sabemos sobre los sentimientos. O si usted prefiere, puede tomar un descanso de la entrevista, hacer una caminata, comer algo, o cualquiera otra cosa para que le ayude, y luego regresar la entrevista cuando se sienta mejor. Pero, si usted sienta tan afectada del daño y no quiere continuar, se puede terminar la entrevista e ir a casa.

¿Qué son posibles beneficios en participar?

En hacer la entrevista, usted esté ayudándole a personas con discapacidades en Guatemala, como usted mismo. Con la información que recaudamos a través de estas entrevistas vamos a construir un programa sin fines de lucro basado en lo que hemos aprendido.

¿Qué pasara si no quiero terminar la entrevista?

Si usted decide no quiere continuar la entrevista, se puede salir e ir a casa sin avisar a nosotros porque. Las notas y el audio que tomamos hasta el punto que usted salga van a ser utilizados.

¿Qué pasa si algo pase mal?

Si usted le preocupa de cualquiera cosa durante su entrevista, solo hay que preguntar a su entrevistador. Si todavía tiene preocupaciones, puede hablar con el gerente de esta clínica.

Si usted quiere hacer una queja sobre el manejo de la entrevista, se debe contactar en inmediato al organizador del estudio, Jonathan Naber por correo electrónico a jnaber2@gmail.com, o por teléfono a +001-618-975-6046.

¿Mantendrán mi entrevista en secreto?

No vamos a compartir su nombre con otras personas fuera de nuestra organización sino que usted nos da el permiso de usar su nombre al público. Si no, usaremos un nombre falsa cuando hacemos referencias a usted en público. Quiere decir que ninguna persona en el público sabrá que fue usted que dijo las cosas en la entrevista.

Si usted nos da el permiso, nos gustaría tener la habilidad de hacer referencias a lo que compartió, por supuesto sin su nombre. Si no, haremos una resumen de que usted dijo con palabras nuestras.

Las notas y grabaciones serán guardados bien por el investigador principal, Jonathan Naber, en su oficina del los Estados Unidos. Cinco años después de la entrevista, revisaremos si debemos destruir el data o continuar en guardarlo por el proyecto.

¿Quién organiza, maneja, y auspicia a este estudio?

Este proyecto es organizado, manejado, y auspiciado Jonathan Naber.

Gastos y pago

Después de la entrevista, le recompensaremos a usted 100 Quetzales en efectivo por su tiempo y gastos del viaje.

Detalles de Contacto

El investigador principal por este estudio es Jonathan Naber. Se puede contactarle por email en jnaber2@gmail.com o por teléfono en +001-618-975-6046.

Usted recibirá una copia de la hoja de información y el formulario de consentimiento que usted firmó para su guardia personal.

Gracias por su tiempo de leer esta información y por considera en participar en este estudio.

Formulario De Consentimiento Informado²

Título de Estudio: Rehabilitación comunitaria en Guatemala.

Yo confirmo que he leído y entiendo la hoja de información sobre participantes para este estudio. Yo he considerado la información, he tomado la oportunidad de hacer preguntas, y he recibido respuestas suficientes.

_____ (siglas de participantes)

Yo entiendo que mi participación es voluntaria y estoy libre a retirar mi participación en cualquier momento, sin dar razones al respeto, y sin afectar a mi cuidado de salud ni mis derechos legales.

_____ (siglas de participantes)

Yo entiendo que partes de mis datos medicales e información coleccionada durante el estudio pueden ser observados por individuos responsables quienes están involucrado en el estudio. Yo les doy permiso al aquellos individuos de tener acceso a mis datos y archivos.

_____ (siglas de participantes)

Yo estoy de acuerdo que mi entrevista sea grabado, y que usen partes para citar.

_____ (siglas de participantes)

²Note: this consent form was adapted from the author's past study in Tanzania, which was adapted from a template from the London School of Hygiene and Tropical Medicine (LSHTM). [21]

Yo me sumo a participar en dicho estudio.

_____ (nombre de participante)

_____ (firma de participante)

_____ (fecha)

Coordinador del Estudio (Andrea Reyes o Fernanda Pinzón)

_____ (nombre de coordinador del estudio)

_____ (firma de coordinador del estudio)

_____ (fecha)

Investigador Principal

Jonathan Joseph Naber _____ (nombre de investigador principal)

_____ (firma de investigador principal)

_____ (fecha)

Si el participante tiene menos que 18 años o por otros motivos no puede firmar, un testigo debe firma también. Yo, como testigo/a, confirmo que toda la información de este estudio fue presentada y que el participante dio consentimiento de participar.

_____ (nombre de testigo)

_____ (firma de testigo)

_____ (fecha)

1 copia por participante; 1 copia por Investigador Principal; 1 copia por los archivos de la clínica

Entrevista para Personas con Amputación

Participant 17
Jonathan Naber
19 February 2016

PARTE 1: INTRODUCCIÓN

Nota para el entrevistador(a):

Por favor recuerde que la integridad emocional del participante es la prioridad máxima durante la entrevista. Las preguntas y comentarios que haga deben ser lo más cuidadosos y compasivos posible. Empiece lentamente y enlentezca el ritmo si cree que esto pueda ayudar al participante. Esté atento(a) por si surge cualquier señal de problemas emocionales, aún si el participante no dice nada al respecto. Si la persona se torna emocionalmente afectado(a), pregúntele inmediatamente cómo se está sintiendo y, dependiendo de su respuesta, ofrezca una pausa en la entrevista para hablar de sus sentimientos o detener la entrevista y volver cuando se sienta mejor. Si ninguna de estas opciones es apropiada para la situación, ofrezca terminar la entrevista por completo para que la persona pueda ir a casa.

Una vez listos, por favor salude al participante, invítele a entrar a la habitación de la entrevista y a sentarse. Permítale leer la hoja de información y responda a sus preguntas. Si el participante no puede leer o prefiere no hacerlo, por favor léale la hoja de información en voz alta, lentamente, y responda a sus preguntas. Una vez que el participante haya firmado o marcado con su pulgar la hoja de consentimiento, la entrevista podrá comenzar. Si el participante dio consentimiento para grabar con audio la entrevista, por favor oprima el botón de 'grabar' ahora. Por favor registre el número del participante y la hora de comienzo de la entrevista en la primera hoja. Durante la entrevista, tome notas sobre reflexiones importantes que puedan ocurrírsele durante la conversación, pero no se preocupe por escribir todos los detalles de la entrevista. Recuerde no escribir el nombre del participante. Por favor léale el siguiente mensaje al participante:

Entrevistador al participante:

"Gracias por participar en esta entrevista. Esto nos ayudará a mejorar la rehabilitación para personas con amputaciones en Guatemala, como usted. Durante esta entrevista, le haré algunas preguntas sobre su salud, educación, trabajo, familia y comunidad para que podamos entender mejor cómo es ser una persona con amputación en Guatemala.

Debido a que estamos hablando sobre su amputación y su vida, es posible que vuelvan algunas malas memorias y que éstas puedan hacerle tener malos sentimientos. Es normal que tenga algunos malos sentimientos sobre su amputación. Si quiere hablar sobre estos sentimientos en cualquier punto de la entrevista, sólo hágamelo saber y podemos detener la entrevista para hablar sobre otras cosas. Por otro lado, si siente que quiere darse un descanso de la entrevista, sólo hágamelo saber y puede ir un momento a caminar, a comer algo o hacer cualquier cosa que necesite para sentirse mejor. Podrá luego volver cuando se esté sintiendo bien. Si se siente muy mal y quiere terminar la entrevista sin volver, sólo hágamelo saber y podrá irse inmediatamente. Queremos asegurarnos de que esté lo más cómodo(a) posible durante la entrevista y por eso le damos estas opciones.

