

# AN OVERVIEW OF THE NEEDS AND REQUIREMENTS OF PERSONS WITH DISABILITIES IN KAMAND VALLEY

A study in collaboration with our sponsor: Enabling Women of Kamand

Written By:

Rebecca Markowitz

Amit Ranjan

Bhanu Singh

Erika Miyajima

Michael Savrin

Brandon Waugh



WPI

EWOM

Enabling Women of Kamand



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Institute of  
Technology  
Mandi

# **An Overview of the Needs and Requirements of Persons with Disabilities in Kamand Valley**

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by  
Rebecca Markowitz  
Erika Miyajima  
Amit Ranjan  
Michael Savrin  
Bhanu Singh  
Brandon Waugh

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Report Submitted to:

Ms. Sandhya Menon  
Enabling Women of Kamand

Dr. Priscilla Gonsalves  
Indian Institute of Technology – Mandi

Dr. Ingrid Shockey and Dr. Gbetonmasse Sommasse  
Worcester Polytechnic Institute

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*<http://www.wpi.edu/Academics/Projects>*

# Abstract

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Due to the negative social, physical, and financial repercussions presented to persons with disabilities (PwD) and their families, it is vital that their needs and requirements are clearly known and addressed in communities. To meet this goal, we assessed perceptions of PwD in the Kamand region. We set out to understand the limitations that are faced by PwD and their families, and we determined the resources available to support PwD. By accomplishing these objectives, we hoped to clarify standards for accessibility in Kamand Valley and to promote greater understanding and independence to those affected by disability.

# Executive Summary

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## PwD in Himachal Pradesh

The Rights of Persons with Disabilities Act of 2016 defines persons with disabilities (PwD) as “a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders [their] full and effective participation in society equally to others” (Ministry of Law and Justice, 2016). Despite improvements to accessibility in India, PwD and their families still face negative social, physical, and financial repercussions (Richard, 2014).



*Figure A. Women with a spinal injury and her husband (photo credit: Savrin, 2019)*

Initiatives to secure resources, services, or opportunities for PwD, can significantly improve the lives of families. Toward this end, Enabling Women of Kamand Valley (EWOK), is interested in contributing to the well-being of women, including those with PwD dependents, in a small community in the heart of Himachal Pradesh. The well-being of a PwD is highly dependent on the support and stability given by their caregivers (Richard, 2014). Therefore, it is vital that the needs and requirements of PwD are clearly known and addressed in communities.

To meet this goal, we assessed perceptions of PwD in the Kamand region. We set out to understand the limitations that are faced by PwD and their families, and

we determined the resources available to support PwD. By accomplishing these objectives, we hoped to clarify standards for accessibility in Kamand Valley and give greater understanding and independence to those affected by disability. Below, we discuss our methods for accomplishing our objectives.

### ***Objective 1: Assess community perceptions of PwD***

We interviewed relevant experts to understand their views on the perceptions of PwD in Kamand Valley. Based on our preliminary discussions and observations, we designed a survey and conducted in-person interviews with the residents of the villages in Kamand Valley.

### ***Objective 2: Identify limitations faced by PwD and their families***

We conducted structured interviews with PwD and caregivers to assess their experiences. We used a sample of convenience and snowball sampling to identify participants.

### ***Objective 3: Determine the resources available to PwD***

To help us determine the resources available, we consulted with local experts such as doctors, teachers, and other relevant professionals. We set up face-to-face unstructured interviews that were tailored to each individual. Finally, we interviewed PwD and asked them to identify what resources were available and beneficial services that operate on their behalf or offer support in the region.

## **Results and Discussion**

The result of our interviews and discussions with PwD and other community members are presented here by objective.

### ***Community Perceptions of PwD***

Our interview strategy with community members did not generate clear answers on questions about their opinions towards PwD. We sensed reluctance when asked to talk about their own opinion, but interviewees opened up when asked about their thoughts on other community members' perceptions of PwD.

In an interview with a special needs educator, we learned that when alienation is taken to an extreme, concealment may also happen within communities. For example, we heard of a nine-year-old boy with 90% mental retardation that is kept confined to his house. Although the special educator is trying to counsel his family, they feel their child is cursed and do not want to be further judged by their community.

While some of the stories we found were quite demeaning, we also observed PwD at school and noticed that the other children were very accepting and excited to play with the students with disabilities. The students with disabilities also confirmed that they had an easy time making friends.

### ***Limitations of PwD***

The findings of our fieldwork revealed educational, social, economic and physical geographical constraints.

A commonly identified limitation is that of educational opportunities, which was evident through interviewing a special needs educator located at a government school in Katindhi. She stated that she was the special needs expert for five other area schools and that her job entailed of counseling students, parents, and teachers as well as baseline education work. Other government schools had a few special needs students, but no one knowledgeable on special needs education to work with them.

Another key limitation for PwD was a system of social beliefs and perceptions about the cause or meaning of disabilities in families. One woman said, "I believe my hearing impairment developed because I was too shy," she further noted, "I pray to god every day that I will be able to hear as I used to" (personal communication, April 6, 2019). Thoughts like this can contribute to negative societal perceptions.

We recorded many stories of financial limitations to PwD and their families. In discussions with caregivers, we have heard that financial resources can be scarce with one man who was caring for his two brothers saying "my very limited financial resources are almost completely consumed by basic amenities" (personal communication, April 4, 2019). One father also admitted to having stopped working in order to support his son's education leading to poor financial standing.

Finally, the difficult landscape of the Kamand Valley is another limitation for those with physical disabilities. According to a school administrator, children with physical disabilities are often kept at home rather than sent to school, as they are not capable of walking to school. This landscape could prevent a PwD from being able to reach the place where they need to go.

### *Existing resources of PwD*

There are ongoing efforts in providing existing resources to PwD such as government stipends for PwD with disability certification, support groups held through NGOs, and a special needs educator working in government schools.

Organizations like EWOK help train women by providing them with educational classes. They are also in the process of expanding their support group system. Chinmaya Organization for Rural Development (CORD) is an NGO in Dharamshala. CORD provides many resources, including engaging local children with disabilities in domestic activities, such as cooking, cleaning, and other tasks so that they can gain more independence as they grow up. At this time, these kinds of resources are in place, but not available to PwD and caregivers in Kamand Valley.

Support for children with disabilities can be seen in local hospitals where they provide anemia acid tablets for children under the age of 15 with red blood cell deficiency. Surgeries and prosthetics are also provided for free to some children in need. CRC Sundernagar and Zonal Hospital in Mandi provide physical therapy. The Katindhi Hospital also helps PwD rehabilitate through medical and vocational training so that they have better living standards. We interviewed a rehabilitation expert, Dr. Narendra Singh, who explained that a disability greater than 40% can get a disability certification, which can qualify PwD for a monthly stipend and free bus passes in Himachal Pradesh.

### *Discussion*

It seems that there are not open conversations about the challenges PwD face, and alienating and concealment of PwD is common. Nevertheless, those PwD that are integrated into the community are generally well perceived. We also observed educational, financial, and physical limitations, which led to many inequalities.

Many individuals declined to answer personal questions. Perhaps there is no certain way to speculate about PwD or perhaps residents are protecting PwD by choosing not to discuss their problems. Given some evidence of karma, and black magic, some may have declined to answer because there are strong beliefs associated with PwD. These perceptions related to black magic and karma enforce the idea that PwD are bad and should not necessarily be helped or incorporated into society. Other answers reflected general understanding of the taboos and stigmas associated with PwD in their society. Concealment and isolation were also shown through this obvious social barrier of the PwD and the community.

At the same time, there were some signs of a surprising openness towards them, specifically amongst the children with disabilities. Both by observation and discussion with the children with disabilities at the Katindhi Government School, we confirmed that the children integrated into a non-special education school were well adapted and able to make friends with their peers.

For children with disabilities, having luck in terms of locally available resources seems to be the primary marker of success. The options, for most, are either to potentially travel a long way to go to a school with a special educator, have your child sent to a special school where they may be separated from other students, or have them sent to a government school where they could



*Figure B. Translator helping with interview in Kahara (photo credit: Markowitz, 2019)*

potentially be rejected because the school does not want to work with PwD. None of these options are optimal which can raise many long-term and compounding problems for a child with disabilities gaining a full education.

Financial limitations also raise clear discussion points. Although the minimum wage in Himachal Pradesh differs depending on the field of work, the minimum wage for an agriculture job, which is typical in Kamand Valley, is 225 rupees per day (Himachal Pradesh Labor and Employment Department, 2018). With this information, the common monthly stipend of 500-1000 rupees is clearly not enough. In cases where more than one family member faces disability, there can be insurmountable implications for a family to give support.

Though landscape issues were not heavily discussed, there were clear problems seen. Not going out into the community and struggling to do so has been mentioned in multiple interviews and there could be a clear correlation between these points.

## **Project Outcomes**

We have four areas of recommendations related to the support and improvement of the quality of life for PwD in Kamand Valley.

