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Exploring Mobility Help-seeking Behavior Among People with Physical Disabilities: A case study of Jaipur Foot

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TABLE OF CONTENTS

ABSTRACT

It is estimated that as many as 90 million people living in India experience some sort of disability (The World Bank, 2007). As India's population keeps growing and aging, not only will the medical aspects, but also the societal impacts of disability need to be brought to the forefront of discussion, developmental strategy, and policy implementation. This study sought to analyze factors influencing the process of seeking help from formal and informal sources for people with physical disabilities. Data was collected from 10 people with physical disabilities receiving a variety of mobility aids from the NGO, Bhagwan Mahaveer Viklang Sahayata Samiti (BMVSS). Six other professionals working at BMVSS and another Indian NGO, Sangath were also interviewed. Overall, it discovered that help-seeking is very nuanced and elicits conflicting thoughts and feelings about independence, dependence, and sympathy. While seeking help from a formal source may be a more straightforward process, several barriers still exist. Informal everyday help-seeking for mobility related difficulties were much more complicated and situational and require further in-depth research. While disability advocates continue to fight for rights, stigma and inaccessibility of services, support, and opportunity still embody the everyday lives of people with disabilities.

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GLOSSARY OF ACRONYMS

AK= Above the Knee Prosthesis

BK= Below the Knee Prosthesis

BMVSS= Bhagwan Mahaveer Viklang Sahayata Samiti; also known as **Jaipur Foot**

CRPD= United Nations Convention on the Rights of Persons with Disabilities

NGO= Non-Governmental Organization

P(s)= Professional(s)

P&O(s)= Prosthetist and Orthotist(s)

PWD= People with Disabilities

PWD Act= Persons with Disabilities Act, 1995

RPWD Act= Rights of People with Disabilities Act, 2016

SU(s)= Service User(s)

UL= Upper Limb (arm or hand) Prosthesis

WHO= World Health Organization

INTRODUCTION

As a condition, disability will affect almost everyone during their lifespan, whether that is in the form of temporary impairment, permanent impairment, or difficulties in functioning at old age. As a construct, most people contribute to the societal context in which disability survives whether they realize it or not. Additionally, most people know of and support family members and friends who are affected by disability. According to the most recent 2011 census data, India's Social Statistics Division found that there are 26.8 million people with disabilities (PWD) in India (Social Statistics Division, 2017). However, alternative studies with more inclusive definitions of disability, suggest a much higher prevalence of disability at around 40-90 million people (The World Bank, 2007). The goal of this study was to answer the question: what factors influence mobility help-seeking behaviors among people with physical disabilities receiving services from Bhagwan Mahaveer Viklang Sahayata Samiti (BMVSS)/Jaipur Foot? The census data also revealed that of those with disabilities, locomotor disabilities were the most common, making up 20% of the total "disabled" population (Social Statistics Division, 2017). This demonstrates that there is a clear and significant population in India in need of mobility aids as well as, rights-based activism so that they are able to achieve independence, inclusion, and participation in Indian society.

Furthermore, the experience of disability in India is shaped by several unique factors including, but not excluded to, a massive population size, diverse cultural beliefs and practices, and a rigid hierarchal structure. This study sought to explore this experience of disability through concepts such as the perception of disability (with an emphasis on physical disability) in India, the NGO BMVSS and the services they provide, and formal (from service providers) and informal (from lay people during everyday life) help-seeking behaviors regarding mobility. By addressing help-seeking behavior, the researcher also hoped to delve into attitudes concerning independence and conversely, dependence.

Help-Seeking Behavior

Help-seeking behavior is a complex decision making-process characterized by three main traits: it is problem focused, there is intentional action, and interpersonal interaction is required (Cornally & McCarthy, 2011). Cornally & McCarthy (2011) define this term as "'the act of looking for or going in search of a relief or cure to fulfil a need.'" The trait of intentional action is considered an essential part in order for help-seeking to occur, but for many with disabilities intentional action might not always be there when helping is involved, such as when people help PWD without that person directly initiating it. This project wanted to explore situations like this further in terms of how help is sought and given and any unwanted/unneeded help. Help-seeking can also be thought of as an interactive exercise or process involving the help-seeker, the problem, and the helper (Cornally & McCarthy, 2011). This idea of a third party, or the helper, is very important and this study also looked to see who fulfilled this role in both formal and informal settings. In literature, often help-seeking behavior is studied or looked at from a health perspective, changing the term to health-seeking behavior instead, and involving problems such as symptoms with diagnosis and treatment from a health professional as the type of help sought out. This study aimed to deviate from the literature and look at help-seeking from a more broad sense relating it to the struggles that people with mobility disabilities face in everyday lives.

Disability in India

What is Disability?

In theory, there should not be one definition of disability or of who can be considered as having a disability. Each person's experience of disability is complex and unique and therefore should not be confined to a standard definition, but concerning a general notion, there are several definitions. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) describes a very broad and inclusive definition of PWD as, "includ[ing] those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (Kothari, 2010). Impairment can be classified as the physical aspects of health that can lead to disability when there is loss of functional capacity (Kumar, Roy & Kar, 2012). It is very important to have a broad definition of disability as to make sure that any legal actions concerning discrimination do not fail on the basis of a technicality when determining who is "disabled" (Kothari, 2010). India used to define disability as per the Persons with Disabilities Act, 1995 (PWD Act) which declared persons with benchmark disabilities as having 40% disability or more in only seven categories: locomotor disability, blindness, low vision, hearing impairment, leprosy affected, mental illness, and mental retardation (Kothari, 2010). This is a very limiting definition as there are so little categories.

Now, India defines PWD as per the Rights of Persons with Disabilities Act, 2016 (RPWD Act) which expands the seven categories to 21 (Narayan & John, 2017). These redefined categories are: blindness, low-vision, leprosy cured persons, locomotor disability, dwarfism, intellectual disability, mental illness, cerebral palsy, specific learning disabilities, speech and language disability, hearing impairment, muscular dystrophy, acid attack victim, Parkinson's disease, Multiple Sclerosis, Thalassemia, Hemophilia, Sickle Cell disease, Autism Spectrum Disorder, chronic neurological conditions, and multiple disabilities including deafblindness (Narayan & John, 2017). In order to assess disability, medical boards across different levels (state, district, and sub-district) are tasked with determining the percentage of disability and issuing disability certificates to those with 40% disability and above (Srivastava & Kumar, 2015). India has taken a necessary stride to a more comprehensive definition of disability, but still does not directly acknowledge in their definition the role that the environment and society play in creating disability.

Disability rights movements in India began to mobilize in the 1980s and 90s (Mehrotra, 2011). These activists embraced a disability rights approach, which was starkly different from the assumptions and notions in which PWD were associated with in India prior (Mehrota, 2011). Activists pushed for the understanding of the social model of disability and away from only a medical understanding (Mehrota, 2011). The medical model of disability looks solely at the medical component of disability, inferring that the problem is within the individual and views a person's limitations as inherent (Eitzen et al., 2013). This way of thinking was the earliest and most common understanding of disability which, consequently, led to the widespread belief that PWD needed to be cured or corrected to become "normal" (Mehrota, 2011). Furthermore, PWD were systematically excluded from social opportunities in India, such as giving social welfare benefits instead of employment opportunities and the segregation of services and education systems (Kothari, 2010). Accompanying the medical model is the charity or welfare model, which infers that PWD are dependent on the assistance of others in the form of charity or welfare (The World Bank, 2007).

Another understanding of disability can be explained through the social model under which, while it does acknowledge the biological aspect of disability, emphasizes the social conditions and barriers as the problem, not the actual disability itself (Eitzen et al., 2013). This model embraces capability, inclusion, individual dignity, and personal autonomy whereas, the medical model highlights inability (Kothari, 2010). People are disabled by society and not their bodies (World Health Organization, 2011). With this transition in viewpoints, the environment which surrounds a person with disability is stressed (WHO, 2011). The environment plays a crucial role in the experience and extent of disability in that interaction with multiple environmental barriers hinders the full extent of inclusion and participation in society (Kothari, 2011).

Prevalence and Population Profile

Disability does not just impact one kind of person, it bisects gender, race, caste, and class divisions (Mehrotra, 2011). Although the most recent census data reported that 26.8 million people were “disabled” in India, other literature has pointed to much higher prevalence rates with more inclusive definitions of disability, such as in categories like mental illness and retardation (The World Bank, 2007). Data on disability for the census was only collected on the seven types of disabilities as determined by the PWD Act, 1995 with an added “other” category (Social Statistics Division, 2017). The census found that among the “disabled population” 56% were males and 44% were females (Social Statistics Division, 2017). Furthermore, the majority (69%) of that population of PWD reside in rural areas and disability in movement is the most prevalent (20%) followed by disability in hearing and seeing (19% each) (Social Statistics Division, 2017). Research has shown that the medical causes of impairments are shifting from communicable disease-based to non-communicable disease and injury-based (The World Bank, 2007). For example, for mobility disabilities, polio was primarily the main cause and now that is changing to different causes such as road traffic injuries (The World Bank, 2007).