Recuerde que nadie podrá saber que fue usted quien dijo lo que registremos en esta entrevista. Recuerde también que no existe una respuesta correcta o incorrecta a las preguntas que le haga. Por

favor sea tan honesto(a) y abierto(a) como le sea cómodo ser, aún si quiere decir algo que cree que pueda sonar negativo. Solamente queremos escuchar lo que tenga que decir. Esta entrevista tomará alrededor de una hora. ¿Tiene alguna pregunta antes de que empecemos?

PARTE 2: INFORMACIÓN GENERAL

Note, there were a couple of points during the interview that Hermalinda had to translate a question into the local dialect/a bit of a response into Spanish.

Entrevistador al participante:

"Vamos a empezar con algunas preguntas básicas"

"¿Cuál es su género?" **Male**

"¿Cuántos años tiene?" **34 years**

"¿De qué ciudad o pueblo es usted?"

REDACTED FOR PRIVACY

PARTE 3: INFORMACIÓN SOBRE AMPUTACIÓN, DISPOSITIVO Y DISCAPACIDAD

Entrevistador al participante:

"Gracias. Ahora le preguntaré sobre su(s) amputación(es)"

"¿Dónde fue(ron) su(s) amputación(es)?"

His leg was amputated above the knee

His amputation took place at Hospital Galeno, a private hospital in Cobán; they did him a favor (with the operation) because he was dying, and he didn't have money

"¿Cuál fue la causa de su(s) amputación(es)?"

The doctor told him that he had either gangrene or cancer

His knee locked up and he couldn't do anything

When he fell from the truck, he got up so quickly that the veins burst

"¿Utiliza algún dispositivo de ayuda para su(s) amputación(es)?"

He uses a prosthesis; it is an economical/simple type

He got his prosthesis at Fundabiem in Cobán

"Me sentía muy... sentí como una persona invalido, que no soy nada."

His family helped him out (i.e. mobility)

A prosthesis has costs, every year; it costs a lot

He had some embarrassment/concern about asking for help for his prosthesis; he didn't want people speaking of him as a beggar; that's why he's just stayed as he is right now

"¿Tiene alguna otra discapacidad?"

No

PARTE 4: INFORMACIÓN DE SALUD

Entrevistador al participante:

"Gracias. Antes de continuar, quiero asegurarme de que se esté sintiendo bien" [si el participante no está bien emocionalmente, ofrézcale detener la entrevista para hablar de sus sentimientos o un descanso. Si estas opciones no son apropiadas, ofrezca la oportunidad de terminar la entrevista]

"¿Está listo(a) para responder algunas preguntas adicionales? Ahora hablaremos sobre su salud"

"Por favor cuénteme un poco sobre su salud" (5 minutos)

Sondas: "¿Cómo siente que está su cuerpo?" "¿Cómo siente que está su mente?" "¿Tiene algún problema de salud?"

He has suffered a lot because of his injury; losing a piece/part of the body is hard; there were no people to help him (resource-wise)

He felt something different (in his head) because of the incident

He had some rocks enter his skin from his accident

"Cuénteme por favor cómo maneja sus problemas de salud" (5 minutos)

Sondas: "¿Dónde consigue ayuda?" "¿Quién lo ayuda?" "¿Tiene que pagar?" "¿Cómo son los costos?" "¿Puede darme algún ejemplo?"

He goes to the Centro de Salud in REDACTED FOR PRIVACY

He doesn't go to the hospital in Cobán because you need money to get there

He no longer goes to Fundabiem, but he used to go every 8 days for physical therapy

PARTE 5: INFORMACIÓN SOBRE EDUCACIÓN

Entrevistador al participante:

"Gracias, ¡lo está haciendo muy bien! ¿Sigue sintiéndose bien?" [si el participante no está bien emocionalmente, ofrézcale detener la entrevista para hablar de sus sentimientos o un descanso. Si estas opciones no son apropiadas, ofrezca la oportunidad de terminar la entrevista]

"¿Está listo(a) para responder algunas preguntas adicionales? Ahora hablaremos sobre su educación"

"Por favor cuénteme un poco sobre sus estudios o entrenamiento" (5 minutos)

Sondas: "¿Hasta qué nivel estudió?" "¿Qué materia(s) estudió?" "¿Qué le gustaba de estudiar?" "¿Había algo difícil sobre estudiar?" "¿Necesitó ayuda durante sus estudios?" "¿Tiene planes para el futuro?"

He was learning a bit, but didn't continue because there wasn't money to pay for his studies, so he doesn't have (a degree/ongoing education)

He arrived at cuarto primario, and then, in order to learn how to do electronic repairs he took a small course but did not finish it

He was studying in primario when his accident happened, so he did not keep going

Being at home, he had to look for a way to spend his life/subsist, so he began the course on electronic repairs but did not finish it for lack of money

"¿Cómo es la educación en su comunidad?" (3 minutos)

Sondas: "¿Que piensa la gente sobre estudiar?" "¿Dónde puede estudiar la gente?" "¿Qué estudia la gente?" "¿Hay oportunidades para las personas con discapacidades?" "¿Puede darme algún ejemplo?"

His children are studying

The level they arrive at depends on various things, especially money

He is fighting to be able to buy their notebooks/pens so that they can study; without studying, we are nothing

For PWDs, school depends on the frequency of the studies (i.e. how often they have to go in to school)

He would like to study, but there is no way to do so

PARTE 6: INFORMACIÓN SOBRE OCUPACIÓN

Entrevistador al participante:

"Gracias. Nuevamente quiero asegurarme de que se esté sintiendo bien antes de continuar" [si el participante no está bien emocionalmente, ofrézcale detener la entrevista para hablar de sus sentimientos o un descanso. Si estas opciones no son apropiadas, ofrezca la oportunidad de terminar la entrevista]

"¿Está listo(a) para responder algunas preguntas adicionales? Ahora hablaremos sobre su trabajo"

"Cuénteme un poco sobre su trabajo" (5 minutos)

Sondas: "¿Cuáles son sus responsabilidades?" "¿Cuánto trabaja por semana?" "¿Qué le gusta de su trabajo?" "¿Hay algo que se vuelva difícil en su trabajo?" "¿Necesita ayuda en el trabajo?" "Tiene planes para el futuro?"

He has fought for his family, by working in electronics (repair); he likes it a lot; it has helped him, also; he doesn't earn much from it – if he buys replacement parts, he only makes (a bit) from his cost of labor; he never will give it up because he likes it

He has had problems in his work resulting from his amputation; he brings electronics (home to work on), and sometimes he will fall (due to instability of prosthesis), and instead of protecting himself, he protects the electronics; it is difficult for him to walk, but he fights

If he is given an opportunity for a (electronics repair) job, he goes after it; sometimes he cries because of what he feels and he cannot explain to others what is happening because he is the only one that is feeling what he is feeling; he feels happy, but inside there is some sadness, some difficulty – that's how life is

"¿Cómo es el trabajo en su comunidad?" (3 minutos)

Sondas: "¿Qué piensa la gente sobre trabajar?" "¿Dónde trabaja la gente?" "¿Qué hace la gente para trabajar?" "¿Qué oportunidades hay para personas con discapacidades?" "¿Puede darme algún ejemplo?"