### ***Addressing Emotional Needs through Support Groups***

Our first recommendation relates to the idea of emotional support groups and the ability to share the hardships that can be related to being a PwD or caring for one. They would bring PwD or caregivers together so they can share their stories and how they may deal with certain hardships. EWOK already has an established infrastructure in the community so they would be able to potentially host a support group of this form. In our research, we have seen a variety of people who stated that a support group is a resource they would utilize if it were available to them.

### ***Addressing Medical Needs through Medical Camps and Assistive Technology***

First, a “medical camp” program could be implemented where PwD could be taken to the Zonal Hospital in Mandi and have dedicated doctors who would provide them with any necessary certification or assistance. The validity of this suggestion was enforced by an interview with a local man whose brother is a doctor and claimed that it was quite easy for him to access resources for his differently-abled wife.

Another medical support need would be access to inexpensive assistive technology. Though affordable assistive technology is not available in Kamand Valley, it could be brought there by bringing these discounting programs to the area or bringing people to these programs.

### ***Addressing Education through Training of School Staff***

As mentioned earlier, there is a clear lack of educators who are trained to work with PwD, with only one educator for the entire Kamand region. A good way to improve this situation would be to train both educators and administrators so that they can better work with students with disabilities. This training could potentially be done by the trained educator for the region or an outside resource could be brought in.

### ***Addressing Financial Inequalities through Trainings and Labor Opportunities***

The final suggestion targets the goal of reducing inequalities with a variety of recommendations regarding employment training and opportunities. The first recommendation would be sponsoring

PwD and caregivers to attend EWOK trainings. These trainings would allow for the improvement of the financial situations of PwD by enabling them to work in more skilled labor.

In the case of unskilled labor, there could be potential improvement through an organization structured to improve area accessibility. This organization could also offer employment to caregivers and PwD who are still able to do physical labor. The development of an organization like this would also allow for flexible work times of PwD and caregivers.

### *Awareness Platform*

At the end of this project, we wanted another medium to show our work in order to make our findings more accessible to our stakeholders. To do this, we created a website displaying our research. The website (<https://tinyurl.com/iitwpipwd>) will be a place where people can not only review our project and see what we have accomplished, but will also work to generate awareness of the hardships PwD face in the community. In the future, EWOK can utilize our website as a platform to communicate the current resources available to PwD and their families.

## **Conclusion**

Due to the variety of challenges presented to PwD by the environment, culture, and political climate, this study is important to understanding the complexities of the area in relation to disabilities. We have assessed perceptions of PwD through a variety of interviews and surveys and found limitations through discussions with PwD and their caregivers. The final aspect that we have worked on involved communicating with officials in the community about the resources that are available to PwD. Our study has given a better understanding of PwD in Kamand Valley as well as how communities function in relation to them. Our sponsor EWOK hopes to use the outcomes of this study to improve lives of caregivers and PwD so that they too can work to empower themselves.

This study can be used to further promote the implementation of our recommendations by either already existing organizations or by the founding of new organizations. These ideas could be used by EWOK to begin work with PwD and caregivers. Some of our recommendations could also be implemented as government initiatives to improve the quality of life for PwD and caregivers.



# Acknowledgements

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We would like to thank the following individuals for their assistance and guidance throughout our time here to ensure our project was a success:

- Our mentors, Dr. Priscilla Gonsalves, Ms. Sandhya Menon, Dr. Ingrid Shockey, and Dr. Gbetonmasse Sommasse for their insight and guidance on our project
- EWOK for their sponsorship of our project
- Vandana Thakur for helping us with translations in the field
- Our teaching assistant Harsh Arora
- All of our interviewees for sharing their stories with us

# Authorship

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Due to the collaborative nature and revision process of this project, the authorship is ambiguous. Rather than listing what each person on the team did individually, we will discuss the process of how this report came into being, including the fieldwork, writing, editing, and revision processes.

Before arriving in India, Rebecca, Erika, Michael, and Brandon worked on a preliminary report that consisted of background information and initial methodology strategies. Each of them did the research for and wrote their assigned subsection. Then all four of them met in person and combined these subsections and made edits to each other's writing. This process involved many open discussions and often members would rewrite other members' sections. Before the four WPI students arrived in Kamand, Amit and Bhanu did archival background research and created preliminary questionnaires for PwD and Caregivers.

After the formalities of introductions were over with, the team got to work. We combined the ideas presented by both the WPI and IIT students. All students contributed to the writing and editing of the report. The same process used by the WPI students before arriving to India was used by all students in our final report. Often text from the preliminary report was borrowed and edited, making it hard to track authorship.

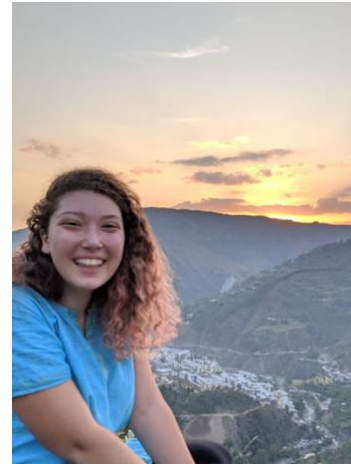


# Meet the Team

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## *Rebecca Markowitz (WPI)*

Hello! My name is Rebecca Markowitz and I am originally from San Diego, California. I am a current sophomore at WPI and am studying Robotics Engineering and Computer Science. The experiences I've had while working on this project have been eye opening. I've enjoyed being able to meet complex individuals that have shared their stories and welcomed us with warm cups of chai. I also had a lovely time working with IIT students and learning about their culture. This project gave me the opportunity to make memories and grow on a professional and personal level.



## *Erika Miyajima (WPI)*

Hi there. My name is Erika Miyajima. I am a Mechanical Engineering student from Nagano, Japan. It has been an amazing experience to be able to complete my IQP at IIT Mandi where I was surrounded by beautiful mountains with many wild animals. I have also loved interacting with cute dogs on campus while enjoying tea time every day. Through our fieldwork, we were able to conduct interviews with villagers in Kamand Valley and hear fascinating stories of their daily lives. I believe the experiences I have gained throughout this project will help me thrive in my future.

## *Amit Ranjan (IIT)*

Hola Amigos! My name is Amit Ranjan, and I am from Bihar, India. I am currently pursuing a major in Mechanical Engineering and a minor in Management at IIT Mandi. I have enjoyed working on this joint project with my WPI teammates. I have learned a lot from this social-technical practicum, specifically the culture and diversity of my very own country, that I was unaware of. Not to mention the welcome greetings received from the community in the villages and the joy of trekking on mountains. It was also a delightful experience working with WPI students for the first time. This helped in getting a cross-cultural experience and was a very enriching experience. I am grateful for the great memories we've created.





***Michael Savrin (WPI)***

Hello there! My name is Michael Savrin and I'm an Electrical and Computer Engineering student from Needham, Massachusetts. I have had an amazing cultural and educational experience with my work on this project. I have appreciated being able to meet and interview so many villagers in order to truly experience this part of India. Interacting with a variety of people and being able to experience the hospitality of our interviewees has contributed greatly to my positive IQP experience.

***Bhanu Singh (IIT)***

Greetings! My name is Bhanu Singh. I am originally from Bharatpur, Rajasthan. Currently, I am an undergraduate student at IIT Mandi in Himachal Pradesh, pursuing a major in Civil Engineering. I really enjoyed this project. I had a wonderful experience working with WPI students. I enjoyed getting to know the ground reality of the villagers and learning about their problems. I would like to thank our project sponsor, EWOK. I also appreciated getting to meet so many interesting people: in the villages, in the schools, in the hospitals and in the NGOs. From everywhere I received greetings and hospitality. I am really grateful for these memories.



***Brandon Waugh (WPI)***

Howdy y'all! My name is Brandon Waugh and I am from Austin, Texas. I am currently studying Robotics and Electrical Engineering at WPI. During my time in India, I really enjoyed learning about the culture and experiencing all Himachal Pradesh had to offer. I am so happy I have gotten to work on this project because I know that it'll lead to something bigger. This project has not only brought me many great memories, but also many new friends. Having a joint program with IIT Mandi has allowed us to experience life here on a whole new level. I really feel like I've grown a lot and the lessons I've learned will help me later in life.

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# Introduction

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## PwD in Himachal Pradesh

The Rights of Persons with Disabilities Act of 2016 defines persons with disabilities (PwD) as “a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders [their] full and effective participation in society equally to others” (Ministry of Law and Justice, 2016). PwD comprise at least 2% of the Indian population (Census, 2011). Despite improvements to accessibility in India, PwD and their families still face negative social, physical, and financial repercussions (Richard, 2014). In parts of northern India, these hardships may be heightened because of limited resources, lack of qualified personnel, and challenges in access assistance or mobility due to the geography of the area (Dring, 2016).

While stigma and discrimination against PwD cannot be fixed overnight, there has been increased global sensitivity to the needs of marginalized people. In fact, the UN Sustainable Development goals specifically point to targets for human rights including Reduced Inequalities, Quality Education, and Good Health and Well-Being. Reduced inequalities means addressing challenges, taboos and stigmas associated with PwD. These barriers worsen financial and social inequalities. Similarly, access to quality education, good healthcare and well-being because ultimately we are trying to improve the living conditions of PwD and their families and caregivers in Kamand Valley.