When looking at other socioeconomic factors, disability in India is often compounded with high rates of illiteracy, poor education outcomes, lower employment rates, and poverty (The World Bank, 2007). Illiteracy rates for PWD is around 52%, significantly higher than the average illiteracy rate (35%) of India’s general population (The World Bank, 2007). Illiteracy is the highest among children with visual, multiple, and mental disabilities (The World Bank, 2007). Also, the proportion of children with disabilities who are out of school is approximately five and a half times the general rate and these children rarely progress beyond primary education (The World Bank, 2007). Employment rates for PWD are substantially lower than the general population in both rural and urban areas and for both genders (The World Bank, 2007). A 2005 survey of Uttar Pradesh (UP) and Tamil Nadu (TN) found higher rates of disability among poorer households and a lower frequency of three meals a day in households with PWD (The World Bank, 2007). Data also indicates that woman with disabilities are around four times more likely to be widowed which is a status that is associated with low social standing, high vulnerability, and lower than average living standards (The World Bank, 2007). Women with disabilities, if they are even married at all, are most likely to be married to notably older men where rates of divorce and abandonment are also established to be high (The World Bank, 2007). Disturbingly, it has been discovered in a study from Orissa, that women with disabilities experienced significant domestic and sexual abuse, especially amongst women with mental impairments reporting that one quarter of them have been raped (with a majority carried out by family members) (The World Bank, 2007). The socioeconomic status of most people and households with disabilities are very low because of various societal barriers that have blocked them from achieving a higher status.

RPWD Act, 2016

It is important to note that along with the expansion of disability categories, there were other salient features of this legislation. The RPWD Act was created to fulfill an obligation laid out by the CRPD in which India ratified in 2007 (Narayan & John, 2017). The CPRD set out guidelines that countries were supposed to follow regarding civil, cultural, political, social, and economic rights (WHO, 2011). There are several important attributes of the Act. With regards to education, it gave the right to free education for all children with benchmark disability (40% disability) between six and 18 years and states that government funded as well as, recognized, educational institutions will have provide inclusive education (Narayan & John, 2017). The Act also increased the reservation for PWD in Government jobs from 3% to 4% with different quotas for different forms of disability (Narayan & John, 2017). Furthermore, standards for accessibility to the physical environment are to be determined and mandated (Narayan & John, 2017). A five year time limit was set for making existing public buildings accessible (Narayan & John, 2017). Other major features involved the creation of special courts in each district to handle cases pertaining to the violation of the rights of PWD and that atrocities committed against PWD were made punishable by imprisonment of six months which is extendable up to five years with a fine (Narayan & John, 2017). While Narayan & John (2017) argue that this is a big step towards more inclusive legislation, implementation will always be the key.

Perceptions and Stigma

With a shift in legislation and continued work by disability activists and advocates, the perception of PWD are changing positively from the more negative historical perceptions. Historical perceptions include those attitudes of charity, pity, exclusion, and karma (Mehrota, 2011). Much of the literature has pointed to religious beliefs such as karma as a major contributing factor to attitudes and stigma (The World Bank, 2007). Certain Brahmanic texts, written by and for the higher castes, tended to deny inheritance from people with some form of disability (Buckingham, 2011). Moreover, Hindu mythology also portrays disability as negative especially regarding the perceived capacities of woman (The World Bank, 2007). For example, in a story from the *Karthink Poornima,* Lord Vishnu refuses to marry the “disfigured” older sister of Lakshmi by arguing that there is no place for disabled people in heaven and instead the sister was married to a peepul tree (The World Bank, 2007). In a study conducted in 2005 concerning households in rural UP and TN, they found that “for both households with and without a disabled member, around half the respondents believed that disability was always or almost always a curse of God” (The World Bank, 2007). This is evidence of a long-held stigmatizing belief still being present in Indian society.

Barriers

Perceptions, attitudes, and stigma are just a few of the barriers faced by PWD in India. Barriers are especially important to study when researching formal and informal help-seeking behaviors because they address what stops someone from acting on a particular problem, thought, want, or need. In fact, there is a lot of literature on barriers to help-seeking, but mostly in regards to what this study has defined as formal help-seeking behavior, which would most likely be from healthcare providers (i.e. doctors) or service providers (i.e. NGOs or the government). According to one such piece of literature, a rural UP and TN survey found that over 70% of PWD reported difficulties in accessing services/benefits from the official institutional network (The World Bank, 2007). The researchers divided the difficulties into three categories: a) physical access problems (due to distance, lack of transport, or physical barriers); b) problems with procedures and/or officials administering; and c) communication difficulties (The World Bank, 2007). In terms of healthcare, that same survey found that reasons for not using health facilities even if needed included (from highest to lowest percentage): could not afford services, no services in the area, transportation, negative attitudes of providers, wait time too long, and other (The World Bank, 2007). It is critical that environmental barriers be erased in order for PWD to reach full social and economic potential, participation, and inclusion in Indian society.

Assistive Devices and Technology: Mobility Aids

Along with barriers to services and healthcare, people with locomotor disabilities also face barriers to receiving assistive devices like mobility aids. Assistive devices and technology, as defined by WHO, are "'any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities'" (WHO, 2011). Common examples of assistive devices for mobility (mobility aids) are crutches, prostheses, orthoses, wheelchair, and tricycles (WHO, 2011). To achieve maximum function, there also needs to be a barrier-free environment in which a person along with their mobility aid can roam around freely and easily. The CRPD also calls for the promotion of the availability of assistive devices and accessible information about them (Khasnabis et al., 2010). Unfortunately, in reality, only 5-15% of the people who require assistive devices have access to them in many low and middle-income countries (Khasnabis et al., 2010). According to India's National Sample Survey (NSS) 58th round in 2002, only around 20% of PWD had ever been advised on aids and appliances (The World Bank, 2007). Furthermore, of those who had acquired such aids (16%), approximately two thirds purchased it themselves and less than one fifth received one through a government scheme (The World Bank, 2007). Access to these devices is crucial and should be critical to a country's developmental strategy, especially

India's, because without these technologies, the cycle of poverty is perpetuated with some never being able to work or receive an education.

METHODS

Sampling

For the purposes of this study and the limited timeframe allotted, the goal was to have a sample of 10 service users (SUs). In actuality, the researcher conducted 12 interviews with SUs, but deemed two of those interviews' data unusable due to factors that are discussed in other portions of this study. In order to ensure varying experiences of disability and ease of mobility, the researcher tried to include people receiving/or ones who had already received a variety of mobility aids such as different types of prostheses (AK, BK, UL, and Calipers) and other aids like wheelchairs, crutches, and tricycles. First time users and returning SUs were also factored in to the sample population. All persons interviewed were above eighteen years of age, as children are ethically considered vulnerable populations to research.

Participants were sourced and contacted with the help of the ISP advisor and translator once the researcher arrived in Jaipur at the NGO. Furthermore, three supplementary interviews were conducted with BMVSS staff in order to understand disability from their point-of-view and the services that the organization provides. These BMVSS professionals interact daily with PWD and the researcher felt it necessary to talk to them and learn about their experience doing so. Fortunately, the researcher was also able to interview D.R. Mehta, the founder of BMVSS. The researcher was given permission to use his name in this project in relation to his organization, but has decided to keep all other data collected on disability in India anonymous and he will be described as a Professional (P). Along with the BMVSS Ps, data from two interviews with Ps outside of BMVSS were also included in the findings. These Ps worked for the NGO, Sangath in Goa. The researcher felt that these interviews taken prior to the project period were applicable when examining the experience of disability in India and certain perceptions, attitudes, stigmas, and barriers. Both professionals were asked for an interview because they worked on services or projects at Sangath that dealt with disability.

Setting

BMVSS/Jaipur Foot

The main setting for this project was at the NGO, BMVSS, also known as Jaipur Foot. The researcher spent four weeks working with this organization at their headquarters in Malviya Nagar, Jaipur. BMVSS is a "non-religious, non-governmental, non-political, non-sectarian, non-regional institution for helping the physically challenged" and it focuses particularly on the financially weak and underprivileged (BMVSS, 2018). It was founded in 1975 by D.R. Mehta and "born on a hospital bed out of personal trauma" after he was in a serious road accident and doctors told him that "they would have to take a limb" (Mehta, personal interview, 2019). After Mehta recovered, he set up BMVSS, which has since grown into an internationally recognized organization for the fitment and distribution of limbs and other aids and appliances.