Depends on your capacities; there are some that study and they go to work in the police or another job; those that haven't studied subsist from the fields (agricultural work)

For PWDs, it depends what they work in

He has fought (worked) in going to collect firewood; being there, he feels like he cannot do anything; after an hour of being there, he comes back (home), because his leg starts to hurt him

"Ya no soy nada para eso."

PARTE 7: INFORMACIÓN SOCIAL

Entrevistador al participante:

"Gracias, ya casi llevamos la mitad de la entrevista ¿Sigues sintiéndote bien?" [Si el participante no está bien emocionalmente, ofrézcale detener la entrevista para hablar de sus sentimientos o un descanso. Si estas opciones no son apropiadas, ofrezca la oportunidad de terminar la entrevista]

"¿Está listo(a) para responder algunas preguntas adicionales? Ahora hablaremos sobre su familia y su comunidad"

"Cuénteme un poco sobre su vida en familia" (5 minutos)

Sondas: "¿Quiénes forman parte de su familia?" "¿Cómo se relaciona con las personas de su familia?" "¿Qué actividades hace con su familia?" "¿Tiene dificultades con su familia?" "¿Su familia lo(a) ayuda?" "¿Tiene familiares con discapacidades?" "¿Cómo afecta a su familia su discapacidad?"

He has a wife (and children)

His side of the family lives in REDACTED FOR PRIVACY

Sometimes he gets help from his wife's side of the family; but there are times when they cannot help, there is no way (economically speaking) to do so; his own mother has helped him, and his father helped him while he was still alive, bringing him firewood... but now his wife goes to get the firewood for cooking... he cannot do anything

He has a nephew (on his side of the family) that cannot walk

"Cuénteme un poco sobre su participación en su comunidad" (5 minutos)

Sondas: "¿Cómo es su relación con otras personas de su comunidad?" "¿Qué actividades realiza su comunidad?" "¿Tiene dificultades con su comunidad?" "¿Su comunidad lo(a) ayuda?" "¿Hay personas con discapacidades en su comunidad?" "¿Cómo afecta a su comunidad su discapacidad?"

He participates in a church; he feels happy when he goes to church; he is part of a small group, which he also likes; plays in small musical groups (bands)

He has had problems with others in his community due to his amputation; sometimes there is some disrespect; sometimes people start to mock (him) – makes him feel bad, weird

PARTE 8: INFORMACIÓN SOBRE EMPODERAMIENTO

Entrevistador al participante:

"Gracias. Ahora estamos casi terminando, pero antes de continuar, quiero asegurarme de que se esté sintiendo bien" [si el participante no está bien emocionalmente, ofrézcale detener la entrevista para hablar de sus sentimientos o un descanso. Si estas opciones no son apropiadas, ofrezca la oportunidad de terminar la entrevista]

"¿Está listo(a) para responder algunas preguntas adicionales? Ahora hablaremos sobre cómo conduce su vida"

"¿Controla usted su vida?" (3 minutos)

Sondas: "¿Siente que toma sus propias decisiones?" "¿Siente que hace lo que quiere hacer?" "¿Conoce los derechos que tiene por ser una persona con discapacidades?" "¿Se respetan sus derechos?" "¿Puede darme algún ejemplo?"

Yes. He does not know his rights as PWD

He does feel that there have been instances of his rights not being respected; when people treat him as a lesser person, discriminate against him

"¿Qué cosas lo(a) limitan en cuanto a vivir como quiere vivir?" (5 minutos)

Sondas: "¿Hay algún límite por su edad?" "¿Hay algún límite por su género?" "¿Lo limita alguna otra persona?" "¿Hay algún límite en cuanto a transporte y accesibilidad?" "¿Hay algún límite en cuanto a dinero?" "¿Hay algún límite en cuanto a las leyes o el gobierno?" "¿Puede darme algún ejemplo?"

Various things that he would like to do

In his house, when it rains there is a problem with the lamina roof (leaking?); he would like to finish re-modelling the house, but he cannot due to his condition (amputation); he cannot go up a ladder onto the roof

"Cuénteme sobre cualquier soporte especial que reciba" (3 minutos)

Sondas: "¿Recibe algún soporte especial del gobierno?" "¿Recibe algún soporte especial de ONGs/ fundaciones?" "¿Recibe algún soporte especial de alguna otra parte?" "¿Conoce de servicios y oportunidades para personas con discapacidades?"

Unfortunately he does not receive any support

He solicited help (from local alcaldes?), but they do not empathize with him on how is his day (/life), OR maybe because they are really busy and they don't pay attention to him; to this day, he has not received any help/support

He mentioned help from (TrickleUp)

He does not know of any organizations that work with PWDs in Guatemala

PARTE 9: INFORMACIÓN ADICIONAL

Entrevistador al participante:

"Gracias, ¡estas son nuestras últimas preguntas! ¿Sigue sintiéndose bien?" [Si el participante no está bien emocionalmente, ofrézcale detener la entrevista para hablar de sus sentimientos o un descanso. Si estas opciones no son apropiadas, ofrezca la oportunidad de terminar la entrevista]

¿Está listo(a) para responder estas últimas preguntas? Ahora vamos a hablar sobre problemas causados por su amputación y cómo pueden resolverse"

"¿Tiene algún problema que haya sido causado por su amputación?" (6 minutos)

Sondas: "¿Tiene algún problema de salud?" "¿Tiene algún problema en los estudios?" "¿Tiene algún problema en el trabajo?" "¿Tiene algún problema en la familia?" "¿Tiene algún problema en su comunidad?" "¿Tiene algún otro problema?" "¿Puede darme algún ejemplo?"

Yes, many

Walking – there are times when he falls; he cannot protect himself (in a fall)

Carrying – he cannot do it

He fights so that he can work; he feels physically bad (/incapable); he tries to do it so that he can move forwards (in life)

"¿Tiene ideas sobre cómo podría resolverse los problemas que usted y otras personas con amputación(es) tienen que afrontar?" (6 minutos)

Sondas: "¿Tiene ideas para mejorar proyectos o programas que ya existan para ayudar a personas con amputaciones?" "¿Tiene ideas para nuevos proyectos y programas para ayudar a personas con amputaciones?" "¿En su comunidad?" "¿En su región?" "¿Que significa para usted estar rehabilitado(a)?" "¿Puede darme algún ejemplo?"

Many forms; there is a lot of need

He wants to work, but there is not (enough opportunity); to have a job – any type

He has never worked in a company (i.e. formal job)

There are many needs in his life; he has a hard time explaining what exactly it is that he needs – he doesn't know how to communicate his needs

To have a job; to be able to maintain his family (economically speaking)

He is not asking for money, he is asking for a way to make a living; it would be bad if he was getting money from us, and then it stopped; but if he is working, he knows when he will get paid and he has the right to get paid

Depends on what they (PWA) need; in his case, he would ask for studies and work; in their (other PWA's) cases, it depends on their capacities

"¿Hay algo más que quiera compartir conmigo?" (1 minuto)

Many things. His wife knows how much he has suffered and exerted himself to move forwards in life, and sometimes she gets sad; she has also fought for them (/their life)

He will never stop maintaining his children (economically) because they are gifts from God

PARTE 10: CIERRE

Entrevistador al participante:

"¡Hemos finalizado la entrevista! Muchísimas gracias por su participación, hemos aprendido mucho hablando con usted.