Toward this end, Enabling Women of Kamand (EWOK), is interested in contributing to the well-being of women and their families in a small community in the heart of Himachal Pradesh. As the well-being of a PwD is highly dependent on the support and stability given by their caregivers, it is vital that the needs and requirements of PwD are clearly expressed and addressed in communities (Richard 2014).

To meet this goal, we assessed perceptions of PwD in the Kamand region. We also set out to understand the limitations that are faced by PwD and their families, and we determined the resources available to support PwD. By accomplishing these objectives, we hoped to clarify standards for accessibility in Kamand Valley and to give impetus to programs promoting greater understanding and independence to those affected by disability.

# Literature Review

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## Political and Social Context of PwD in Himachal Pradesh

In this section, we discuss the political and social limitations that PwD face in Himachal Pradesh. We also explore challenges faced by PwD in regards to access to support, to resources, and to rights. Finally, we describe the vision and mission of Enabling Women of Kamand (EWOK) and how they helped guide us through our research process.

### *Political Context*

In an attempt to mitigate discrimination, government initiatives in India, as well as the state of Himachal Pradesh, have recently updated laws pertaining to the rights and resources for PwD. The most current law is the Rights of Persons with Disabilities Act of 2016. This act provides a variety of rights, including those concerning access to education, the right to vote, and access to public resources, as well as outlining requirements of the government in order to meet basic accessibility



*Figure 1. Katindhi government school (photo credit: Savrin, 2019)*

standards. The policies included in this act provide quite comprehensive guidelines, but still put the burden of enforcement of policies onto the individual states (Ministry of Law and Justice, 2016).

To match the Rights of Persons with Disabilities Act, Himachal Pradesh also has its own policy for PwD, including the right to vote and the right to education (see figure 1). This legal document also provides encouragement for research about standards for PwD. In terms of offering other concrete support to PwD in Himachal Pradesh, however, the laws are vague. The regulations at the state level do not outline any specifics for potential support unlike those governing all of India. In some cases, the policies could be better informed by how needs could be met through the Rights of Persons with Disabilities Act and other international standards (Department of Social Justice and Empowerment, n.d.).

### *Social Context*

PwD typically face two types of challenges. First, the limitations caused by their physical or cerebral conditions. Second, the challenge to be included and accepted in their communities. Individuals facing such scenarios from a young age can grow up to have low self-esteem. This can lead to feelings of inferiority, social withdrawal, and social rejection, which in turn can contribute to health problems, as well as psychosocial disorders and a diminished well-being (Sandeep, 2011).

Despite being the world's largest minority, PwD are largely ignored by society. Social response to disability often sees similar discrimination patterns as those against religion, caste, gender, age, and so forth. This is important, as these negative social constructs can also compound. When it comes to rural low economic regions of India, not only do female PwD face the difficulties of being a woman with a disability, but they may also face additional social barriers, associated with caste, and status. If discrimination worsens the situation, neglect can make rehabilitation difficult. In some cases, families contribute to this intolerance and feel ashamed and embarrassed about



being related to a PwD. Stigma and prejudice can also restrict PwD from building skills (Das, 2010).

## **The Challenges Faced by PwD in India**

Around the world, disability is often perceived as a hindrance to the person affected. In reality, PwD have a wide range of conditions some of which limit the person affected more than others, and vary according to contextual expectations and opportunities within families and communities. Additionally, there are common requirements for all persons, regardless of ability.

### ***Access to Support and Services***

Immediate family is a strong support system for sick or disabled family members. The role of caregiving in India is “unique as compared to the developed world,” since caregiving is most typically done by the family as opposed to “formal” or outside paid care. While caregivers may not see their disabled family members as a burden, caregiving can hinder their ability to secure income or participate in other community activities (Jagannathan, 2014). Caregivers also need short or long term relief options for when they themselves cannot provide service to their dependent.

### ***Access to Resources***

Even with the same medical condition, experts are clear that there can be no universal definition of individual disabilities. Therefore, as trained medical supervision can be scarce, expensive, or distant, misdiagnosis of disability happens frequently. Not only is it expensive to get the supportive medical treatment PwD deserve, but therapy is rarely in the form of simple medicine. Research has shown that education also can help lessen the hardships PwD face. Poverty is one of the biggest factors that influence PwD. Mothers who live in poverty are more likely to suffer from malnutrition. Poverty and malnutrition compound problems in pregnancy, and women often are not given proper medical guidance or care during pregnancy and birth. Factors such as population growth and aging population can be a big contributor to the increasing number of PwD (Raay, n.d.).

### ***Access to Rights***

In a blog titled “Dear non-disabled people, we are human beings and citizens too,” Nidhi Goyal, an Indian standup comedian and disability advocate who is a PwD herself, reflects about access to rights for PwD. We are born with “coats of stigma, prejudice, and misconceptions”, says Goyal (Goyal, 2018). The reason for these attitudes can be that social perception towards PwD are outdated, and are often highly influenced by cultural and religious beliefs (Edwardraj et al., 2010).

A life of being denied access takes a toll that impacts employment and future with independence. “Imagine someone not believing when you say ‘I can do this’,” says Goyal as she talks about PwD seeking employment and how it can often end with the response of rejection despite the qualifications they may have. Progress has been made, although positive stories are less common. For example, Haley Moss is a lawyer who has autism and works in a top law firm. Joseph Zumpano, who offered Moss the job, says he wanted to show that “if you align people to their strengths then given the chance, they excel” (Erblat, 2019).

In addition to the considerable challenges in employment or mobility, access to basic comforts such as buying clothes can be hard for PwD. The limited offering seems to imply, “Why do you want new clothes? Why would you want to dress up?” (Goyal, 2018). PwD are denied even the

right to “feel beautiful” (Goyal, 2018). Not only the appearance of clothing but also the functionality of the clothing can be a big challenge in the lives of PwD. It can be difficult for some PwD to use buttons or zippers. They may require help, making it almost impossible to have independence. Although adaptive fashion, clothing that specifically focuses on people with physical disabilities or impaired movement, is still limited in India, some mainstream designers such as Tommy Hilfiger as well as a handful of Indian designers have been launching disabled-friendly clothing (Dhar, 2019).

With rights comes well-being, and the opportunity for PwD to have the quality of life others would expect. Social ignorance can discourage PwD from something that is considered normal for a non-disabled person, such as seeking work, marriage, or travel. PwD are stared at when they are in public, lending little privacy. When it comes to dating and marriage, they are seen as an “unfit” partner who will not be a good future parent. When they are with companions, they are often ignored and the conversations are directed toward the companion (Goyal, 2018). Whether in terms of accessibility or discrimination, PwD are systematically denied certain human rights.

## **Changing How Persons with Disability are Perceived**

The perceptions of PwD are being changed through progressive movements of social change makers and entrepreneurs. From a global health point of view, the UN Sustainable Development goals call for support for healthcare access and affordability for all. But other change makers are setting up locally-based options for PwD to succeed in their own community. Durell Coleman is a social entrepreneur who is the creator of a design firm called DC design. DC design focuses on Human-Centered Design while eliminating social challenges that are faced by marginalized people. One example of his social entrepreneurship can be seen in the summer program, Design the Future, that he started for high school students. The students implement the concept of DC design while focusing on daily problems faced by people with physical disabilities (Design The Future, n.d.).

Positive social change initiatives with regard to disabilities is active across India. For example, EnAble India is an NGO that supports PwD in training and employment. They have received recognition for their work such as Special Consultative Status by the United Nations Department of Economic and Social Affairs (DESA), as well as a National Award from the president of India. Some stories of people benefiting from this NGO include Cornelius who attended a ten-month Employment training with EnAble India, which focused on life skills, computers, English and mobility. He says, “I am now employed at Rediff in the spam operations team. I am the first visually impaired employee in the company and the only family member to have got a degree and to be employed in a well-paid job” (EnAble India, 2017). There are more opportunities for and better awareness of PwD because of organizations like EnAble India.

## Enabling Rural Opportunities Through EWOK

The Kamand Valley is a medium sized collection of villages located in Mandi District in the heart of mountainous Himachal Pradesh. It is a generally rural area, but experiencing new growth with the development of IIT Mandi in the region. The communities are traditionally agricultural, but the university has brought some additional service sector employment (Census Population, 2011).

Set in this valley, Enabling Women of Kamand (EWOK) (offices featured in figure 2) state that their mission is: “To enable the women of Kamand Valley in ways to better utilize their skills for economic gains and in general to improve quality of life” (EWOK - About Us). The NGO also makes clear that with the introduction of IIT Mandi to the Kamand Valley, there is much more potential for change that should be fully utilized by the women of the area (EWOK - About Us). When it comes to care-taking, women in the family are often obligated to take this role and do not have time of their own or to financially support their dependents. EWOK is positioned to bring women more skill set options to better provide for themselves and the community (Menon, personal conversation, March 14, 2019). In order to understand the needs and requirements of those affected by disabilities and mitigate some of the problems and difficulties faced by PwD, it is important to understand the stories and personal experiences of those affected directly.