From 1975 to 2018, BMVSS has fitted and provided over 1.7 million limbs and other aids in their 23 branches/centers throughout India (BMVSS, 2018). Additionally, BMVSS, through active limb fitment camps in approximately 29 countries, has provided for another 27,743 limbs, making it the "world's largest organization for the handicapped" (BMVSS, 2018) and "30 times larger than the second largest organization fitting prostheses" (Mehta, personal interview, 2019). All services, including custom prostheses and other aids, lodging facilities for all accompanying persons, food, and other specified needs are completely free of cost (BMVSS, 2018). Mehta acknowledges that "everything costs money" and that is why BMVSS "survives only with the support of donors" (Mehta, personal interview, 2019). Most donors are from Indian sources, but there are also a multitude of international donors (Mehta, personal interview, 2019). Since all limbs are free of cost to PWD, BMVSS bears the cost which is currently, on average $60 USD per Jaipur limb (BK prosthesis) (BMVSS, 2018). In contrast, the reported cost of a comparable limb in the USA would cost around $15,000 USD (BMVSS, 2018).

BMVSS has developed a unique approach to providing services since the population that they cater to is both physically disabled and disabled by societal conditions with many financially dependent on family members, from rural areas, and in poverty. BMVSS follows a patient-centric attitude towards providing services (Mehta, personal interview, 2019). A main component of this attitude is the open-door policy where any person can just walk in at any time of day without any formal prior appointment or registration process (BMVSS, 2018). Another essential element is that that "[until] the beneficiary gets what he needs, according to doctor's advice, he stays put at the center for one to three days at the expense of BMVSS," ensuring that the process is quick and doesn't require multiple visits over weeks or months just for the fitment of a limb which could come at a "considerable cost and hardship" for the beneficiaries (BMVSS, 2018). BMVSS utilizes technology such as the Jaipur Foot and the Stanford-Jaipur Knee Joint, which was developed in partnership with BMVSS, in their prostheses (BMVSS, 2018). The Jaipur Foot was first created in 1968 at S.M.S. Medical College in Jaipur and allows for mobility in all three planes, dorsi-flexion, inversion/eversion, and transverse rotation (BMVSS, 2018). It is internationally recognized as being durable, functional, and low-cost (BMVSS, 2018). This foot is a part of all lower limb prostheses (BK, AK, Hip Disarticulation) created at the centers. For those with amputations above the knee, along with the option for a simple knee joint, which is low cost with a simple design but has many gait restrictions, BMVSS also offers the Stanford-Jaipur Knee which has been fitted to over 14,000 patients so far (BMVSS, 2018). This knee was even recognized by Time Magazine in 2009 as one of the "50 Best Inventions of the World" (BMVSS, 2018). All prostheses are fitted and custom made by Prosthetists and Orthotists (P&Os) and then examined and approved by doctors. The fitting and fabrication of the prosthesis can take anywhere from one to a few days. BMVSS also makes arm prostheses and calipers. Calipers are a type of orthosis that provide support to a weakened limb most commonly used for polio patients (BMVSS, 2018). When asked about the future, Mehta replied that he would like to increase the volume and reach of the organization. He also would like to continue bettering the technology through “frugal engineering that is highly efficient” (Mehta, personal interview, 2019). BMVSS is doing an abundance of work physically rehabilitating patients and so the researcher thought that this would be the perfect setting to sample PWD utilizing mobility aids and then ask them about other aspects and difficulties that they face in their life because of impairment and disability.

Sangath

Two additional supplementary interviews about disability in India from other professionals outside of BMVSS were also included. Both interviews were conducted at the NGO, Sangath in Goa, India prior to the researcher’s arrival in Jaipur. The researcher was working with Sangath for a five day workshop learning about their organization and the services they provide. Sangath is one of the largest NGOs in Goa and works to bridge the “treatment gap” for people with developmental disabilities and mental health problems across the lifespan in India (Sangath, n.d.). They strive to achieve this through “empowering existing community resources to provide appropriate physical, psychological and social therapies” involving the primary focus areas of child development, adolescent and youth health, and adult health and chronic disease management (Sangath, n.d). Sangath was started in 1996 as a clinic for children with developmental disabilities but changed their mission to one involving developing research and intervention programs in the community (Sangath, n.d.). Like BMVSS, lack of affordable care lies at the heart of the issue. Sangath’s strategy to provide care at no to little cost is to mobilize and train lay or ordinary people in the community along with community health works to deliver that care along with supervision from experts.

Data Collection and Management

This project is a qualitative study that utilized interviews as well as observations as forms of data collection. In-depth interviews were conducted with both BMVSS service users and professionals at the organization and any observations pertaining to those interviews were recorded. The researcher felt that out of the 12 SUs interviewed, the sample population for interview data would only include 10 of those SUs. The two interviews were excluded from the data set because of factors such as the interview being stopped towards the beginning because of tiredness on the interviewee's part and accompanying members speaking completely on behalf of the individual being interviewed. Although the physical data gained from those interviews will not be referred to, observations made during and to why the researcher believed the interviews shouldn't be used will be included in this project as other data. Observations of BMVSS's facilities and workshops were also important to the study when trying to understand how these mobility aids are fitted, made, and distributed.

Interviews were semi-structured with predetermined interview guides (Appendix A, B, and C) and space built in to elaborate or expand upon topics if needed. There were two differently structured sets of questions for the SUs and the Ps. Prior to the start of any interview, consent was verbally asked and the scope of the study was explained. Consent was also asked in order to audio record interview responses. Once consent was given, all responses were recorded on a recording device to be transcribed later. In order to protect the confidentiality of data, the researcher used an identifier code, instead of the real name of any of the SUs, in all transcriptions and they continued to be used throughout the course of this report and all shared published, or presented results. Participants were either coded as a service user (SU) or a professional (P) and given a number (ex. SU1 or P1), including D.R. Mehta, when not talking about BMVSS directly. All interviews were intended to take upwards of 30 minutes, but interviews lasted anywhere from 15 minutes to 1 hour. The researcher found it difficult with most SUs to get in-depth answers to the questions and this challenge, among others, will be discussed later on in the report. Lastly, all interviews at BMVSS took place between 13 April and 11 May, 2019 and the Sangath interviews were conducted on 26 March and 27 March, 2019.

Data Analysis

Once the data was collected and transcribed as per the audio recordings, the researcher applied thematic content analysis to identify the common themes across the interview data. The researcher then developed a codebook in order to analyze, compare, contrast, and present data. Pertinent quotes were selected, analyzed, and used as supporting evidence to the themes/results discovered.

CODING SYSTEM

Codebook

CODE	**DESCRIPTION**
Theme I: Fluctuating attitudes and perceptions	
Negative self-perceptions of impairment	SUs mostly used negative words/phrases to describe how they felt about their disability such as angry, sad, burden, and suffering.
Acceptance of situation	SUs who had dealt with their physical impairment/disability longer were more likely to report that they had accepted their situation now, but that did not mean that they did not also express negative thoughts.
Destiny/God	Destiny and/or God was referred to when talking about their current situation. It seemed as if these concepts have helped them deal with their situation but it also was a point of questioning why this had happened to them.
Conditional thinking	SUs would commonly use if, then statements when asked about their situation and for most, who had experienced life without a physical disability, they would make statements retrospectively, referring back to before the injury/accident and comparing it to how they feel now.

Change in the way people see/think about PWD	Almost all Ps reported that there is a shift in perceptions of PWD by the public to a more positive accepting one.
Disability as a challenge	Ps defined disability as causing some sort of challenge(s) in one's life.
Disability as a mindset and not just an impairment	Disability is defined not only by an (physical) impairment, but also by the thinking process of the person with the impairment.
Theme II: BMVSS: a formal service provider	
Word of mouth direction to services at BMVSS	Most SUs said that they heard of BMVSS and were educated about the services that they provide from either a friend, village member, or hospital.
Experiential testimony	The experiences of others who had received limbs from BMVSS was also a powerful tool in attracting SUs and bringing awareness to BMVSS.
Free of cost services	All services at BMVSS are free of cost, including accommodation and food for the entire timeframe that a person is there. This was commonly brought up in interviews when referring to satisfaction or to why they came here.
Good facilities	The headquarter in Jaipur is well-known as the best BMVSS facilities. One SU even pointed out that they came specially to the headquarters because they heard the facilities were better there than at the branches.
Before and after transformations	BMVSS Ps expressed that the most rewarding part of their job was to see and follow the change in people from before they received a limb and after they learned to walk again.
Theme III: Everyday struggles and actions	
Treated normally	When asked if they felt they are ever treated differently because of their impairment/disability, the most common answer was that they are treated like everyone else, normally.
Isolation	Isolation was a common part of everyday life especially when someone is recovering from an injury and unable to walk. Some SUs