Antes de que se vaya, solamente quiero asegurarme de que se esté sintiendo bien [Si el participante no se encuentra emocionalmente bien, hable de sus sentimientos. Si esta opción no es apropiada, ofrezca la oportunidad de irse].

A su salida por favor acérquese al/a la recepcionista, quien le dará una copia de la hoja de consentimiento que usted firmó/marcó con su pulgar antes de que empezáramos la entrevista y le dará dinero por su tiempo y traslado. ¿Tiene alguna pregunta antes de irse?

Nota para el entrevistador(a):

Por favor detenga la grabación de audio ahora y organice el papeleo. Por favor escolte al participante hasta llegar al/ a la recepcionista y asegúrese de que el participante reciba una copia de la hoja de consentimiento que firmó antes de la entrevista y su compensación monetaria. Por favor despídase y regrese a la habitación de entrevistas y escriba notas sobre cualquier reflexión relevante que haya tenido durante la entrevista. Siéntase libre de darse un descanso antes de conducir la siguiente entrevista y hágale saber a Jonathan si tiene alguna duda o preocupación.

Participant 17	
Will this participant benefit from, contribute to, or influence a CBR program for people with amputation in Guatemala?	
Strengths	Weaknesses
<p>Has prosthesis; has some training in electronic repairs; has some training in electronic repairs; importance placed on, and fight for, his childrens' educational attainment; has desire to study; fight for his family (economic wellbeing); experience in electronics repair; like for, and benefit from, electronics repair; persistence in, and like for, electronics repair work; has fight to walk; takes advantage of opportunities he is given to work (in electronics repair); feels happy; he controls his life; fights so that he can work; persistence so that he can move forwards in life; desire to work; has desire to work and maintain family (economically speaking); he has desire to work instead of receiving donation; he wants to study and work; he has fought to move forward in life; is motivated to maintain his children (economically)</p>	<p>Serious lack of self-esteem (following amputation); hesitance to ask for help for prosthesis out of fear of what others would think; suffering due to his injury; difficulty of losing a piece/part of the body; something changed in his head (psychologically?) because of his accident; rocks entered his skin in his accident; had to stop studying due to lack of money; low level of education; stoped his primary schooling due to his accident; he got stuck at home; did not finish course on electronic repairs due to lack of money; there is no way for him to study; limited earning from his electronics repair work; falls when carrying electronics due to instability of his prosthesis, gets hurt because he falls in a way to protect the electronics; difficult to walk; tough feelings/ crying, and cannot explain to others; has some lingering sadness, difficulty inside; feeling of inability in firewood collection; pain in leg in firewood collection; limitations in activities (i.e. firewood collection); he does not know his rights as a PWD; activity limitations, such as inability to finish re-modelling house, climbing up the ladder onto the roof; lack of knowledge of organizations working with PWDs in Guatemala; problems walking, namely falling and not being able to protect himself; inability to carry; feels physically bad (/incapable); he has never held a full-time job; he has many needs, and has difficulty explaining/communicating those needs; he has suffered</p>
Opportunities	Threats
<p>Received donated/subsidized amputation at private hospital; received prosthesis from FUNDABIEM; help from family (i.e. mobility); medical attention at Centro de Salud; received regular PT at Fundabiem; sometimes he gets help from wife's side of family; help from his parents; his wife goes for firewood; participation in church/small group/musical groups; help from (TrickleUp); wife's fight for them (/their life)</p>	<p>Recurring + high costs of prosthesis; no people to help him (resource-wise); avoids hospital in county seat because of transportation costs; his childrens' educational attainment depends on various things, especially money; PWD schooling depends on frequency they have to go in to the school; sometimes his wife's side of the family cannot help due to economic limitations; disrespect/mocking from others in his community due to his amputation, making him to feel bad and weird; instances of rights being mis-respected, through mistreatment and discrimination; does not receive any support; lack of help (from local alcaldes?) due to lack of empathy or busy schedule; has not received any help/ support; there is a lot of need (in PWAs); not (enough opportunity to work); wife sometimes becomes sad because of his suffering/fight to move forwards</p>

Participant 17

What resources does this participant have that a CBR program for people with amputation in Guatemala could use or build upon?

Human

Help from family (i.e. mobility); has some training in electronic repairs; has some training in electronic repairs; importance placed on, and fight for, his childrens' educational attainment; has desire to study; fight for his family (economic wellbeing); experience in electronics repair; like for, and benefit from, electronics repair; persistence in, and like for, electronics repair work; has fight to walk; takes advantage of opportunities he is given to work (in electronics repair); feels happy; sometimes he gets help from wife's side of family; help from his parents; his wife goes for firewood; he controls his life; fights so that he can work; persistence so that he can move forwards in life; desire to work; has desire to work and maintain family (economically speaking); he has desire to work instead of receiving donation; he wants to study and work; he has fought to move forward in life; wife's fight for them (/their life); is motivated to maintain his children (economically)

Material

Received donated/subsidized amputation at private hospital; prosthesis; prosthetic care at FUNDABIEM; medical attention at Centro de Salud; regular physical therapy at FUNDABIEM; help from (TrickleUp);

Structures

Private hospital, Hospital Galeno; FUNDABIEM; public health system; FUNDABIEM; participation in church/small group/ musical groups; TrickleUp;

Participant 17		
What problems are facing people with amputation/stakeholders that work with them?		
Concise summary of the problem	Root causes of the problem	Effects of the problem
He had a serious lack of self-esteem (following amputation)		
A prosthesis is expensive and has recurring costs		
He avoided asking for help for a prosthesis		
He suffered a lot due to his injury	He feared people would speak of him as a beggar	He's just stayed as he is right now
Something changed in his head (psychologically)	It is difficulty losing a piece/ part of the body; there were no people to help him (resource-wise)	
He had some rocks enter his skin	His accident	
He avoids going to the hospital in Coban	His accident	
He discontinued his studies	Money is needed to transport there	
He did not finish his small course in electronic repairs	There wasn't money to pay for his studies	He doesn't have (a degree/ ongoing education)
He discontinued his primary studies		
He got stuck at home	His accident happened	
He did not finish his course in electronic repairs		
His childrens' educational attainment depends on various things, especially money	Lack of money	
PWD schooling depends on frequency they have to go in to the school		
There is no way for him to study		
His earnings from electronics repair work are very limited		
He sometimes falls when carrying electronics	He buys replacemet parts; charges little for his cost of labor	
He has difficulty walking	The instability of his prosthesis	He gets hurt because he falls in a way to protect the electronics

Appendix 5 - Example Worksheet for Participant

Participant 17

What problems are facing people with amputation/stakeholders that work with them? (continued)