In summary, we identified several points that informed our framing of the problem. First, when finding inclusive solutions to the problems faced by PwD, it is necessary to take into account site-specific community and support systems. Individuals experience disabilities differently depending on their experience with other social constructs, such as gender, caste, region, religion, and so forth. Finally, the geographical, political, and economic climate of the community will play a role in accessibility requirements and constraints that can shape the outlook and futures for PwD.



*Figure 2. EWOK offices (photo credit: Savrin, 2019)*

# Methodology

Here we discuss the strategies used to evaluate the needs and requirements of persons with disabilities in Kamand Valley. Towards that goal, our objectives were to:

1. Assess community perceptions of PwD in Kamand Valley
2. Identify limitations faced by PwD and their families
3. Determine the resources available to PwD

These objectives were accomplished through interviews, observations, and surveys of experts, residents, and PwD as outlined in figure 3 below, and then discussed in detail.

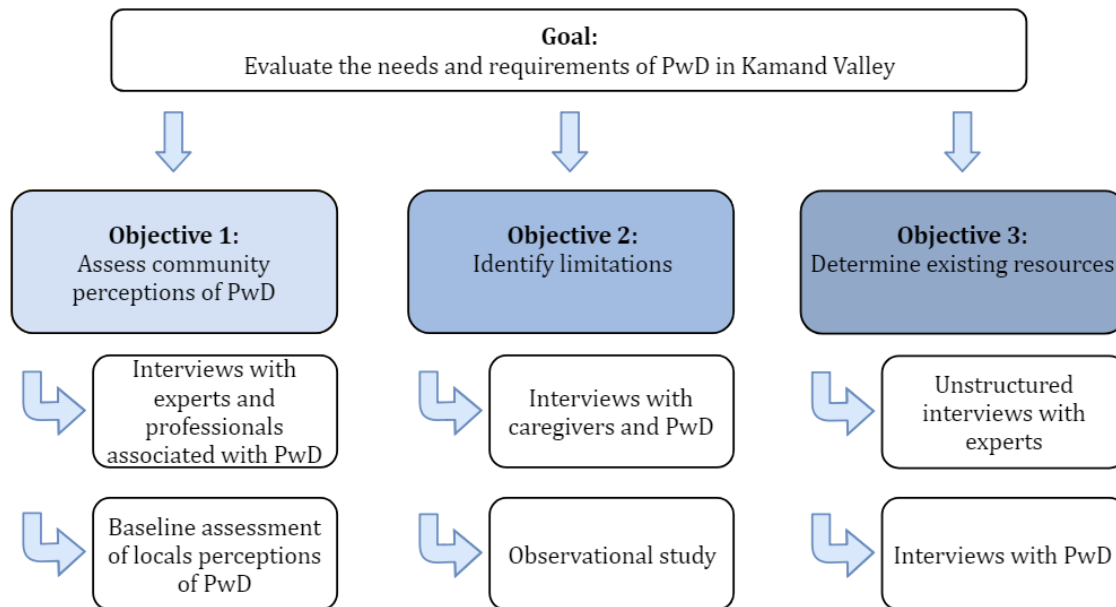


Figure 3. Methodological strategies

## Objective 1: Assess community perceptions of PwD

We interviewed relevant experts to understand their views on the perceptions of PwD in Kamand Valley. Experts included doctors, educators, government officials, and NGOs engaging with or supporting PwD. Based on our preliminary discussions and observations, we designed a survey for the residents of the villages in Kamand Valley. We then interviewed participants, including individuals with disabilities and those who have family members who are PwD, in addition to residents with no relation to PwD. These in-person interviews were approximately 15 minutes in length.

## **Objective 2: Identify limitations faced by PwD and their families**

We conducted a baseline assessment of the experiences of the PwD or caregiver by conducting structured interviews related to living with or being a PwD (see figure 4). We used a sample of convenience and snowball sampling to identify approximately twenty participants of PwD and caregivers. Selected participants were shadowed briefly following interviews as a part of an observational study. This allowed us to gain more insight into the limitations that surround their daily life in Kamand Valley.



*Figure 4. Interviews in the field (photo credit: Markowitz, 2019)*

## **Objective 3: Determine the resources available to PwD**

To help us determine the resources available, we consulted with local experts such as doctors, teachers, and other relevant professionals. Because we wanted to focus on qualitative data analysis, we set up face-to-face unstructured interviews (in-depth interview) that were tailored to each individual so that we were guaranteed to cover the areas of interest. To identify relative experts, we used a snowball sampling in which one professional recommends more experts in the field.

Finally, we interviewed PwD and asked them to identify what resources were available and beneficial services that operate on their behalf or offer support in the region. The purpose of the interview was to get accurate answers from PwD themselves while gaining insight into support systems the community provides.

# Results and Discussion

The result of our interviews and discussions with PwD and other community members are presented here by objective. Below, figure 5, illustrates the types of interviews we conducted and the number of participants from each category we interviewed.

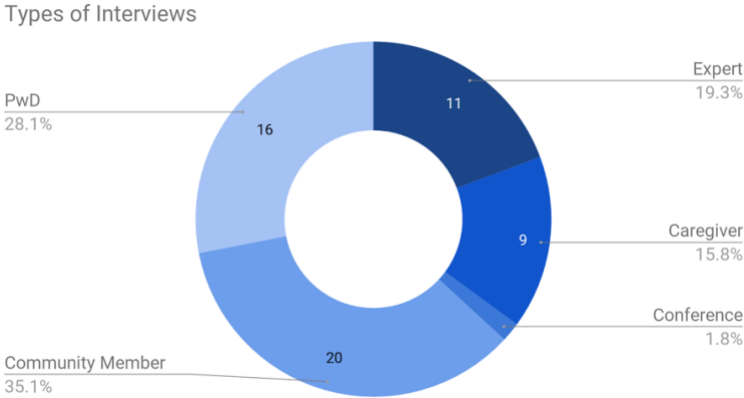


Figure 5. Types of Interviews

## Community Perceptions of PwD

Community perceptions were gathered through interviewing community members, observing the children with disabilities at the Katindhi Government School, and engaging with professionals, including a Site Director for Special Needs programs at an NGO and one special needs teacher. Although many of the community members were reluctant to respond, as seen in figure 6, the perceptions identified were that concealment and alienation of PwD from the community is common, perhaps due to social taboos.

Our interview strategy with community members did not generate clear answers on questions about opinions towards PwD, specifically those questions with regard to the involvement of PwD in the community and improvements in PwD’s lives. Residents we spoke with also declined to answer many of the questions especially “how often and where do you interact with a person affected by disability?” We sensed reluctance when asked to talk about their own opinion, but interviewees opened up when asked about their thoughts on other community members’ perceptions of PwD.

Many of the caregivers and community members also separated themselves from the PwD by not including or talking with them or alienating them in the community. Dr. Narendra Paul, a site director for special

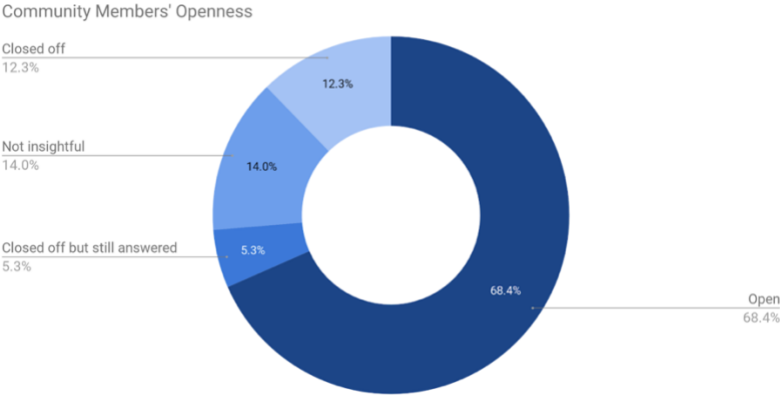


Figure 6. Community members’ openness to questioning

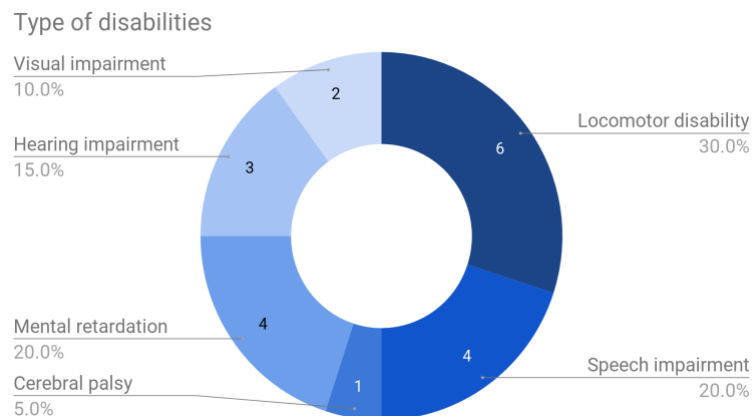
needs programs, discussed the adversities of separating PwD from the community. He explained this concept with the example of children in special needs schools. He said that “specials schools are the biggest discouraging model of community exclusion” (N. Paul, personal communication, March 16, 2019) citing how the students are negatively impacted because they are isolated during their developmental stages and as adults, it is hard for them to adjust. In addition, the community members cannot comprehend the challenges that PwD face because they are isolated from view in a single community and othering occurs as a result. Othering is exhibited through labeling PwD as an independent group of people not included in the community. It allows many community members to abstractly talk about PwD without attaching themselves to the taboos associated with them. This can be dangerous because it encourages the ideas of discrimination towards the “other” or in this case PwD.