	even gave specific situations as to when they feel the most isolated.
Familial support	Family was the biggest and main support system for the SUs, whether that was helping them and/or accompanying them to BMVSS or assisting with everyday tasks.
Difficulty with self-care	Activities of daily living, such as ones involving dressing, grooming, bathing, and house work, were the main source of everyday difficulty because of impairment/disability.
Difficulty navigating public spaces	Along with self-care, some SUs reported that when they go outside, there are often problems with crowds, stairs, and transportation. Most SUs said that they usually have someone with them when they go outside and some responded that they don't go outside to public spaces.
Verbally asking for help	When a SU needed help with a specific task, verbally asking was the most common and direct way to initiate help from others.
Helping without verbal initiation	It was also found that help was given to a person even without any verbal cue to help. There were mixed results on how this made SUs feel, some really appreciated this approach while others were much more disapproving of it.
Do not seek help	Whereas some SUs described their help-seeking behavior, other SUs insisted that they do not ever seek help.
Uncomfortable when seeking for help	SUs were overall very uncomfortable seeking help from others even if it was from family members. Some added that they are the most uncomfortable when asking people they don't know well or people not in their family.
Theme IV: Barriers to help-seeking	
Cost	Many admitted that if this aid/prosthesis from BMVSS was not free, then they would not get it. Cost was probably the biggest barrier considering the financial status of most people coming to BMVSS.
Lack of knowledge	Another one of the main barriers discussed was the lack of knowledge or awareness of certain services whether that was of BMVSS or other/future services. A couple of the SUs had their impairment for

	many years and this was their first time getting a mobility aid to help with it due to lack of knowledge.
Distance	How far someone lived from where the services were being provided also could prevent or hinder someone from receiving the needed services. Often what is closest is the most convenient.
Lack of services in rural areas	Like the distance barrier, Ps brought up that most services for PWD were located in urban settings, but as studied, most PWD live in rural areas and so there is a clear disconnect with where the services are located.
Quality of service/product	The quality of the service/product came up as a barrier when discussing what would stop someone from seeking a prosthesis and a few SUs mentioned that they heard or through experience learned that the quality of the prosthesis was not good at another provider.
Loss of decision making power	Ps were the only ones to converse about the loss of power that a person with disabilities may experience. This loss in power could lead to families deciding what, when, and where that person should or would receive services. Additionally, observations were also included as support for this code.
Themselves	SUs would also say that sometimes they were the reason that they did not seek everyday help. Those who revealed this said they did not exactly know why they did, but it could be because of past experiences, lack of confidence, or they wanted to present themselves in a certain way.
Theme V: Striving for independence	
Mobility aids as a step towards independence	All SUs believed that they would be more independent or were more independent after receiving a prosthesis and/or mobility aid.
Being able to work for family as a determinant of independence	For those who were receiving an aid for the first time, many said that they hoped the aid will help them work again so that they can make money and support their family.
Negative feelings towards dependence	Along with not feeling comfortable seeking help, many expressed that they felt anger or sadness when they have to rely on other people to help them every day.

Emphasized trying hard to do tasks without any help	SUs, frequently the ones who have experienced their disability for a longer period of time, emphasized trying to be as independent as possible and doing these everyday tasks by themselves without any help from others.
Adapted self-care skills	Others shared that in order to be more independent they have adapted the way that they did a daily task to fit their current impairment situation.
Unwanted/unneeded help	SUs did respond with situations or instances when they have received help when they felt that they did not need it or want it. Most of this type of help was from the public and not initiated by the person receiving the help.
Theme VI: Varying experiences of sympathy	
Conflicted feelings about sympathy	Of those who revealed that they feel people are more sympathetic towards them because of their disability, some disclosed that they feel both happy and also embarrassed or bad because they do not like when people pity them.
Feels good when other people help them	Others had just responded that they feel really good when other people are willing and do help them.
Lack of sympathy	Some SUs were adamant that they had received no sympathy from the public and that no one helps them.
Greater public sympathy for the physically impaired than the mentally impaired	Ps were in agreement that Indian society will show more public sympathy towards those struggling physically than for those with mental/cognitive/social disabilities because their disability is more visible.
Theme VII: Future services	
Want for future services	When asked if they would like to seek out services in the future, most SUs replied that yes they would if the opportunity arose.
Lack of knowledge about other services	Although SUs responded that they would want to seek out future services, they had trouble expressing what other types of services they would like to receive and some even said that they did not know.

Government needs to do more for PWD	All Ps and a couple of SUs expressed opinions that the government is obligated to pay more attention to the needs of PWD and gave some areas and ideas where they believed should be improved.

Coding Process

Once the transcribing process was over, each interview was processed and certain quotes that could represent emerging codes and themes were highlighted. Then, a list of these codes were compiled along with a recording of which participant said something related to that code. There were not any pre-determined codes or themes, but some questions or probes in the interview guides led to emerging codes or themes. The codebook was only created with codes that multiple participants included in their interviews. Once the codebook was created, interviews were analyzed again and pertinent quotes and paraphrases were organized under each theme and code. This coding process was a way for the researcher to operationalize and methodically organize the data in order to present the findings in a clear, structured way.

DISCUSSION OF RESULTS

Sample Population

During the beginning of each interview, basic data such as age and gender was taken for all participants, both SUs and Ps. Additionally for SUs, more specific personal information like marital status, where they are from, employment status, impairment, impairment cause, and how long they have had their impairment for was also accounted for in order to understand their personal situation. A brief analysis was conducted from that general data and graphs were created (Appendix D). In total, 16 people made up the sample population including 10 SUs and six Ps.

Among the SU population, seven were male and only three were female (Appendix D, Figure 1). Female SUs that were available to interview were extremely hard to find at BMVSS and as observed, many came with their husbands, if they had one, who would often speak on their behalf when answering questions. Ages ranged from the youngest at 19 to 54. 60% of SUs were married with children, including two out of the three women. Employment status was very low with only one person reporting that they were currently employed as a tailor (Appendix D, Figure 2). Out of the rest, two were students and the remaining seven were unemployed. When breaking down the seven that said they were unemployed, all four men reported that they had jobs before their impairment, while two of the three women were housewives, and the third woman had never held a job before. The 10% (one person) that reported being employed is much lower than the all-India level finding of 36% of PWD working (Social Statistics Division, 2017). 60% of the SUs came from Rajasthan while the other 40% came from states such as Uttar Pradesh, Jharkhand, and Haryana (Appendix D, Figure 3). Moreover, 80% of SUs were living in villages or rural areas. This follows the trend that more PWD reside in rural areas, but this percentage is much higher than the country-wide prevalence (69%) found in the 2011 Census data (Social Statistics Division, 2017). All SUs had some sort of locomotor disability with most the result of an amputation due to some sort of injury. 50% of this population suffered an injury from either a vehicle, machine, electric shock, or attack that lead to their impairment (Appendix D, Figure 4). 30% of SUs' impairment could be attributed to polio, while 20% was congenital, meaning they were born with it. This data could represent the "disability transition" where the cause of impairment or disability is shifting from communicable diseases, like polio, to non-communicable causes like injury or diseases such as diabetes (The World Bank, 2007). It is important to note that the researcher specifically sought out a portion of polio interviewees because they were receiving/using calipers, which is a different kind of prosthesis that does not involve an amputation. When asked about the causes of impairment/disability that they see at BMVSS, all BMVSS Ps reported injuries/trauma as the number one cause followed by diabetes or cancer. They also were all in agreement that polio cases have declined, but they still see polio cases because “as long as they survive, they will need calipers” (P4, personal interview, 2019). Four types of prostheses (AK, BK, UL, and Calipers) were received or used by the SUs along with other mobility aids such as crutches (7%) or a hand-pedalled tricycle (7%), but the researcher wishes that she was able to find and interview more people utilizing a greater variety of the mobility aids supplied by BMVSS such as walkers, splints, and wheelchairs (Appendix D, Figure 5). This makes sense though, as non-prosthesis mobility aids make up a significantly smaller portion of what BMVSS has provided in the past (BMVSS, 2018). Importantly, some SUs reported using more than one kind of prosthesis or mobility aid. Lastly, 50% of SUs were at BMVSS for the first time, while 50% were repeat visitors. Interestingly, the repeat population was only made out of caliper SUs and reasons for their return involved needing a bigger size or a fix/replacement of velcro straps or damaged plastic due to frequent use.

Amid the P sample population, four were female and two were male. Four of the Ps worked at BMVSS including the founder, D.R. Mehta. Besides D.R. Mehta, the other three worked as P&Os at BMVSS. They were all fairly young with ages ranging from 25-31 and time at BMVSS ranging from 1 year- 12 years. All of the P&Os held either a diploma, bachelors, or masters (MA) in Prosthetics and Orthotics, with one also holding a BA and MA in Public Administration. Previous to Mehta’s position as Founder and Chief Patron of BMVSS, he was also the Chairman of the Securities & Exchange Board of India along with other finance positions with the Govt. of India. Also included in the P sample population were two Ps working in the field of disability and mental health at the NGO, Sangath. Both of these Ps hold MAs in Psychology and have been working with Sangath for 20 plus years. Although both are psychologists by training and have practiced clinically, they currently are designated project leaders for Sangath research interventions involving disability. P5 was even a trained teacher before accepting a position at Sangath.

Theme I: Fluctuating Perceptions and Attitudes

People thought about impairment and disability in several different ways whether that was SUs reflecting on their own situation or Ps discussing definitions and perceptions of disability in India. Thoughts and attitudes were not stagnant, but more dynamic, fluctuating between negative views to a more accepting outlook and back. Moreover, how people in India see and treat PWD can alternate between cities v. rural areas, inclusion and exclusion, and tropes of capability and incapability.