Concise summary of the problem	Root causes of the problem	Effects of the problem
He has tough feelings/crying, and cannot explain to others what is happening	He has some lingering sadness, difficulty inside; he is the only one feeling what he is feeling	
He has difficulty collecting firewood	He feels like he cannot do anything; his leg starts to hurt him	He comes back (home)
Sometimes his wife's side of the family cannot help	There are times of economic difficulty	
He has limitations in activities (i.e. firewood collection)		
He has experienced disrespect/mocking from others in his community due to his amputation		Makes him feel bad, weird
He does not know his rights as a PWD		
He has had instances of his rights being mis-respected, through mistreatment and discrimination		
He has activity limitations, such as inability to finish re-modelling house, climbing up the ladder onto the roof	His amputation	The problem of the lamina roof (leaking?) persists
He does not receive any support		
He has not received the help he solicited (from local alcaldes?)	The lack empathy of his situation; or they are too busy to pay attention to him	
He does not know of any organizations that work with PWDs in Guatemala		
He has problems walking	His amputation	There are times when he falls, and he cannot protect himself (in a fall)
He has problems carrying	His amputation	
He feels physically bad (incapable)	His amputation	
There is a lot of need (in PWAs)		
There is not (enough opportunity) for him to work		
He has never held a full-time job		
He has many needs in his life	He has difficulty explaining/communicating those needs	
He has suffered		
His wife sometimes becomes sad	His suffering/fight to move forwards	

Appendix 5 - Example Worksheet for Participant

Participant 17

What objectives do people with amputation/stakeholders that work with them have that could be consistent with a CBR program for people with amputation in Guatemala?

Concise summary of the objective	Problem being addressed	Intended outcomes
He didn't want to ask for help for his prosthesis	He feared people would speak of him as a beggar	
He doesn't want to go to the hospital in Coban	Money is needed to transport there	
He wanted to learn how to do electronic repairs		
He wanted to find a way to spend his life/ subsist	He got stuck at home	He began the course on electronics repairs
He wants to enable his childrens' educational attainment		
He would like to study	There is no way for him to study	
He wants to fight for his family (economic wellbeing) through electronics repair		
He wants to persist in his electronics repair work		
He wants to fight to walk	He has difficulty walking	
He wants to take advantage of opportunities he is given to work (in electronics repair)		
He would like to be able to do certain activities, such as finish remodelling his house, climbing up the ladder onto the roof	He has activity limitations, such as inability to finish re-modelling house, climbing up the ladder onto the roof	To fix the problem of the lamina roof (leaking?)
He wanted to get help (from local alcaldes?)		
He wants to fight to work	He feels physically bad (/ incapable)	So that he can move forwards in life
He wants to work	There is not (enough opportunity) for him to work	
He wants to have a job		To be able to maintain his family (economically speaking)
He has a desire to work instead of receiving a donation		Certainty when he will be paid; right to be paid
He wants to study;		
and work		
He has fought to move forward in life	He has suffered	
He wants to always maintain his children (economically)		

Appendix 6 - Example Coding Sheet for Participant

[Please click here to view the coding sheets for Participant 17, as this file is too large to include in the appendix.](#)

Thematic Analysis of Participants

P1, P2, P3, P4, P5, P6, P7, P8, P9, P10, p11, p12, p13, p14, p15, p16, p17, p18, p19.

STRENGTHS

- [DEVICE/REHABILITATION] – p1, p2, p3, p4, p5, p7, p8, p9, p10, p11, p13, p14, p15, p17, p18, p19, ((16))
- [FAITH] – p1, p6, p8, p12, p14, p15, p18, ((7))
- [AMBITION/WILL] – p1, p3, p4, p5, p6, p7, p8, p12, p13, p14, p15, p16, p17, p18, ((14))
- [POSITIVITY/COPING] – p1, p3, p5, p9, p10, p11, p12, p13, p14, p17, p18, ((11))
- [SELF-RELIANCE/INDEPENDENCE] – p2, p3, p4, p5, p7, p11, p13, p14, p15, p17, p18, p19, ((12))
- [HEALTH MANAGEMENT/WEALTH] – p3, p4, p7, p8, p10, p11, p13, p14, p15, p18, p19, ((11))
- [WORK EXPERIENCE, SKILLS, ATTITUDE] – p3, p5, p6, p7, p8, p9, p10, p12, p13, p14, p15, p17, p18, p19, ((14))
- [HOME ENVIRONMENT] – p3, p4 ((2))
- [WRITING ABILITY] – p7, p15, ((2))
- [LAND/CAPITAL] – p9, p14, ((2))
- [EDUCATION] - p11, p13, p14, p15, p16, p18, ((6))
- [AWARE OF RIGHTS] - p11, p13, p19, ((3))
- [VOLUNTEERISM/SOCIAL CHANGE AGENT] - p11, p12, p13, p14, ((4))
- [GOOD PROGNOSIS] - p12, ((1))
- [VEHICLE] - p14, ((1))
- [AWARE OF PWAs/NEEDS] - p14, p15, ((2))
- [ACTIVITY CAPABILITIES] - p15, ((1))
- [CHILDRENS' EDUCATION] - p17, p18, ((2))
- [ABILITY TO STUDY] - p18, ((1))
- [COMMITMENT TO MARRIAGE] - p18, ((1))

WEAKNESSES

- [PAIN/EFFECTS OF AMPUTATION/ACCIDENT] – p1, p2, p5, p7, p9, p12, p14, p15, p16, p17, p19, ((11))
- [IMPEDED/INHIBITED EDUCATION] – p1, p12, p13, p17, p18, ((5))
- [DEPRESSION/PSYCHOLOGICAL PROBLEMS] – p1, p2, p3, p4, p5, p8, p9, p10, p12, p13, p14, p15, p17, p18, ((14))
- [DISEMPOWERED/MENTAL BARRIERS] – p1, p4, p5, p6, p8, p9, p10, p11, p12, p13, p14, p15, p16, p17, p18, ((15))
- [OTHER HEALTH PROBLEMS] – p2, p3, p5, p6, p8, p10, p16, p18, p19, ((9))
- [LIMITED EDUCATION/LITERACY] – p2, p3, p4, p5, p6, p7, p8, p9, p10, p12, p15, p17, p19, ((13))
- [UNEMPLOYMENT/BARRIERS TO WORK] – p2, p4, p5, p6, p8, p9, p10, p12, p13, p16, p17, p18, p19, ((13))
- [FINANCIAL HARDSHIP/LIMITED EARNING/COSTS] – p2, p5, p6, p7, p8, p9, p10, p17, p18, p19, ((10))
- [OTHER DISABILITY/ACCIDENT] – p3, p9, ((2))
- [AGE] – p3, p16, ((2))
- [ACTIVITY/MOBILITY LIMITATIONS] – p5, p8, p9, p10, p13, p14, p15, p16, p17, p18, ((10))
- [NO/INADEQUATE PROSTHESIS/DEVICE] – p6, p8, p12, p16, p18, p19, ((6))
- [ADVERSION TO STUDYING] – p6, p7, ((2))
- [BREAKING/RUINING/AGING PROSTHESIS] – p7, p10, p13, ((3))
- [LACKS KNOWLEDGE OF SERVICES] – p8, p11, p16, p17, ((4))
- [DEVICE PROBLEM/LIMITATION/PAIN] – p8, p11, p14, ((3))
- [POOR HEALTH MANAGEMENT/SERVICES] – p8, p12, p18, ((3))
- [ALCOHOLISM] – p9, p15, p18, ((3))
- [SOCIAL LIMITATIONS] – p9, ((1))
- [LACKS TOOLS/VOCATIONAL CAPABILITY/CAPACITY] – p10, p12, p14, p19, ((4))
- [UNCERTAINTY] - p12, ((1))
- [LACK OF PROSTHETIC CARE] - p13, ((1))
- [DIFFICULT WORK CLIMATE/ENVIRONMENT] - p13, p14, p18, ((3))
- [GENERAL LIMITATIONS] - p13, ((1))