In an interview with the special needs educator, we learned that not only is othering common, but taken to an extreme, concealment may also happen within communities. For example, we heard of a nine-year-old boy diagnosed with 90% mental retardation who is kept confined to his house. Although the special educator is trying to counsel his family, they feel their child is cursed and do not want to be further judged by their community. Another man, who is a caregiver to two of his brothers, explained that one of his brothers with 100% mental retardation is physically able to attend social events, but he chooses not to attend these events. While we do not know why he avoids social events, we can see that this decision can lead to social isolation and concealment.

While some of the stories we heard were quite demeaning, we also observed PwD at the Katindhi Government School and noticed that the other children were very accepting and excited to play with the students with disabilities. The students with disabilities also confirmed that they had an easy time making friends.

## Limitations of PwD

Based on our interviews with a variety of PwD, shown in figure 7, the findings of our fieldwork revealed limitations for PwD in the region. These limitations included educational, social, economic and physical geographical constraints. Limitations were clearly identified around a few key themes. A commonly identified limitation is that of educational opportunities. There are resources available in the area including a special needs educator located at a government school in Katindhi. When we interviewed this official, she stated that she was the special needs expert for five other area schools and that her job entailed more than just baseline education work. She told us that her work included counseling students, parents, and teachers as well as creating an awareness of discrimination against PwD. This also means convincing administrations and leadership at local schools to be more accepting of PwD. The value of her work was evident from our visits to other government schools where there were a few special needs students, but no one knowledgeable on special needs education to work with them. This lack of special needs educators can restrict PwD from access to a proper education.



*Figure 7. Type of Disabilities*



*Figure 8. Father and son with cerebral palsy (photo credit: Waugh, 2019)*

Another key limitation for PwD was a system of social beliefs and perceptions about the cause or meaning of disabilities in families. It was said in one of our interviews that some families who give birth to a PwD would assume that the birth was caused by some form of negative karma affecting the family or even black magic. Other individuals believe that their disability is something that god has cursed them with. One woman says, “I believe my hearing impairment developed because I was too shy,” she further noted, “I pray to god every day that I will be able to hear as I used to” (personal communication, April 6, 2019). As noted earlier, these perceptions can exacerbate rejection of the PwD or their family in the community, and bring shame or concealment of the disability on top of the strain for resources or support.

We recorded many stories of financial limitations to PwD and their families. In discussions with caregivers, we have heard that financial resources can be scarce with one man who was caring for his two brothers saying “my very limited

financial resources are almost completely consumed by basic amenities” (personal communication, April 4, 2019). When asked about financial status most of the interviewees appeared either uncomfortable with the question and gave a vague response. Some gave an honest answer such as with an interview with the father of a 14-year-old boy with cerebral palsy shown in figure 8. This father mentioned that he was very worried about his financial state. This father also admitted having stopped working in order to support his son’s education, but was in need of financial resources and that there was stress surrounding his ability to obtain these resources.

Finally, the difficult landscape of the Kamand Valley is another limitation for those with physical disabilities as seen in figure 9. According to a school administrator, children with physical disabilities are often kept at home rather than sent to school, as they are not capable of walking to school because of the landscape and distance of the school. She also said that parents would rather prioritize their occupation and finances, than support their child’s education. We observed the challenging routines of daily life in the steep terrain and our own exploration of the landscape. One example from our work included the particularly harsh walk for a PwD to the Salgi Panchayat House. As is common in the region, it meant climbing many flights of stairs, which managed to tire everyone in our team out. This kind of walk could prevent a PwD from being able to reach the place where they want to go or would need to go in order to fully participate in society.



*Figure 9. Narrow path posing difficulty (photo credits: Markowitz, 2019)*



## Existing Resources of PwD

There are ongoing efforts in providing existing resources to PwD such as government stipends for PwD with disability certification, support groups held through NGOs, and the special needs educator working in government schools. Organizations like EWOK help train women by providing them with educational opportunities varying from English classes to learning how to do data entry on Excel. They are also in the process of expanding their support group system to provide a platform where women can openly discuss their hardships without worrying about people's perceptions. This kind of support is important and welcome. For example, the father of a PwD with cerebral palsy listed support groups as helpful resources along with social opportunities, financial support, and support in special education. At this time, these kinds of resources are in place sporadically, but not available to all.

Chinmaya Organization for Rural Development (CORD) is an NGO in Dharamshala that provides solutions using holistic approaches by looking at the person and the issues surrounding them as a whole rather than simply treating the disability. As government implementations are an issue that cannot be ignored, CORD focuses on providing support groups by helping people “from the community for the community” (N. Paul, personal communication, March 16, 2019). For example, CORD engages local children with disabilities in domestic activities, such as cooking, cleaning, and other tasks so that they can gain more independence as they grow up.

Support for children with disabilities can be seen in local hospitals where they provide anemia acid tablets for children under the age of 15 with red blood cell deficiency. Surgeries and prosthetics are also provided for free to some children in need. The Katindhi Hospital also helps PwD rehabilitate through medical and vocational training so that they have better living standards. We interviewed a rehabilitation expert, Dr. Narendra Paul, who explained that a disability that is greater than 40% can get a disability certification. A certification can help financially because it makes PwD and their families eligible for stipends every few months. Additionally, certified PwD can get travel passes for public transportation for free. Although these resources are beneficial, Dr. Narendra Paul says “some individuals illegally obtain multiple disability certifications to claim excess benefits” (N. Paul, personal communication, March 16, 2019). This corruption makes it more difficult for individuals with actual needs to access the same benefits.



*Figure 10. Discussion with special needs educator (photo credit: Waugh, 2019)*

We interviewed a special needs educator at the primary school of Katuala, Ms. Reema (see figure 10). She discussed the previously mentioned case of the boy with cerebral palsy having received physical therapy from CRC Sundernagar and Zonal Hospital Mandi twice a month. He used to get around by crawling on his four limbs up to the age of 8 or 9, however, we were able to observe that, despite needing some assistance, he is able to walk on both of his legs at the age of 14. Apart from working as a special needs educator at the school, Ms. Reema's duties also include consultation with parents as well as the teachers who are having trouble working with children with disabilities. She also assists PwD in getting medical certificates and aid from other governmentally sponsored programs. She tries to convince school administrators to intake children with disabilities via admissions. Although she is making an effort to increase

the number of children with disabilities at schools, we observed that schools in the region still lack the resources for proper education. Her primary effort is to raise awareness for PwD in the communities and lessen the discrimination they face.

## **Discussion**

Although the lack of openness made it difficult to assess community perceptions of PwD in Kamand Valley, there were compelling trends in our findings. It seems that there are not open conversations about the challenges PwD face. It appears that talking about PwD may be considered impolite, or a taboo, and that othering and concealment of PwD is common. Nevertheless, those PwD that are integrated into the community are generally well perceived.

Our survey, unfortunately, revealed very little with many declining to answer personal questions. Perhaps there is no certain way to speculate about PwD or perhaps residents are protecting PwD by choosing not to discuss their problems. Given some evidence of superstitions, karma, and black magic, some may have declined to answer because there are strong beliefs associated with PwD. When asking community members what they thought their villages' perceptions of PwD were, we heard more considerate responses, reflecting general understanding of the taboos and stigmas associated with PwD in their society.

Furthering the complexity, there was also clear indication of concealment of PwD in the communities. Othering occurred with almost everyone we interviewed, in the form of separating themselves from PwD. Concealment and isolation were also shown through this obvious social barrier between the PwD and the community.

At the same time, there were some signs of a surprising openness towards them, specifically amongst the children with disabilities. Both by observation and discussion with the children with disabilities at the Katindhi Government School, we confirmed that the children integrated into the non-special education school were well adapted and able to make friends with their peers. Furthermore, we encountered a child with down syndrome and her friends at a local snack shop after school and observed that she was well perceived by the shop owner and the other kids her age.

For children with disabilities, having luck in terms of locally available resources seems to be the primary marker of success. For most, there are few options available. The options are either to potentially travel a long way to go to a school with a special educator, have your child sent to a special school where they may be separated from other students, or have them sent to a government school where they could potentially be rejected because the school does not want to work with PwD. None of these options are optimal which can raise many long-term and compounding problems for a child with disabilities gaining a full education.

The societal views on PwD also cause issues. These perceptions related to black magic and karma enforce the idea that PwD are bad and should not necessarily be helped or incorporated into society. The previously discussed idea of othering and concealment of PwD is an example of the negative viewpoints that can stem from these kinds of ideas.