Overall, most SUs expressed negative attitudes when asked about how they felt in regards to their impairment or disability. Some participants were a lot more willing to elaborate on this and others were not, responding most commonly with “not good” or “bad.” Several SUs revealed feeling like a burden to their family. One SU, who was a student born with a congenital condition living with his family, recounted feeling like a “burden” when he and his sisters have to travel by auto just for him instead of walking along with all the other children and their friends. In relation to this example, he used the phrase, “I know my sisters are suffering too” (SU3, personal interview, 2019). In the same moment though, he also expressed feeling normal and used to his condition, saying he was more accepting of it now. Another SU, one who contracted polio when she was three years-old, reported feeling “unhealthy” and “bad,” but “when [she] was living with her parents [she] felt secure” and it was not until she “entered into the real world” that she started feeling very unhappy about her situation (SU8, personal interview, 2019). As time is very important when it comes to healing and rehabilitation, SUs with either polio or a congenital causes of impairment that led to them having a longer history with their disability, were more likely to indicate acceptance of their disability with one SU saying, “gradually I accepted my situation… I don’t have any choice but to accept it, this is what life is, you just have to go on” (SU6, personal interview, 2019). Interestingly, acceptance could also be implied when several SUs referenced destiny or God seemingly as a way to justify or deal with and accept their situation. This can be shown through quotes like “it is all destiny, because of destiny it happened” (SU2, personal interview,

2019) and “it’s destiny, I cannot do anything, it is what God has planned for me” (SU5, personal interview, 2019). Conversely, SU7 believed that “God had given [him] a second life,” but questioned why God had given him that second life causing him much conflict because he was also grappling with sadness and self-pity (SU7, personal interview, 2019). Karma and reasonings such as sins of past lives or a curse were never directly mentioned by SUs. Lastly, a significant pattern when discussing the self-perceptions and attitudes of the SUs, was conditional thinking, meaning that they would often say statements that would reflect how much better it was before they were injured like, “life is very bad, when I had legs, life was really good” (SU4, personal interview, 2019) and “earlier it was better and I was happy, now I pity my situation” (SU7, personal interview, 2019). SUs seemed to fluctuate between not only times of acceptance, normalcy, and negativity, but also between different degrees of each of those distinct attitudes.

Five out of the six Ps believed that perceptions surrounding PWD were changing to ones of inclusion and acceptance. P4 felt that PWD were “never looked down upon” and so there was never a change (P4, personal interview, 2019). P5 emphasized that this change has been drastic in the past 10 years, but cautioned that this more forward and complex understanding may only be “the case in small pockets of India” (P5, personal interview, 2019). Other Ps seemed to agree saying that PWD in cities are often treated better than PWD in villages. PWD may be thought of as incapable of doing anything and therefore, excluded from activities. Additionally P3 brought up that people may feel ashamed or “gross” bringing someone with a disability places, especially if the person was a female with disabilities. Both P5 and 6 discussed that other historical perceptions of disability still occur today in more rural areas and include that of karma and “sins of past generations” (P5, personal interview 2019). Greater education and awareness, P2 and 3 suggest, are responsible for teaching people to not “ignore disabled people” and instead try to understand and include them in society (P2, personal interview, 2019).

When asked about a definition of disability, Ps gave various different responses, but most included the common threads of there being some sort of challenge and it being a mindset instead of only an impairment. When framed as a challenge, Ps defined it anywhere from a challenge in walking, life, mindset, capabilities, and day to day functioning. P5 reflected on challenges in a broader and more conceptual sense,

> "Disability is … my challenge in accessing whatever systems that are in place, my challenges in accepting it, and also I would look at it as how the environment aggravates my challenge. I may have certain challenge, but how sensitive this environment is to support me or hinder my progress" (P5, personal interview, 2019).

While P5's definition is the most similar to that of the CPRD which acknowledges and even stresses environmental factors and barriers as contributors to disability, other Ps' understandings were not as inclusive of those environmental factors, laying somewhere between the medical and the social models. P6 included the language "[hinders] proper day to day functioning," which could imply that there is a "proper" way to function (P6, personal interview, 2019). P2 points to a "process" of recovery and mindset after injury as disability, explaining that its not just the impairment, but what happens after it, hinting at a some sort of social aspect of disability, not just the impairment itself (P2, personal interview, 2019). Another P seemed to agree with this insight stating that "disability is not in the limb, it is all in the mind," but when asked to clarify whose mind, P3 responded the mind of the person with the disability (P3, personal interview, 2019). Similarly, another P believed that disability was only in the mind of the person with the impairment and illustrated that after receiving a prosthesis, some people think very positively and are able to work and get jobs and therefore, are not disabled any more, but others think negatively and so they are still disabled. While prostheses and other assistive technologies may lessen the impact of disability, this P seemed to place the sole responsibility of the state of mind on the person, without acknowledging other outside factors that might influence their mindset, such as treatment from other people and barriers in employment for PWD. P1 also concluded that if more PWD had that positive mindset, then others would look at and treat them better. This puts the blame on the person instead of the society that harbors such negative views of them. Lastly, P4 replied that disability was “40% or more incapacity in doing something,” which exactly mirrors India’s own definition of disability as defined by legislation and is similar to that of the medical model (P4, personal interview, 2019). While some parts of definitions were more progressive and forward thinking, other segments still highlighted incapability and placed the responsibility on the person to become “normal” and even change the minds of the people around them instead of the people around them becoming more accepting of others’ differences and abilities.

Theme II: BMVSS: A Formal Service Provider

As outlined by this project, BMVSS is a formal source in which people can seek out to provide them services. This study found that the most common and possibly the most effective way in which BMVSS got their name out to the public was through other people. This word of mouth communication was then broken down further into two more categories: from friends/family/villagers or from hospital staff. Eight people responded that they were directed to come to BMVSS by other people and 50% of them said it was from friends/family/villagers, while the other 50% noted that it was hospital staff who, most times after a surgery, told them about BMVSS. The SUs who were not directed by other people heard of BMVSS through a tv ad and a book. Another persuasive tactic that encouraged SUs to come to BMVSS was experiential testimony of those who had already received limbs or other aids/appliances at BMVSS. The experiences of others was helpful for SUs because they got to hear directly that it was successful for other people and in some instances got to see the prosthesis themselves. SUs also mentioned that they heard the facilities at the headquarters in Jaipur, specifically, were the best. SU4 even stated that he travelled to the Jaipur branch because he heard it had better facilities than the branch that was closer to his home. Many SUs travelled over two hours on public transportation to get to BMVSS in Jaipur. One returning SU travelled 18 hours from Bangalore on the train. When asked about their experience at Jaipur, SUs said that it was “very good” and some even listed the good facilities as a reason for their positive experience. Another possible reason for such a great experience, was that all services are free of cost. While SUs did not directly equate their good experience at BMVSS with all services being free, the fact that it was mentioned quite often and listed as a direct reason for coming here could lead to cost being a big factor in degree of satisfaction. Half of SUs said that if the prosthesis or other aid that they needed cost money, then they would not get it. Only one SU, who has been back to BMVSS several times, criticized their experience at BMVSS. SU8 believed that when she first started coming to BMVSS the products were better than they are now, citing velco damage in the matter of days instead of months like it used to be. No other complaints were given by other returning SUs.

When asked about the most challenging and rewarding part of their job at BMVSS, Ps described the transformations that they have seen in their patients. P1 described her feelings quite eloquently as, “the most beautiful part of my job is the self-satisfaction I get when someone comes in on the floor and walks out… I feel like crying… that is the most beautiful part of my job” (P1, personal interview, 2019). This sentiment seemed to translate to all the BMVSS workers and their love for their job was evident. P2 expressed that he was proud to be able “give new life” (P2, personal interview, 2019).

In all, SUs described positive help seeking experiences through BMVSS. It was most likely that they became aware of BMVSS through informal sources such as other people, than formal sources like advertisements. By traveling to the center, they initiated the help and because of BMVSS’s open door policy, they were easily able to be seen and helped by the P&Os and doctors at BMVSS. The reasons for coming were simple, all SUs expressed that they wanted to be able to walk and they believed that BMVSS would allow them to do that.

Theme III: Everyday Struggles and Actions

While walking was the main everyday challenge for most SUs, this project sought to learn more about how having trouble walking affected them and what actions they took in order to relieve some of those struggles. Interestingly, when first asked “are you ever treated differently because of your impairment or disability,” seven SUs responded that they are treated normally, this was a much more positive answer than expected. Although, for some SUs, further on in the interview they revealed details that conflicted with their declaration of being treated normally, such as SU3 who said he was teased by classmates and people in the village when he did not have his prosthesis. Furthermore, feelings of isolation were also expressed. Both SU3 and SU10 talked about feeling isolated when they are with their friends because they are not physically able to do all the things that their friends are. SU3 also gave the example of at weddings, when he is with his family, he feels isolated and alone because they are running around taking pictures and he is unable to keep up. Other SUs revealed that they did not often leave their own house and frequently would sit in one place alone.