- [DEPENDENCY] - p16, ((1))
- [GENERAL SUFFERING] - p17, ((1))
- [STUCK AT HOME] - p17, p18, ((2))
- [LACK OF TRANSPORTATION] - p19, ((1))

OPPORTUNITIES

- [EDUCATIONAL ENVIRONMENT] – p1, p9, p11, p13, ((4))
- [WORK CLIMATE/ENVIRONMENT] – p1, p2, p7, p9, p12, p13, ((6))
- [FAMILY RELATIONSHIPS/HELP/PRODUCTIVITY/INVOLVEMENT] – p1, p2, p4, p5, p6, p7, p8, p9, p10, p11, p12, p13, p14, p15, p16, p17, p18, p19, ((18))
- [COMMUNITY INVOLVEMENT] – p1, p9, p10, p12, p13, p14, p15, p17, p18, p19, ((10))
- [SOCIETY] – p1, p2, p6, p7, p10, p19, ((6))
- [FRIEND RELATIONSHIPS] – p1, p5, p13, p18, ((4))
- [PROSTHETIC/REHABILITATION CARE] – p1, p7, p9, p10, p11, p12, p13, p14, p15, p17, p18, ((11))
- [MEDICAL CARE/MEDICINES] – p2, p3, p4, p6, p7, p8, p9, p10, p12, p13, p14, p15, p17, p18, p19, ((15))
- [EDUCATIONAL CLIMATE] – p2, p4, p5, p8, p10, p12, p18, p19, ((8))
- [INVOLVEMENT/INTERACTION w/ PWDs/DPOs] – p3, p7, p8, p9, p13, p14, ((6))
- [PENSION] – p3, p4, p5, p9, ((4))
- [INSTITUTIONAL HELP] – p4, p5, p12, p13, p17, ((5))
- [MILITARY CLASSES/TRAINING] – p6, ((1))
- [LIVELIHOOD/JOB] – p6, p7, p13, p15, ((4))
- [COMMUNITY RELATIONSHIPS/HELP] – p3, p7, p8, p10, p15, p16, ((6))
- [PSYCHOLOGICAL CARE] – p9, ((1))
- [INTERVIEW] – p10, ((1))
- [CHURCH SUPPORT] - p14, p18, p19, ((3))
- [SERVICE] - p15, ((1))
- [CHILDREN's EDUCATION] - p18, ((1))

THREATS

- [EDUCATIONAL CLIMATE/ENVIRONMENT] – p1, p4, p8, p10, p12, p13, p15, p17, p18, p19, ((10))
- [PERCEPTION/TREATMENT BY OTHERS] – p1, p2, p3, p4, p5, p6, p8, p9, p10, p12, p13, p14, p15, p16, p17, p18, ((16))
- [LACK OF CONNECTION/AWARENESS] – p1, p5, p6, p7, p8, p9, p11, p12, p13, p15, ((10))
- [WORK CLIMATE/ENVIRONMENT] – p1, p2, p3, p5, p6, p7, p9, p10, p12, p13, p14, p15, p16, p17, p18, p19, ((16))
- [EXTERNAL CONTROL] – p1, ((1))
- [LIMITED INSTITUTIONAL HELP] – p1, p4, p6, p7, p8, p9, p10, p11, p12, p13, p14, p15, p16, p17, p18, p19, ((16))
- [MEDICAL/PROSTHETIC CARE GAPS/INSUFFICIENCIES] – p2, p4, p5, p6, p8, p9, p10, p12, p13, p14, p16, p17, p18, p19, ((14))
- [FINANCIAL HARDSHIP/LIMITED EARNING/COSTS] – p2, p6, p8, p9, p10, p12, p16, p18, p19, ((9))
- [TRANSPORTATION DIFFICULTY/DISCRIMINATION/COSTS] – p2, p3, p9, p10, p17, p18, ((6))
- [FAMILY PROBLEMS/DISCRIMINATION/CHANGES] – p3, p4, p5, p6, p8, p14, p18, ((7))
- [HOME ENVIRONMENT] – p3 ((1))
- [EXCLUSION BY/DISCRIMINATION BY/BARRIERS TO LAWS/PROJECTS/INSTITUTIONS] – p3, p5, p8, p9, p10, p12, p14, ((7))
- [NON-HOME ENVIRONMENT] – p4, p8, p9, p15, ((4))
- [IMPACT ON FAMILY] – p6, p9, p10, p12, p13, p17, p18, p19, ((8))
- [LACK OF COMMUNITY HELP] – p6, ((1))
- [IMPEDED/LIMITED EDUCATION] – p7, p9, p15, ((3))
- [LIMITED/THREATENED EDUCATION IN FAMILY] – p8, p17, p18, ((3))
- [AGRICULTURAL LAND AND CAPITAL] – p9, ((1))
- [GENERAL BARRIERS] – p9, ((1))
- [DIABETES PREVALENCE/MISMANAGEMENT] – p10, p19, ((2))
- [LACK OF COMMUNITY INVOLVEMENT] - p11, ((1))
- [COMMUNITY DRUG/YOUTH PROBLEMS] - p14, ((1))
- [DIVISIONS/EXCLUSIONS BY SOCIETY] - p14, ((1))
- [FLAWED MODEL OF HELP] - p14, ((1))

- [PWDs DESPERATION/BEGGING/PSYCHOLOGICAL PROBLEMS] - p14, p15, p18, p19, ((4))
- [POOR HEALTH MANAGEMENT] - p16, ((1))
- [LIMITED HELP FROM FAMILY] - p17, ((1))
- [GENERAL NEED OF PWAs] - p17, ((1))
- [HAI RISK POST-AMPUTATION] - p19, ((1))
- [WAR PROVOKED DIABETES] - p19, ((1))

RESOURCES – HUMAN

- [TEACHERS/PEERS AT SCHOOL] – p1, p11, p13, ((3))
- [VOCATIONAL TRAINING/SKILLS/EXPERIENCE] – p1, p2, p3, p5, p6, p7, p8, p9, p10, p13, p14, p15, p17, p18, p19, ((15))
- [FAMILY RELATIONSHIPS/RESOURCES/HELP] – p1, p2, p4, p5, p6, p7, p8, p9, p10, p11, p12, p13, p14, p15, p16, p17, p18, p19, ((18))
- [AMBITION/WILL] – p1, p3, p4, p5, p6, p7, p8, p12, p13, p15, p16, p17, p18, ((13))
- [FRIENDS/ACQUAINTANCES] – p1, p4, p5, p13, ((4))
- [POSITIVITY/COPING] – p1, p3, p5, p9, p10, p12, p13, p14, p17, p18, ((10))
- [MEDICAL PERSONNEL/PSYCHOLOGICAL PERSONNEL] – p2, p3, p6, p8, p9, p14, p18, p19, ((8))
- [WORK SUPPORT/RELATIONSHIPS – COLLEAGUES/FAMILY] – p2, p7, p9, ((3))
- [COMMUNITY MEMBERS/HELP] – p2, p3, p6, p7, p8, p10, p15, p16, p18, ((9))
- [AWARENESS OF/INVOLVEMENT/INTERACTION WITH PWDs] – p3, p7, p8, p9, p13, p14, ((6))
- [SELF-RELIANCE/INDEPENDENCE] – p4, p5, p7, p11, p13, p14, p15, p17, p18, p19, ((10))
- [FAITH] – p6, p8, p12, p14, p15, p18, ((6))
- [HEALTH/PSYCHOLOGICAL WELLBEING/MANAGEMENT] – p7, p8, p9, p10, p11, p13, p14, p15, p18, p19, ((10))
- [WRITING ABILITY] – p7, p15, ((2))
- [WORK ENJOYMENT/ATTITUDES] – p7, p8, p14, p17, ((4))
- [COMMUNITY INVOLVEMENT] – p9, ((1))
- [EDUCATION] - p11, p13, p14, p15, p16, p18, ((6))
- [KNOWLEDGE OF RIGHTS] - p11, p13, p19, ((3))
- [VOLUNTEERISM/SOCIAL CHANGE AGENT] - p11, p13, p14, p15, ((4))