*Figure 11. A caregiver (left) and his brother  
(photo credit: Savrin, 2019)*

Financial limitations also raise clear discussion points. Many of the PwD we spoke to, one shown in figure 11, receive a monthly stipend from the government, but when this is compared to the amount of time the family spends with the PwD and the fact that many caregivers have to either stop working or work less in order to support their family, this stipend is not enough. Although the minimum wage in Himachal Pradesh differs depending on the field of work, the minimum wage for an agriculture job, which is typical in Kamand Valley, is 225 rupees per day (Himachal Pradesh Labor and Employment Department, 2018). While a stipend of 500-1000 rupees (~7. 50-15 USD) a month can be helpful to families, it is clear from our research that it is

not enough to fully compensate for the complex needs of families facing a variety of challenges. In any case, the ripple effect for caregiving comes at a cost for lost income or work time amongst other family members. In cases where more than one family member faces disability, there can be insurmountable implications for a family to give support.

Though landscape issues were not heavily discussed, there were clear problems seen. Not going out into the community and struggling to do so has been mentioned in multiple interviews and there could be a clear correlation between these points.

# Recommendations and Conclusion

## Recommendations

We have four areas of recommendations related to the support and improvement of the quality of life for PwD in Kamand Valley. These recommendations could help overcome some of the limitations identified and looking at the big picture, could contribute to the achievement of some targets set as part of the United Nations Sustainable Development goals, as seen in figure 12.



Figure 12. Recommendations related to sustainability goals

### Addressing Emotional Needs through Support Groups

Our first recommendation relates to the idea of emotional support and the ability to share the hardships that can be related to being a PwD or caring for one. This recommendation works with the UN Sustainable Development goal of health and well-being. It would do so by developing support groups where caregivers or PwD can be brought together and share their stories and how they may deal with these hardships. It can be very helpful to speak with likeminded people who are experiencing similar problems regarding mental health and the ability to share. Additionally, it can help to overcome common problems because other people who have dealt with the same issues can help with how they overcame the obstacles they have faced. With the complexity of traveling the area, it would also be potentially helpful to have transportation to these support groups. EWOK already has an established infrastructure in the community so they would be able to potentially host a support group of this form. In our research, we have seen a variety of people who state that a support group is a resource they would utilize if it were available to them. A good amount of these participants were men, however, given EWOK’s priority on women in the valley. Nevertheless, a good support group could be formed for all caregivers of diverse backgrounds from the area.

### Addressing Medical Needs through Medical Camps and Assistive Technology

Another area relating to the Sustainable Development goal of health and well-being is improving access to medical support. Through our interview with CORD, we learned of a system they use to bring together medical experts and PwD in order to certify PwD and assist them in getting the required treatments. This could be potentially implemented in Kamand in a way where PwD are given a time frame where they could go to the Zonal Hospital in Mandi and have

dedicated doctors who would provide them with any necessary certification or assistance. It would also be favorable to arrange transportation to get those who are unable to arrange their own travel to these “medical camps.” The validity of this suggestion was enforced by an interview with a local man whose brother is a doctor, and who claimed that it was quite easy for him to access resources for his wife. The recommendation would be to set weekly, monthly, or quarterly times where PwD could go to the hospital and get the same form of preferential treatment this man's wife received. This small change could expedite medical processes for many PwD.

Another medical support needed is access to inexpensive assistive technology. Though there are certain ways and places where there is discounted access to technology, it is somewhat unavailable in this part of northern India. This discount could come through a variety of methods or could even be implemented by making resources that are accessible elsewhere more accessible in Kamand Valley. Examples of useful assistive technology include simple but critical items such as crutches, hearing devices, and prosthetics.

### *Addressing Education through Training of School Staff*

The next suggestion targets the UN Sustainable Development goal of quality education. It specifically relates to the targets of ensuring all children have access to free and quality education. It also relates to the goal of equal access to education that should be available to all, including PwD and a variety of other groups facing adversities. As mentioned earlier, there is a clear lack of educators who are trained to work with PwD, with only one educator for the entire Kamand Valley region. A good way to try to improve this situation would be to train educators so that they can better work with students with disabilities. This training could potentially be done by the trained educator for the region or an outside resource could be brought in. This training would have two target areas. The first would be training for teachers on how to cater to students with disabilities while also keeping a balanced classroom. The other training would be for administrators on the benefits of including PwD in the classroom as well as acceptance of PwD and why they should be integrated with other students.

### *Addressing Financial Inequalities through Trainings and Labor Opportunities*

The final suggestion targets the goal of reducing inequalities. It fits the specific target of creating economic inclusion for people regardless of disability. There are a variety of recommendations that can help to reach this target. The first recommendation would be to sponsor PwD and caregivers for training towards employable skills that are provided by EWOK. While EWOK provides affordable trainings, it would be more utilized by PwD and caregivers if it were a resource available to them for a lower cost. These trainings would allow for the improvement of the financial situations of PwD by enabling them to work in more sustainable labor where they would be able to provide for their families while not having to work as much.

In the case of unskilled labor, there could be potential improvement through an organization structured so that it can improve area accessibility. This organization could also offer employment to caregivers and PwD who are still able to do physical labor. The development of an organization like this would also allow for flexible work times of PwD and caregivers interested in working fewer hours in order to cover other responsibilities. The employment of PwD and caregivers to improve accessibility of the area would be a dual-pronged approach where one organization promoting one idea is able to improve lives of PwD in multiple ways. This method of improvement provides not only financial support but also improves the area so that PwD can more easily participate equally in the community.

## *Awareness Platform*

At the end of this project, we wanted another medium to show our work in order to make our findings more accessible to our stakeholders. To do this, we created a website displaying our research. Along with our full paper, the website features a storybook that highlights meaningful excerpts from interviews we have had with experts, PwD, their caregivers, and the community around them. This storybook is a very powerful tool that allows the reader to immerse themselves in the stories of the community participants.

The website (Appendix H) will be a place where people can not only review our project and see what we have accomplished, but will also work to generate awareness of the hardships PwD face in the community. In the future, EWOK can utilize our website as a platform to communicate the current resources available to PwD and their families.



*Figure 13. Stories tab on our website*

## **Conclusion**

Due to the variety of challenges presented to PwD by the environment, culture, and political climate, this study is important to understanding the complexities of the area in relation to disabilities. We have assessed perceptions of PwD through a variety of interviews and surveys and found limitations through discussions with PwD and their caregivers. The final aspect that we have worked on involved communicating with officials in the community about the resources that are available to PwD. Our study has given a better understanding of PwD in Kamand Valley as well as how communities function in relation to them. Through this increased understanding, the well-being of both PwD and caregivers can be greatly improved by making the resources clear and communicating the stigma surrounding disability in Kamand Valley. With more clearly understood needs and resources caregivers will be able to fully utilize these resources in order to better their own quality of life. Our sponsor EWOK hopes to use the outcome of this study to improve lives of caregivers and PwD so that they too can work to empower themselves.

To that end, this study can be used to further promote the implementation of our recommendations by either already existing organizations or by the founding of new organizations. These ideas could be used by EWOK to begin work with PwD and caregivers. Some of our recommendations could also be implemented as government initiatives to improve the quality of life for PwD and caregivers. Our recommendations and research can be a strong foundation for all future work for PwD and caregivers in Kamand Valley.

# References

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- Addlakha, R (2007 June). Mainstreaming disability into the child rights agenda. InfoChange News & Features.
- Das, S. (n.d.). Hope for the Invisible Women of India: Disability, Gender and the Concepts of Karma and Shakti in the Indian Weltanschauung. In *Hope Against Hope: Philosophies, Cultures and Politics of Possibility and Doubt* (pp. 129–147). Amsterdam, Netherlands: Rodopi.
- Design The Future. (n.d.). Retrieved from <https://www.designthefuture.dcdesignltd.com/>
- Dhar, S. (2019, January 22). The wheelchair wardrobe: How fashion is becoming more disabled-friendly - Times of India. Retrieved from <https://timesofindia.indiatimes.com/home/sunday-times/the-wheelchair-wardrobe-how-fashion-is-becoming-more-disabled-friendly/articleshow/67605199.cms>
- Dring, E.W., Maalouf, J.R., Johnson, V.K. (2016). Improving Healthcare Communication in the Mandi District (Interactive Qualifying Project). Retrieved from <http://www.wpi.edu/Pubs/E-project/Available/E-project-050216-002701/unrestricted/>
- Edwardraj, S., Mumtaz, K., Prasad, J. H., Kuruvilla, A., & Jacob, K. S. (2010, August). Perceptions about intellectual disability: A qualitative study from Vellore, South India. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/20633202>
- EnAble India. (2017). Home. Retrieved February 20, 2019, from <http://www.enableindia.org/>
- Erblat, A., & South Florida Community News. (2019, February 21). Breaking barriers: Woman with autism becomes lawyer at a top law firm. Retrieved from [https://www.heraldmailmedia.com/news/nation/breaking-barriers-woman-with-autism-becomes-lawyer-at-a-top/article\\_794b95c2-6598-50a1-ae2e-fe7cd1608031.html](https://www.heraldmailmedia.com/news/nation/breaking-barriers-woman-with-autism-becomes-lawyer-at-a-top/article_794b95c2-6598-50a1-ae2e-fe7cd1608031.html)
- EWOK. (2016). EWOK Home. Retrieved January 19, 2019, from <http://ewok.iitmandi.ac.in/index.php>
- Family Advisory Councils for Empowerment Statewide, G.E.A.R Parent Network, THRIVE. (2009). Retrieved February 8, 2019, from <https://www.surveymonkey.com/r/HRSB95T>
- Fernandes, H. L., Cantrill, S., Shrestha, R. L., Raj, R. B., Allchin, B., Kamal, R., . . .
- Grills, N. (2018). Lived Experience of Psychosocial Disability and Social Inclusion: A Participatory Photovoice Study in Rural India and Nepal. Retrieved January 15, 2019, from <http://dcidj.org/article/view/746/393>
- FocusEconomics. (2018, November 8). The World's Largest Economies (2019-2023). Retrieved February, 2019, from <https://www.focus-economics.com/blog/the-largest-economies-in-the-world>
- Gettleman, J., Schultz, K., & Raj, S. (2018, September 6). India Gay Sex Ban Is Struck Down. 'Indefensible,' Court Says. *The New York Times*. Retrieved January 24, 2019, from <https://www.nytimes.com/2018/09/06/world/asia/india-gay-sex-377.html>
- Goyal, N. (2018, December 04). Dear non-disabled people, we are human beings and citizens too. Retrieved January 24, 2019, from <https://www.telegraphindia.com/opinion/dear-non-disabled-people-here-are-so-e-thoughts-for-world-disability-day/cid/1677331>