Fortunately, everyone indicated that they have received support from their family in several different ways. They described receiving support from family members during the process at BMVSS, through surgeries and other medical treatment, and with everyday tasks. Although some SUs came alone to the center, most SUs were accompanied by at least one other family member. Self-care activities such as grooming, bathing, dressing, and doing housework caused some sort of a challenge for all SUs. Not surprisingly, it was the female SUs who mentioned housework as a specific difficulty, since often it is the woman who bear most housework in Indian society. These woman cited having a hard time standing for long periods of time and getting tired easily. Since all but one SU lived with their family, the family was the main source of help when needed for these tasks. SUs also recounted troubles when navigating public places such as using public transportation. Two SUs said it was especially difficult for them to go to metro or train stations when it is so crowded and there are many stairs. Another SU expressed that the most difficult part of transportation was physically getting in and out of the train because of large crowds and he is unable to move fast. Some added that they had experiences using transportation where people don't give up their seat to them, while others said that people always give up their seat for them. SU1 is able to use a tricycle in which he pedals with his hands to travel to public places. SU1 got this tricycle from an organization close to his home, not BMVSS, and said it is very helpful and he uses it whenever he leaves his house. He gave the example of riding in it to go get groceries for his family, but at the same time, he also described that he did not leave his house often. There was also a mix of responses when asked if someone accompanies them when they go out of the house. No pattern was discovered here with some saying they never left the house without another person and others insisting that they only like to travel alone. Both of the women with husbands said that their husband is always with them when going out.

As difficulties with self-care and navigation were clear, the researcher also wanted to know how they acted when these problems arose. There seemed to be three clear ways in which they responded. The first was that they verbally initiated help by asking someone for it. SU9 simply put it that asking for help "is her necessity" (SU9, personal interview, 2019). Most commonly this helper was a family member, since that was who they lived with. Uniquely, SU10 lived on his own. He was living in Bangalore, far from his family, going to school to get a bachelor's degree in technology and so, he was the only one to declare friends as his main support system. The rest of SUs replied with family members like their husband or wife, mother, and siblings. A father was only mentioned once. Help was also initiated and/or received when the potential helper would ask if the SU needed any help. SUs who reported this role reversal, seemed to really appreciate it, especially when coming from family. The second course of action was the SU just being helped without any verbal communication. This was more complicated to understand without seeing if there was any initiation, through motion or otherwise from the SU. Moreover, there was differing feedback as to how they felt about this kind of help. For example, SU9, who pronounced that asking for help “is her necessity,” conveyed being very grateful for her mother-in-law , now deceased, who would help her without her having to ask for it. Perhaps she felt this way because for once she did not have to ask and someone was just attentive enough to her needs that asking was not necessary. Some SUs who reported on this, replied that it was just normal for this to happen describing it as part of a daily routine. Another SU, on this same topic, talked about how it made him feel bad, like people were pitying him by thinking he was unable to do whatever he was trying to do on his own. Lastly, the third way of dealing with problems was not seeking for help at all. It was common for SUs to interject that they do not seek for help at all. It seemed as if there were two overarching reasons for this lack of seeking out help, wanting to do things on their own and be independent and/or the attitude that no one helps. SU5 did not seek for help and held the view that “it is only God who will help me” (SU5, personal interview, 2019). These feelings and attitudes surrounding issues of help, independence, and sympathy will be further discussed in other themes later on.

Regarding their feelings about seeking out everyday help, all ten SUs said they were uncomfortable doing so, adding in other emotions such as anger, sadness, and “helpless[ness] even when asking [her] mother” (SU6, personal interview, 2019). SUs drew a distinction between seeking help from family members and people they were not as familiar with or they did not know. With family members, there was a sense of greater comfortability, whereas with others, SUs felt very uncomfortable. One SU said he “is afraid how they will react” when referring to asking for help from guests at his house (SU3, personal interview, 2019). Others described it as feeling like they were a burden on their family every time they sought help from them. Seeking for help was found to be quite emotional for SUs.

Theme IV: Barriers to Help-Seeking

Several barriers to help-seeking were discovered for both formal and/or informal settings. The barriers listed as codes under this theme were ones that multiple participants brought up during interviews. Other barriers were not deemed as codes because only one or two people mentioned them. These additional barriers include: physically accessibility of buildings that house the services, human personnel attitudes and behaviors, guardianship, tedious bureaucratic systems, inaccessibility to online forms and data, and inability of the service providers to cater to such a large population. Many of the barriers discovered in this project are similar and well-known in disability literature.

Cost was determined as the biggest barrier to receiving mobility aids and other disability services in general. This makes sense particularly when considering the generally lower socioeconomic status of those with disabilities in India and reflects the findings of other literature having to do with access to healthcare services for PWD. Cost as the biggest barrier was shown when the SUs were asked, “if these mobility aids cost money, would you still get them” and 50% of SUs replied that they would not. Ps were also asked about barriers that might stop or hinder someone from being able to access BMVSS’ services or other services. Cost was always mentioned in each interview. In fact, P1 added that she thought, “if [BMVSS] made [prostheses] only 50 rupees, only half of the patients would come,” somewhat mirroring the data which this study collected, except this study did not ask about a price threshold. Cost was obviously a big concern for the demographic that BMVSS caters too, but exactly for this reason, the organization provides all services free of cost.

Another barrier that participants noted was the lack of knowledge about such mobility aid services and others. P2 made the distinction that, “internationally [BMVSS] is very famous, but in rural areas it is not known, people are not aware of the facilities or what the organization is for… if a person [undergoes an] amputation, they do not know what to do next” (P2, personal interview, 2019). Data on this barrier was also collected from the SUs. For example, SU5 had his left arm amputated in 2001, but this was his first time (in 2019) trying to get a prosthesis. When asked why he did not get one earlier, he responded that he did not know of any places that would give him one and that he only heard of BMVSS when someone from his village told him about it and so he came there. For another SU, it took him three years after his accident for him to try to get a prosthesis, also citing that he did not know of anywhere to go. To combat this problem, service providers need to really focus on bringing awareness to their organization, what it does, and other organizations that may be similar or provide supplementary services. BMVSS could improve knowledge of disability services by educating SUs about other NGOs/ services in the area or by their homes before each person leaves the center.

Possibly going hand-in-hand with lack of knowledge, distance and the scarcity of services in rural areas were prominently represented in results. As P2 observed that BMVSS is not well-known in rural areas, this leads to many people, once they hear about it, having to travel to urban or somewhat-urban areas to receive those services. Most SUs reported traveling at least two and a half hours on public transportation in order to come to the BMVSS Jaipur headquarters. Other SUs said they traveled over five hours and one even travelled 18 hours to be there. Having to travel long distances for services stems from the root problem of often the unavailability of services in rural areas. Again, the 2011 census found that 69% of PWD live in rural areas (Social Statistics Division, 2017) and 80% of the SU population of this study resided in villages and not cities. P5 referred to this barrier when arguing for the need of services in “less central locations,” also suggesting that if there were more services in rural areas then lack of knowledge would not be as big of a problem (P5, personal interview, 2019). There is a huge disconnect between where the services are provided and who needs them.

The quality of the service or product was also something to consider. SU4 was frustrated with the prosthetic limb that he had received from another organization and so that stopped him from going back there to fix it, instead coming to BMVSS, when he heard of it. He complained of the knee joint not opening and closing properly and as a result tearing all of his clothes. Another SU had heard that the quality of the prostheses supplied by an organization by his house was not good and so he avoided going there. Ps at BMVSS talked about the importance of providing high quality prostheses, while also keeping costs low. P3 also mentioned that some people have extremely complicated cases where BMVSS' fairly simple prostheses would not be able to do much for them and so in those cases the quality of the product would act as a barrier to the service. P3 and P4 added that this is only in very rare cases.

Furthermore, Ps talked about a loss of decision making power that a person with disability often experiences. Only Ps breached this topic and it wasn't mentioned by any SUs. A loss in decision making could result in the person's family choosing for them whether services would be sought out or not. If a family or family member choses to seek services, they also could determine which ones, when, and where those services will be sought. P2 described that he often sees that the family becomes in charge of everything relating to that person and if they do not want or are not willing to take the person to get a prosthesis, then the person is not taken and a prosthesis is not received. PWD face this very unique barrier and a loss of autonomy can have some serious ethical concerns and consequences especially concerning care, legal guardianship, and services and treatment. Regarding care, this could also be a barrier to informal help-seeking when family members control the lives of the person with disabilities, deciding when, who, and how they will be helped in everyday circumstances. During the time period spent at BMVSS, there were several instances in which the power dynamic between the person with a physical disability and the people surrounding them was unequal. This dynamic was evident especially during interviews where family members would respond to all the questions, even ones regarding feelings and opinions. Although PWD may be more dependent, the dignity of PWD should always be honored and respected like any other person.