- [AWARENESS OF FLAWED “HELP” MODEL] - p14, ((1))
- [ACTIVITY CAPABILITIES] - p15, p18, ((2))
- [AWARENESS OF PWA NEEDS] - p15, ((1))
- [FOCUS/ATTAINMENT - CHILDRENS’ EDUCATION] - p17, p18, ((2))
- [IMPROVING MOBILITY] - p18, ((1))
- [ABILITY TO STUDY] - p18, ((1))
- [COMMITTMENT TO MARRIAGE] - p18, ((1))

RESOURCES – MATERIAL

- [DEVICE/REHABILITATION] – p1, p2, p3, p4, p5, p6, p7, p8, p9, p10, p11, p12, p13, p14, p15, p16, p17, p18, p19, ((19))
- [EDUCATION CLIMATE] – p1, p2, p8, p10, p12, ((5))
- [MEDICINES/MEDICAL CARE] – p2, p3, p4, p5, p6, p7, p8, p9, p10, p12, p13, p14, p15, p17, p18, p19, ((16))
- [TOOLS/FACILITY/CAPITAL FOR WORK] – p2, p6, p14, ((3))
- [PENSION] – p3, p4, p5, p9, ((4))
- [INSTITUTIONAL HELP] – p5, p8, p11, p12, p17, ((5))
- [CROPS/PRODUCE] – p7, p9, ((2))
- [LIVESTOCK] – p8, p9, ((2))
- [TRANSPORTATION/VEHICLE] – p8, p9, p14, ((3))
- [WORK OPPORTUNITIES/JOB] - p12, p13, p15, ((3))
- [WORK ENVIRONMENT] - p13, ((1))
- [CHURCH DONATION] - p14, ((1))
- [LAND/HOME] - p18, ((1))

RESOURCES – STRUCTURES

- [MILITARY HEALTH/CADEG] – p1, p2, p3, p4, p5, p6, p7, p8, p9, p15, ((10))
- [LIVELIHOOD INSTITUTIONS] – p2, ((1))
- [DISABILITY SPORT] – p3, ((1))
- [DISABILITY POLICY/ADVOCACY] – p4, p13, ((2))
- [PUBLIC HEALTH] – p8, p9, p10, p13, p17, p18, p19, ((7))
- [LOCAL GOVERNMENT] – p8, p13, ((2))
- [CHURCH COMMUNITY] – p8, p9, p10, p12, p13, p14, p15, p17, p18, p19, ((10))
- [NGOs] – p10, p11, p12, p14, p17, ((5))
- [SERVICE GROUP] - p12, ((1))
- [INTERINSTITUTIONAL COLLABORATION] - p13, ((1))
- [DISABILITY-RELATED ORGANIZATIONS] - p13, p17, p18, p19, ((4))
- [PRIVATE PROSTHETICS CLINIC] - p14, ((1))
- [COMMUNAL WORK/COMMUNITY DEVELOPMENT] - p15, p19, ((2))
- [PRIVATE HOSPITAL] - p17, ((1))
- [ELECTORAL CAMPAIGN] - p18, ((1))
- [GENERAL COMMUNITY] - p19, ((1))

PROBLEMS

- [Participant has pain/other effects in his residual limb and other parts of his body.] – p1, p2, p5, p7, p9, p12, p14, p15, p17, p19, ((10))
- [Participant faces difficult educational climate and environment.] – p1, p4, p10, p12, p13, p15, p17, p18, p19, ((9))
- [Participant faces adverse perceptions and treatment/lack of help from others.] – p1, p3, p4, p5, p6, p8, p9, p10, p12, p13, p14, p15, p17, p18, ((14))
- [Participant lacks an awareness of, and connection to, the disability community/services.] – p1, p5, p6, p7, p8, p11, p12, p15, p16, p17, ((10))
- [Participant faces difficult work climate/environment.] – p1, p2, p5, p6, p7, p9, p10, p12, p13, p14, p15, p16, p17, p18, p19, ((15))
- [Participant has depression/psychological problems.] – p1, p2, p3, p4, p5, p9, p10, p12, p13, p14, p15, p17, p18, ((13))

- [Participant's education has been interrupted/made difficult.] – p1, p12, p13, p17, p18, ((5))
- [Participant experiences disempowerment/general limitation/mental barriers.] – p1, p4, p5, p6, p9, p10, p12, p13, p14, p15, p16, p17, ((12))
- [There is limited institutional help.] – p1, p2, p3, p4, p6, p7, p8, p9, p10, p11, p12, p13, p14, p16, p17, p18, p19, ((17))
- [Participant has difficulty walking/mobilizing/exercising.] – p2, p4, p5, p8, p9, p10, p14, p16, p17, p18, ((10))
- [There are gaps/insufficiencies in medical/prosthetic care.] – p2, p4, p5, p6, p8, p9, p10, p12, p13, p14, p16, p17, p18, p19, ((14))
- [Participant has other health problems.] – p2, p3, p5, p6, p8, p10, p16, p18, p19, ((9))
- [Participant has a limited education/literacy.] – p2, p3, p4, p5, p6, p7, p8, p9, p10, p15, p19, ((11))
- [Participant faces financial hardship/limited income/high costs.] – p2, p6, p7, p8, p9, p10, p12, p17, p18, p19, ((10))
- [Participant's work has been interrupted/made difficult.] – p2, p3, p4, p6, p8, p9, p10, p12, p14, p16, p17, p18, p19, ((13))
- [Participant is not connected with members of/participating in his community.] – p2, p11, ((2))
- [Participant faces difficulty/discrimination in transportation.] – p2, p3, p9, p10, ((4))
- [Participant lacks a prosthesis.] – p3, p6, p8, p16, p18, p19, ((6))
- [Participant has another type of disability/had another accident.] – p3, p9, ((2))
- [Participant faces adverse treatment by/relationship with/limited help from family members.] – p3, p4, p5, p6, p8, p14, p17, p18, ((8))
- [Participant faces difficulty in daily activities.] – p3, p8, p15, p16, p17, p18, ((6))
- [There is exclusion of, and barriers to, PWDs by projects/laws/institutions.] – p3, p8, p12, p14, p17, ((5))
- [Participant is without a partner.] – p4, ((1))
- [Participant is disqualified from receiving help from some organizations.] – p5, p14, ((2))
- [Participant seldom seeks/is avoidant towards medical care.] – p6, p17, p18, ((3))
- [There are many people who lack a prosthesis.] – p7, ((1))
- [Participant's prostheses break/get ruined.] – p7, p13, ((2))
- [There are many PWDs/PWAs.] – p7, ((1))
- [Participant had recurring diabetic ulcer in her leg.] – p8, ((1))