- Gupta, V. (2011). How Hindus Cope with Disability. *Journal of Religion, Disability & Health*, 15(1), 72–78. <https://doi.org/10.1080/15228967.2011.540897>
- India Brand Equity Foundation (IBEF). (2019, January). ABOUT INDIAN ECONOMY GROWTH RATE & STATISTICS. Retrieved from <https://www.ibef.org/economy/indian-economy-overview>
- Himachal Pradesh Labor and Employment Department. (2018, August 7). Notification of Minimum Wage. Retrieved from [https://himachal.nic.in/showfile.php?lang=1&dpt\\_id=14&level=2&lid=18223&sublnkid=17758](https://himachal.nic.in/showfile.php?lang=1&dpt_id=14&level=2&lid=18223&sublnkid=17758)
- Jagannathan, A. (2014, October-December). Family caregiving in India: Importance of need-based support and intervention in acute care settings. *Journal of Postgraduate Medicine*, 60(4), 355. Retrieved from [http://link.galegroup.com/apps/doc/A392159684/AONE?u=mclin\\_c\\_worpoly&sid=AONE&xid=bff9f2b2](http://link.galegroup.com/apps/doc/A392159684/AONE?u=mclin_c_worpoly&sid=AONE&xid=bff9f2b2)
- Janardhana, N., Muralidhar, D., Naidu, D., & Raghevendra, G. (2015). Discrimination against differently abled children among rural communities in India: Need for action. *Journal of Natural Science, Biology and Medicine*, 6(Shrivastava, 2018), 7–11.
- Lee, Alexander. (2015). How (and How Not) to Use Archival Sources in Political Science. Retrieved February 8, 2019, from [http://www.rochester.edu/college/faculty/alexander\\_lee/wp-content/uploads/20107/archives.pdf](http://www.rochester.edu/college/faculty/alexander_lee/wp-content/uploads/20107/archives.pdf)
- Mathers, Nigel & Fox, Nick & Hunn, Amanda. (2000). Using Interviews in a Research Project. Retrieved February 8, 2019, from [https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2013/05/15\\_Using-Interviews-2009.df](https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2013/05/15_Using-Interviews-2009.df)
- Menon, S. (2019, February 17). Personal Interview.
- Puri, N. (2016, July 15). Why Won't Indian Parents Let Go Of Their Grown Sons? Retrieved February 2, 2019, from [https://www.huffingtonpost.in/natasha-puri-1/why-wont-indian-parents-1\\_b\\_986826.html](https://www.huffingtonpost.in/natasha-puri-1/why-wont-indian-parents-1_b_986826.html)
- Raay. (n.d.). Blog. Retrieved January 24, 2019, From <https://www.raayfoundation.com/blog-3.php>
- Richard, B. O. (2014). Families, well-being, and inclusion: Rethinking priorities for children with cognitive disabilities in Ladakh, India. Retrieved January 15, 2019, from <https://journals.sagepub.com/doi/pdf/10.1177/0907568214526264>
- Roberts, A.A., Vigneau, C.P., Palma, M.J., Battistini, T.E. (2003). Recommendations to improve quality of life at the Pakkred Home (Interactive Qualifying Project). Retrieved from <https://digitalcommons.wpi.edu/cgi/viewcontent.cgi?article=4958&context=iqp-all>
- Sandeep Singh, R P Sharma, Suresh Chandra, Seema Nigam, & Punit Varma. (2011). A STUDY OF SOCIAL SUPPORT IN PHYSICALLY DISABLED STUDENTS IN AN EDUCATIONAL INSTITUTE OF KANPUR. *Indian Journal of Community Health*, 22(2), 20–22. Retrieved January 24, 2019, from <https://doaj.org/article/d4adbeb1e2854319bbd1c1fe4d4e66f0>
- Sharma, S., Raina, S., Bhardwaj, A., Chaudhary, S., Kashyap, V., & Chander, V. (2015). Socio demography of mental retardation: A community-based study from a goitre zone in rural sub-Himalayan India. *Journal of Neurosciences in Rural Practice*, 6(2),



- 165–169. <https://doi.org/10.4103/0976-3147.153220>
- Shrivastava, A. (2018, August 01). Disability in India Is Still All About the Able. Retrieved January 24, 2019, from <https://thediplomat.com/2018/08/disability-in-india-is-still-all-about-the-able/>
- The World Bank. (2018, September). Labor force, female (% of total labor force). Retrieved February, 2019, from <https://data.worldbank.org/indicator/SL.TLF.TOTL.FE.ZS>
- Trahant, G. (2019, January 18). The 35 Social Entrepreneurs To Watch For In 2019. Retrieved from <https://www.causeartist.com/social-entrepreneurs-to-watch-for-2019/>
- World-Bank. People with Disabilities in India: From Commitments to Outcomes. Human Development Unit: South Asia Region. Retrieved 2007
- World Health Organization (2019). Model Disability Survey Brief Version. Retrieved from <https://www.who.int/disabilities/data/mds/en/>
- Yanchulis, D. (2017, January). Guidelines and Standards. Retrieved from <https://www.access-board.gov/guidelines-and-standards>

# Appendices

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## Appendix A - PwD Interview Guide/Survey

For the Interviewer: Quantitative options are included only if the PwD is struggling to give qualitative answers or if the questions need to be given in more of a survey format.

1. Are you or a person you live with affected by a disability? If yes, what is it?
  - a. If they say they live with PwD and are caregiver, go to caregiver baseline assessment
2. What are the hardships associated with disabilities in Kamand?
3. Environmental Factors - These questions will be answered with a number between 1 and 5. 1 means very easy and 5 means very hard.
  - a. Do places where you socialize or attend community events make it easy or hard for you to do so?
  - b. Do places where you shop make it easy or hard for you to do so?
  - c. Should you need help, how easy is it for you to get help from:
    - i. Family
    - ii. Friends/Co-workers
    - iii. Neighbors
  - d. Do you feel independence in your day to day life?
  - e. Do you feel respected? For example, do you feel that others value you as a person and listen to what you have to say?
4. Functioning - These questions will be answered with a number between 1 and 5. 1 means no difficulties and 5 means you cannot complete the activity.

How much difficulty do you have walking 1 km?

  - a. How much difficulty do you have looking after your health: eating well, exercising or taking medicine?
  - b. How much difficulty do you have remembering day to day tasks?
  - c. How much difficulty do you have getting household tasks done?
  - d. How much difficulty do you have getting things done at school/work?
  - e. What level of education have you received?

5. Personal Well-Being - These questions will be answered with a number between 1 and 5. 1 means no difficulties and 5 means you cannot complete the activity.
  - a. How much difficulty do you have with sleeping?
  - b. How much difficulty do you have with feeling sad or anxious?
  - c. How much difficulty do you have with getting along with those close to you?
6. Assistive Technology
  - a. Do you use any of these assistive products? (ex: Cane or Walking Stick, Crutches, Protheses, Walkers, Wheelchairs, Spectacles, White Cane, Hearing Aid)
  - b. If no, do you think you may need one?
7. Resources
  - a. Do you get any form of assistance from the government? If so, explain.
  - b. Do you receive any assistance from NGOs? If so, explain.

These questions were adapted from the World Health Organization Model Disability Survey (World Health Organization, 2019).

## Appendix B - PwD Interview Guide/Survey (Children)

For the Interviewer: Quantitative options are included only if the PwD is struggling to give qualitative answers or if the questions need to be given in more of a survey format.