Lastly, the SUs listed themselves as a barrier, especially concerning everyday help-seeking. SU10 tried to explain why he finds himself stopping himself from reaching out for help. He gave three possible reasons and other SUs seemed to think similarly. The first reason was because of past experiences that ended in the person not helping him. SU10 gave the example of when he asked people in his village if they would be willing to share their bike with him and take him somewhere, but they were not willing to do so. This made him very sad and frustrated with his disability. Similar negative past experiences with asking for help occurred for SU4 and 8 too. Both rationed that this could contribute to why they stop themselves from seeking further help. The next reason was because of a lack of confidence. This lack of confidence could stem from many factors such as those past experiences, degree of comfortability, and/or self-esteem. SUs had expressed both a high degree of uneasiness seeking help, even from family members, and pretty negative attitudes and perceptions about their own impairment/disability, eluding to some sort of issue surrounding self-esteem and self-efficacy, their own belief in their ability which could affect their belief in their ability to reach out for help. Conversely, SU10 also cited the want to be independent as another possible reason. Instead of having a lack of confidence in his own ability, sometimes he wanted to show the people surround him that he was in fact capable of doing whatever task, proving to himself and others that he can be independent.

While BMVSS is working to break down barriers, these barriers are just examples of some of the social and systematic barriers that PWD face every day. It can be very difficult to truly create an inclusive environment, but service providers must work with their target population in order to reach as many people as possible. PWD should never feel uncomfortable asking for help nor should they feel that they have to prove to others that they are capable human beings.

Theme V: Striving for Independence

Independence is often taken for granted until it is taken away. As the purpose of a prosthesis/mobility aid is to grant some degree of independence back, this was a topic that was very important to SUs. All SUs believed or reported back that their mobility aid would/did help them to become more independent. SU6 described her experience as being dramatically different with her calipers. She talked about how she was unable to walk due to a congenital condition and how her mother used to carry her places. Now, she says, “I roam around and go anywhere I want… I have been given the chance to grow and get to higher places” (SU6, personal interview, 2019). SU6 then added that she wanted to be completely independent and get a job. When asked what job she would like to do, she replied with any that would take her. Equating working with independence was a common impression among the SUs. The want or need to work was also discovered as a main reason for wanting a mobility aid. Almost all the of the SUs were found to be financially dependent on their family. SUs with impairment due to injury, were more likely to report that they were financially independent before the accident and then dependent on their family after. The two woman who were housewives did not indicate that having a “job” was important to them. In the Indian context, there is an emphasis on the men of the family financially supporting other members, and this is probably one of the driving forces behind the SUs mindset. As disability has also been associated with poverty, there is also a dire need for the men of the family to work in order to survive. To the SUs, it seemed as if ability to work, besides just the extent a person was able to walk, was the most prominent assessment of independence.

Not surprisingly, this project found that negative feelings were associated with being helped and dependence. SUs articulated emotions like sadness and anger in relation to having to rely on another person to do the most basic tasks such as going to the bathroom. SU7 asked, “a man who needs help, what does that say about his situation” and questioned why God has put him in this predicament because “[he] hasn’t harmed anyone in his life” (SU7, personal interview, 2019). Perhaps these negative perceptions have steered some SUs away from thinking about dependence and towards focusing on increasing independence. This significant change of thinking and attitude can take quite a lot of time to manifest. The SUs who had experienced impairment and disability for the longest were most likely to highlight their independence when discussing help-seeking behaviors. These five SUs were all caliper recipients, with one also receiving a BK prosthesis, and all returning members to BMVSS. Not only had this group has time to process their abilities and degree of independence, but also time to experience and figure out how to best use their mobility aid(s). Along with emphasizing doing tasks by themselves, SUs also mentioned specific adapted self-care skills that they have developed. These are everyday skills that they have learned or figured out to do differently with their impairment. SU1, who had both legs amputated, learned how to walk with his hands lifting his whole body weight off the ground. SU5 talked about learning how to eat properly with his remaining hand (which was not his dominant one). SU5 also mentioned that he now gets dressed laying down and uses whatever he is laying on to help pull up his pants. Learning skills like these is not easy and takes time and patience.

Furthermore, a fascinating finding of this study was the presence of unwanted or unneeded help. Some SUs even recounted that it happens to them quite often. In the instances that were mentioned, the role of the helper was played by the public, meaning that they did not know/ know well the person/people “helping” them. Tasks involved included retrieving items, offering money, and assisting movements. Some SUs could not remember any specific occasions but still confirmed that they had experienced this. SU10 indicated that he was unsure of how to feel about these incidences. On one hand, he felt happy that people were willing to help him, but he also felt that their actions were out of pity and belittlement of his capabilities. He felt like they assumed that he was not able to do something and needed their help. In order to maintain and respect the dignity of PWD, a person should always ask before assuming the need for help. By asking first, the person is has the right to refuse or accept depending on their own needs at the time.

Theme VI: Varying Experiences of Sympathy

Sympathy was another complicated subject to understand because there were such different attitudes and opinions represented in the SU population. First, it was interesting to discover the ways in which people defined sympathy. To some, sympathy was synonymous with pity whereas, others seemed to define it as people's willingness to help them. These different interpretations then appeared to inform how that SU felt about sympathy. Of the people who acknowledged the presence of sympathy, experiences were varied and situational. They told of a struggle between feeling appreciative of the help and ashamed that others look down upon them. Not all felt this way though. When also asked about sympathy, other SUs replied that it feels really great when people are willing to help them, especially in public settings. One SU even declared that "it feels like they are family" (SU6, personal interview, 2019). These responses were starkly different from other responses where it was stated that they experience no sympathy at all and they wish that others would be sympathetic.

Ps also discussed different attitudes surrounding people with physical vs. mental/cognitive/social disabilities and sympathy played a major differential role. In general, they concluded that since physical disabilities are, in most cases, visible, there is better acceptance from society that it is considered a disability, but they also acknowledged that along with the "physical disability" label comes greater sympathy. In this case, Ps also associated sympathy with charity, pity, and helping behavior. Charity and pity were seen as the negative side of sympathy, whereas helping behavior was seen for the most part as a more positive side of sympathy. All Ps concluded that a person with physical disabilities were more likely to be helped as opposed to someone with mental/cognitive/social disabilities. Types of disabilities such as autism or learning disabilities, which are much less visible, are more likely to be perceived as you are "faking it" or as "madness" which elicits whole other sets of negative connotations and stigma (P5, personal communication, 2019). P6 explains this phenomena as,

> "You may look 'normal,' and that's the reason people may actually get the wrong perception. So they might actually feel that if you are not there or if you are not talking, you're rude or you like to remain isolated, or you look fine but you are just pampered so much that you don't go and get stuff for yourself, everything has to be brought to you… so the blame would be either being lazy or being pampered or parents are overprotective" (P6, personal interview, 2019).

If someone isn't even viewed as having a disability, then their specific needs could be neglected, especially in the public eye, which leads to a false perception of them. There is a fine line between advantages and disadvantages of experiencing public sympathy due to disability and neither is ideal. Either way, people with physical or mental/cognitive/social disabilities are seen as "other" and different, but there can be significant distinctions between how people with varying disabilities are viewed and therefore, treated.

Instead of taking a sympathetic approach towards PWD, empathy should be practiced. An empathetic viewpoint would start with acknowledging that the experience of having a disability includes both positives and negatives, just like anyone else. Sympathy tends only to be a reaction towards perceived negative aspects of disability. Furthermore, empathy encourages truly supportive measures. Truly supportive measures are ones that directly cater to the needs of PWD unlike charity, where it is dictated what PWD need. Like putting the needs as expressed by the people first, the unique individual person should also be stressed. Maintaining dignity and autonomy of one's own self is a right that should not be taken away. Disability should be understood as natural part of the diversity of abilities.

Theme VII: Future Services

This study also asked SUs if they would wish to seek out more services for their disability in the future. Most SUs said that they would like to. Some seemed satisfied with where they were at and declared that they would not seek out additional services. One person reasoned that because she wanted to be independent, she did not want to receive additional help or services. Additionally, some SUs reported that they had already received services from other organizations such as a pension from the government or a hand-pedalled tricycle from another NGO. Many were optimistic about the future and replied that if the opportunity presents itself they would of course seek out other services, but often did not know what additional services they would like to seek out. This points back to a lack of awareness and knowledge of the services available. Two SUs were able to convey ideas for what they would like going forward. SU6 wanted to find an adapted scooter for her to ride. She hoped to find an organization that would create one or donate one to her with the hope it will allow her to roam around more independently. SU7, who recently lost his arm below the elbow and his other hand was injured in an attack, told of an experimental surgery that he would like to eventually try out. It was a hand transplant surgery that was carried out at a private hospital in Kerala and he talked about possibly consulting them in the future to see if he could be a candidate. Overall, SUs wanted to continue seeking out help from formal sources like NGOs and the government, but the problem lies with not knowing other options for services. PWD deserve to know what is already available to them by either the government or other organizations, like BMVSS.