- [Participant has unsuccessful/poor management of her diabetes/other health condition.] – p8, p16, ((2))
- [Participant’s current/future device presents problems/limitations/pain.] – p8, p10, p11, p13, p14, ((5))
- [Participant does not own motorcycle for transporting himself.] – p9, ((1))
- [Harvest harmed by climate.] – p9, ((1))
- [Participant faces difficulty in home environment.] – p9, ((1))
- [Participant struggled with alcoholism.] – p9, p18, ((2))
- [Participant faces general social limitations.] – p9, ((1))
- [Diabetes is prevalent/poorly managed in the community.] - p10, p19, ((2))
- [Participant faces uncertainty about the details and impact of his pending amputation.] - p12, ((1))
- [Participant lacks specific vocational capacity/has gaps in capacity.] - p12, p14, p19, ((3))
- [Participant’s amputation will have/had a psychological/general impact on family members/ friends.] - p9, p10, p12, p13, p17, p18, p19, ((7))
- [Participant’s amputation will cause/has caused general suffering.] - p12, p17, ((2))
- [Families of PWDs face poverty.] - p13, ((1))
- [The selling/distribution of drugs in public areas is affecting the youth.] - p14, ((1))
- [Participant lacks sufficient manpower in his business.] - p14, ((1))
- [The model for “help” is flawed.] - p14, ((1))
- [PWDs are becoming desperate/begging/dying.] - p14, p15, p18, p19, ((4))
- [Participant does not own the wheelchair she is using.] - p16, ((1))
- [Participant’s family is unable to see her.] - p16, ((1))
- [Participant got stuck at home.] - p17, p18, ((2))
- [Participant’s children’s educational attainments are uncertain/threatened.] - p6, p17, p18, ((3))
- [There is a lot of general need in PWAs.] - p17, ((1))
- [Participant’s family was not in agreement with his decision to amputate.] - p18, ((1))
- [There is a risk of an HAI staying at the hospital.] - p19, ((1))
- [The war caused/provoked participant’s diabetes.] - p19, ((1))

OBJECTIVES

- [Participant wants to restart studies/study for career development.] – p1, p3, p5, p7, p12, p13, p15, p17, ((8))
- [Participant wants to not beg.] – p1, ((1))
- [Participant wants to be positive/respect himself.] – p1, p3, ((2))
- [Participant wants there to be institutions/projects supporting people with prosthetic/medical needs and who are suffering.] – p1, p13, p16, p19, ((4))
- [Participant wants to work] – p2, p4, p5, p6, p8, p12, p13, p17, p18, ((9))
- [Participant wants tools/vehicle to facilitate his work.] – p2, p14, ((2))
- [Participant wants his children to be sufficiently educated.] – p2, p9, p17, p18, ((4))
- [Participant wants to connect with people in his community.] – p2, ((1))
- [Participant wants for there to be self-help groups.] – p2, ((1))
- [Participant wants medicines/help for other medical conditions.] – p2, p10, ((2))
- [Participant wants for there to be psychosocial support.] – p2, p9, p15, ((3))
- [Participant wants to have better psychological health.] – p3, p10, ((2))
- [Participant wants to connect with and support/help PWDs.] – p3, p7, p11, p13, p14, ((5))
- [Participant wants discrimination to be reduced/awareness to be increased.] – p3, p18, ((2))
- [Participant wanted to establish CADEG.] – p3, ((1))
- [Participant wants increased inclusion of PWDs in projects/laws/institutions/society in general.] – p3, p14, ((2))
- [Participant wants improved/new prosthesis.] – p4, p10, p13, ((3))
- [Participant wants for there to be work for PWDs.] – p6, p12, ((2))
- [Participant wants a prosthesis.] – p6, p8, p14, p18, ((4))
- [Participant wants there to be programs/centres to help.] – p6, p7, p9, p18, ((4))
- [Participant wants to receive help.] – p6, p17, ((2))
- [Participant wants to diversify his livelihood/have greater economic capacity/improve economic situation.] – p7, p9, p10, p12, p17, p18, ((6))
- [Participant wanted to not be hospitalized.] – p8, ((1))
- [Participant wants to do activities/make the best of being at home.] – p8, p10, p15, p17, p18, ((5))
- [Participant wants to walk.] – p8, p16, p17, ((3))

- [Participant wants to stay at home.] – p8, p10, ((2))
- [Participant wants a motorcycle in order to mobilize himself.] – p9, ((1))
- [Participant wants to improve the steps in his home.] – p9, ((1))
- [Participant wants to mentor young people.] – p9, ((1))
- [Participant wanted to accept his amputation/carry onwards.] – p9, p10, p12, p13, p14, p15, p17, p18, ((8))
- [Participant’s husband wants her to let out her pain/feelings.] - p10, ((1))
- [Participant wants increased clarity/generosity on part of prosthetics institutions.] - p10, ((1))
- [Participant wants to continue his participation in his service group.] - p12, ((1))
- [Participant wants to proceed with his pending amputation.] - p12, ((1))
- [Participant wants to facilitate inter-institutional collaboration focused on disability.] - p13, ((1))
- [Participant wants to learn his rights as a PWD.] - p13, ((1))
- [Participant wants to take on physically-challenging activities.] - p13, ((1))
- [Participant wants to be independent/self-reliant.] - p14, p18, ((2))
- [Participant wants to maintain/repair his prosthesis on his own, and wants it to truly be part of him.] - p14, ((1))
- [Participant wants to create employment for others.] - p14, ((1))
- [Participant wants to be an instrument of social change in his pueblo.] - p14, ((1))
- [Participant wanted to persist/improve in his work.] - p14, p17, ((2))
- [Participant wants PWDs to be treated as “normal” people, and to feel useful/valued.] - p14, p15, ((2))
- [Participant wants to be positive.] - p14, ((1))
- [Participant does not want to take advantage of “rights” as PWD.] - p14, ((1))
- [Participant wants changed model of “help” and increased accountability by beneficiaries.] - p14, ((1))
- [Participant wants to rest from prosthesis use at night.] - p14, ((1))
- [Participant wants to live by his faith.] - p15, ((1))
- [Participant wants to go to church.] - p16, ((1))
- [Participant wants to see her family.] - p16, ((1))
- [Participant’s family wants the family to be united in helping the participant.] - p16, ((1))

- [Participant wanted to not ask for help for his prosthesis.] - p17, ((1))
- [Participant wants to not travel to the hospital.] - p17, ((1))
- [Participant wanted to prepare for prosthesis use.] - p18, ((1))
- [Participant wanted to overcome alcoholism.] - p18, ((1))
- [Participant wanted to focus on marriage.] - p18, ((1))
- [Participant wants to help, in general.] - p18, ((1))
- [Participant wants to start a business.] - p18, ((1))
- [Participant wants to volunteer in an electoral campaign.] - p18, ((1))
- [Participant wants family to make decisions together.] - p18, ((1))
- [Participant wants to manage his health problems.] - p19, ((1))
- [Participant wants to respect religious diversity.] - p19, ((1))



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