1. General Questions
  - a. What is your name? age/grade?
  - b. What is your favorite and least favorite subject in school?
  - c. What do you enjoy doing for fun?
2. Environmental Factors
  - a. Do you enjoy playing with other children?
  - b. What are some of your favorite games? Are you good at them?
  - c. Who are you the closest to?
    - i. Family
    - ii. Friends
    - iii. Neighbors
3. Functioning
  - a. Do you need any help while walking?
  - b. Do you have any difficulty doing your schoolwork?
  - c. Do you have any difficulty with accomplishing your hobbies?
4. Personal Well-Being
  - a. Where do you feel the happiest? At school, home, or other place?
  - b. Do you like making friends at school or in your neighborhood? What do you like doing with them?
5. Assistive Technology
  - a. Do you use any assistive products? If yes, which ones?
    - i. Cane or Walking Stick
    - ii. Crutches
    - iii. Prostheses
    - iv. Walkers
    - v. Wheelchairs
    - vi. Spectacles
    - vii. White Cane
    - viii. Hearing Aid
    - ix. Other? \_\_\_\_\_
  - b. If no, do you think you may need one?
    - i. Cane or Walking Stick

- ii. Crutches
  - iii. Prostheses
  - iv. Walkers
  - v. Wheelchairs
  - vi. Spectacles
  - vii. White Cane
  - viii. Hearing Aid
  - ix. Other? \_\_\_\_\_
- c. Is there anything you wished you had?

These questions were adapted from the World Health Organization Model Disability Survey (World Health Organization, 2019).

## Appendix C - Caregiver Baseline Assessment

In the following section, please share your thoughts and opinions on the opportunities and limitations you face as a caregiver. Each question in the survey is completely optional, and the information that you provide through this survey will remain confidential.

1. How old are you?
2. How long have you been living in this area for?
3. What is your relationship with the PwD?
4. What disability does the PwD have?
5. Do you have a clear understanding of the PwD's disability?
6. How old is the PwD?
7. How long have you been a caregiver for?
8. Employment
  - a. Has being a caregiver prevented you from gaining employment? (circle "Yes" or "No")

Yes

No

If yes, please describe how it has prevented you from gaining employment.

- b. Has being a caregiver caused you to reduce the number of hours you work? (circle "Yes" or "No")

Yes

No

- c. Has being a caregiver caused you to stop working? (circle "Yes" or "No")

Yes

No

If yes, please describe how it has stopped you from working.

If yes, please describe how many hours you used to work and how many hours you work now.

Hours you used to work: \_\_\_\_\_ hours

Hours you work now as a caregiver: \_\_\_\_\_ hours

9. Emotion
  - a. How content do you think families who live with PwD are in this village? Do you think it is difficult for some families? (5 being very content, 1 being very discontented)  
  
1 ----- 2 ----- 3 ----- 4 ----- 5
  - b. Do you feel that the PwD is not able to express their emotions?

10. Family

- a. When PwD was first diagnosed in what way did you get extended family support? (5 being very supportive and 1 being no support.)
- b. In what way do you get extended family support now? (5 being very supportive and 1 being no support.)

11. Time

- a. How much time do you spend caring for a PwD?
- b. What do you spend your time on when you are not caring for PwD?
- c. What were your priorities before becoming a caregiver?
- d. Have those priorities changed?

12. Experience

- a. Do you feel supported by friends and community members?
- b. Has it been stressful receiving or obtaining service for PwD?
  - i. No
  - ii. Yes, in obtaining services
  - iii. Yes, in receiving services
  - iv. If yes, explain the difficulty.

13. Financial

- a. Do you think families who live with PwD in this village are worried about their financial status? (5 being very worried and 1 being not at all worried.)

1 ----- 2 ----- 3 ----- 4 ----- 5

14. Do you receive any of these services?

- i. Support group
- ii. Social opportunities
- iii. Events-educational
- iv. Financial support
- v. Formal exercise, support and educational physical
- vi. Formal diet and nutritional supply
- vii. Other (please specify)

15. What services would be helpful?

- i. Support group
- ii. Social opportunities
- iii. Events-educational
- iv. Financial support
- v. Formal exercise, support and educational physical
- vi. Formal diet and nutritional supply
- vii. Other (please specify)

16. What are the barriers to receiving the services mentioned above?

17. What do you wish for your daughter/son/PwD?

## Appendix D - Perceptions Survey/Guide

In the following questions, please share your thoughts and answer each question to the best of your ability. Each question in the survey is completely optional, and the information that you provide through this survey will remain confidential.

1. What is your gender? (circle)  
Male                  Female                  Other                  Prefer not to answer
2. How old are you?
3. What is your occupation?
4. What is your level of education?
5. Do you live with a person with disability? (circle)  
Yes                  No
6. If no, how often and where do you interact with a person affected by disability?
7. What types of disabilities affect them?
8. Where do you see the most room for improvement in the lives of PwD in regards to physical landscape, access issues, social inclusion, and resource support?
9. What is your opinion on the involvement of PwD in your community?
10. What are the perceptions of PwD in your community?



## **Appendix E - Interview Questions for Dr. Nupur at Kataula Health Centre**

1. What is your experience with working with PwD?
2. What do you feel are societies perceptions of PwD in Kamand Valley?
3. Give a general demographic view of the disabled population distribution across the Kamand Valley in all the villages.
4. Is there a main cause of the disabilities within the village? If so what are they caused by?
5. What are the primary problems faced by the PwD in the valley?
6. What resources are available to PwD in Kamand Valley?
7. What do you think can be changed or incorporated in order to improve the quality of life for PwD?
8. Can you tell us some of the Govt. Schemes in the field of medicinal facilitation for the disabled people?
9. Ask for contacts that may be helpful in assessing the disabled people such as primary caregivers.

## **Appendix F - Interview Questions for CORD**

1. What is your experience with working with PwD?
2. Can you give us an overview of what CORD does?
3. What do you feel are societies perceptions of PwD in northern rural India?
4. What are the primary problems faced by the PwD?
5. What resources are available to PwD? What resources does your organization provide?
6. Have you seen any improvements over for PwD while working in the field? What do you think can be changed or incorporated in order to improve the quality of life for PwD?
7. Ask for contacts that may be helpful in assessing the disabled people such as primary caregivers.
8. What disabilities does CORD focus on?
9. Do you work with caregivers?
  - a) If so what challenges do they tend to face?
  - b) What resources are in place for caregivers?

# Appendix G - Poster



## An Overview of the Needs and Requirements of Persons with Disabilities (PwD) in Kamand Valley

Rebecca Markowitz, Erika Miyajima, Amit Ranjan (b16090), Michael Savrin, Bhanu Singh (b16128), Brandon Waugh (WPI)  
 Advisors: Dr. Priscilla Gonsalves, Sandhya Menon, Dr. Ingrid Shockey, and Dr. Gbetonmasse Somasse



### Abstract

It is vital that the needs and requirements of PwD are clearly known and addressed in communities as PwD and their families face a number of negative social, physical, and financial repercussions. We assessed local perceptions of and attitude towards PwD in the Kamand region. We set out to understand the limitations that are faced by PwD and their families, and we determined the resources available to support PwD. We clarified standards for accessibility in Kamand Valley. We hope our study will bring greater understanding of the problems and needs of the PwD and their families and this will lead to more independence and respect for PwD.

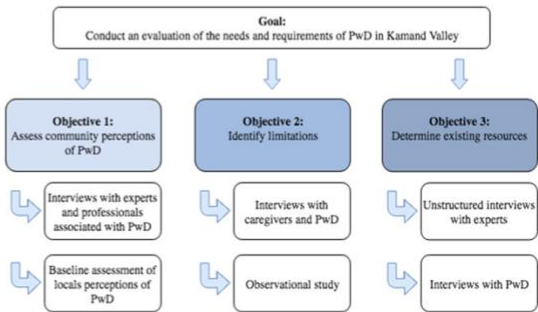
### Background

- PwD comprise at least 2% of the Indian population
- Hardships for PwD associated to geography are heightened in Kamand Valley
  - Limited access to government and NGO support
  - Lack of qualified personnel
  - Challenges in accessibility and mobility
- Immediate family is a strong support system PwD
- Individuals experience disabilities differently depending on their experience with other social constructs, such as gender, caste, region, religion, and so forth

### Goal



Evaluate the needs and requirements of Persons with Disabilities (PwD) in Kamand Valley



### Results

#### Community Perceptions

- Alienation and concealment
- Karma and black magic
- Taboos and stigmas
- Children were accepting

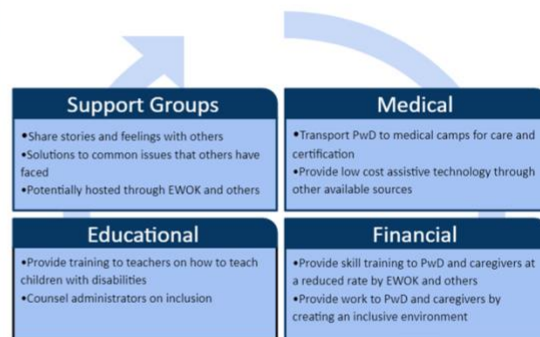
#### Limitations

- Educational
- Social beliefs and perceptions
- Financial
- Physical geographical

#### Existing Resources

- Government stipends
- Transportation passes
- Special needs educator

### Project Recommendations



Special thanks to Enabling Women of Kamand, Harsh Aurora and everybody that participated in this study. We could not have done it without you all.

Take a picture to view the whole project



## Appendix H - Website

<https://tinyurl.com/iitwpipwd>

<https://sites.google.com/view/overviewofpwdinkamandvalley/home>