Along with wanting more services in the future, participants, from both SUs and Ps, also urged that the government should do more for the well-being of PWD. As one SUs put it, “the government is not doing enough to ease the people [with disabilities] and the organizations [who serve those with disabilities]” (SU7, personal interview, 2019). While the government was acknowledged for the work they were doing, participants believed that there was still a lot of work to be done especially in the area of accessibility. Ps noted that there have been changes made especially in metro stations and airports that make it more accessible to physically challenged people, but they said this was definitely not the case in rural areas. P3 suggested adding more ramps, increasing the availability of modified scooters in places like airports where someone could be walking for very long distances, and lowering elevator buttons so that a person in a wheelchair could easily reach them. SU7 voiced that he would like someone assigned to him and other PWD at the railways to help them navigate the station and get on the train. Besides accessibility, P4 thought the government should be more involved in rehabilitation efforts and SU10 wanted the government “to motivate [PWD] to think that they are valuable” (SU10, personal interview, 2019). As there are many barriers that still exist in India, the government needs to keep making strides to creating an accepting and inclusive environment for all people.

Challenges and Limitations

Challenges and limitations also need to be recognized for this study. The most obvious and greatest challenge and limitation that the researcher faced was the language barrier even with the help of a translator. Researching through a third party is never ideal because it involves relying solely on the translator to accurately convey the answers of the interviewees. Additionally this can pose other limitations when the translator’s own biases and intentions influence the what and how they translate conversations. During interviews, the researcher had difficulty getting some of the SUs to speak more than a few words, even when probed further. The researcher tried to make most questions open answered but for other questions tried to approach it as a yes/no standpoint in order for that to act as an open door to follow up questions. This lack of content could be due to an uncomfortableness with the researcher which points to other limitations of this study, the researcher’s position as a foreigner and short placement at the NGO. Since the researcher is a foreigner, the SU might trust them less with sensitive material. Moreover, the researcher had only been at BMVSS for at most two weeks by the time interviews were completed and during that very small timeframe it was hard to build up rapport with the people, especially when there were new SUs everyday filtering through the center. Another unique challenge that could be more specific to the population that the study was working with, was the loss of autonomy in answering questions that the researcher observed while conducting these interviews. Frequently, when there was a woman involved, the husband would speak for the woman whether that was to the registration desk and P&Os or to the researcher and translator. The researcher had situations like this this occur twice to the point where the interview was discarded because of a lack of the person’s own answers about how they personally felt. This happened once with a husband and wife couple and once with several village members who brought in another person for a prosthesis. Lastly, a greater sample size with more woman would have provided for a more comprehensive report and better representation of people with physical disabilities in India.

CONCLUSION

According to the social model of disability, theoretically a person with an impairment would not be considered “disabled” if society was barrier-free and therefore, did not treat them differently. Obviously countries all over the world, not just India, have a long way to go before this happens. A barrier-free inclusive environment is the ultimate goal, and arguably may never be fully achieved, but that shouldn’t dissuade countries from doing everything in their power to ensure participation and inclusion for people with disabilities. BMVSS, a NGO providing mobility aids and other assistance services as needed, is just one of many NGOs working throughout India to address the needs of PWD. BMVSS provides all services free of cost “as help rather than a dole or charity” focusing on self-respect and the dignity of PWD (BMVSS, 2018). Mobility aids should not be thought of as a way to make PWD “normal,” but instead as a tool that can support a person in achieving their right to mobility, like any other person should have. Furthermore, it is important to note that the need for help and the process of seeking help is not exclusively for PWD and should not be thought as so. Help is a completely normal everyday human interaction that all people experience, but PWD may experience this interaction very differently than others.

This study found several factors that could influence mobility help-seeking behaviors for people with physical disabilities. First, it found that self-perceptions and perceptions/attitudes of others can play a major role in determining the context or the situation a person is in when they are seeking out help. Many of the SUs fluctuated between thinking negatively of and accepting their current situation which could then impact when, how, who, and their comfortability seeking help. How PWD are perceived by others also could influence whether PWD decide to seek help or not. These stigmas and perceptions surrounding disability, specifically physical disabilities in India, also influence the helping behaviors of potential helpers. Ps described that people in India might be more willing to help someone with physical disabilities as opposed to someone with mental/social/cognitive disabilities. It was also cautioned though that these helping behaviors may stem from feelings of sympathy and pity. With sympathy, SUs had varying experiences and very mixed feelings, sometimes conflicting ones.

Regarding seeking help from a formal service provider, word of mouth communication was the most common way in which BMVSS attracted its SUs. Overall, SUs were very satisfied with the services that BMVSS was providing. Barriers such as cost, lack of knowledge, distance, quality of service/product, lack of services in rural areas, and loss of decision making power were all listed by SUs and Ps as something that might stop a person from seeking and receiving formal services. Also, many SUs wanted to seek out services in the future, but did not know what services they wanted.

Components involved with everyday help-seeking established by this study included the family as the main support system, difficulty with self-care tasks and navigating public spaces, verbal and nonverbal initiation, and thoughts surrounding independence and dependence. SUs also revealed that sometimes they themselves act as the barrier in these informal situations. SUs did not give a clear reason why they stopped themselves from seeking help, but gave a few possibilities. All SUs communicated that they wanted to become more independent and believed that their mobility aid would or did help. SUs seemed to equate seeking help exclusively with dependence and some were adamant to say they never sought help and were independent. While a person may seek more help if they are “dependent,” this does not mean that people who are independent do not seek any help at all. There needs to be the understanding that everybody seeks help, no matter how independent or dependent they may think they are.

When visualizing a barrier-free environment, PWDs should be able to seek help without barriers and pity. Others should also be willing to help but at the same time respect PWD' dignity and always ask before assuming someone needs help. P5 envisions such an inclusive environment "where there aren't intentional efforts being made, but [supports] are just there" (P5, personal interview, 2019). As the second most populous country in the world with an increasing number of people with disabilities, India has the responsibility to ensure the rights of all its people. Intentional efforts, such as legislation, by the Government of India have been forged in recent years, yet stigma and inaccessibility of services, support, and opportunity still embody the everyday lives of PWD.

Additional Recommendations for Future Studies

As this study was very limited with the timeframe and sample size, additional research should be conducted with a larger and more representative group of people with physical disabilities such as including more woman, impairments, and a greater variety of mobility aids. Looking further into specific topics or concepts discovered in this project like help without any verbal initiation, unwanted/unneeded help, and sympathy would also make interesting courses of additional study.

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Professional 5. Personal Interview. Porvorim, Goa. 26 March, 2019.

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Service User 4. Personal Interview. Malviya Nagar, Jaipur. 18 April, 2019.

Service User 5. Personal Interview. Malviya Nagar, Jaipur. 22 April, 2019.

Service User 6. Personal Interview. Malviya Nagar, Jaipur. 22 April, 2019.

Service User 7. Personal Interview. Malviya Nagar, Jaipur. 24 April, 2019.

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APPENDICES

A: Service Users Interview Guide

General:

1. What is your name?
    a. Age?
    b. Gender?
2. Do you have a job?
    a. Did you have a job?
    b. What is/was it?
3. Where do you live?
    a. Rural or Urban?
4. Are you married?
    a. Do you have children?
5. What type of impairment do you have?
6. How long have you had your impairment/disability?
7. What was the cause of your impairment?
8. Are you ever treated differently because of your impairment/disability?
    a. What happened?
    b. In what situations?
    c. How does that make you feel?
9. How do you feel about your impairment/disability?
10. Is this your 1st time at BMVSS/Jaipur Foot?

Formal and informal help seeking behaviors:

11. What type of mobility aid are you seeking? OR What type of mobility aid did you receive?
12. How have you gone about getting this aid?
    a. Have you received support from others in this process?
        i. Who?
13. Why did you want a _____ (type of mobility aid)?
    a. Did you try to get this before?
        i. What made it possible for you to get it this time?
14. How did you hear of BMVSS/Jaipur Foot?
    a. Did you know of any other places to get a ____ (type of mobility aid)?
        i. If yes- Why did you choose this organization?
    b. What has the process been like?
        i. What kind of help have you receive from_____ (above)?
        ii. Where there others involved as well?
        iii. Are there any people with you here today?
    c. What would stop you from getting a prosthetic?
        i. If this _____ (type of mobility aid) cost money, would you still get it?
15. In your everyday life, what tasks, if any, do you have trouble with because of your impairment? (feeding, bathing, grooming, housework…)
    a. Do you have difficulty moving around your house?
        1. Stairs?
        2. Public areas (roads, going to the market, going into public buildings, going to the park…)
        3. Transportation (cars, buses, trains)?

    b. How does the difficulty or inability to do those tasks make you feel?
16. Do you ever feel like you need help with those tasks?
    a. When you feel this way, do you ever seek help?
    b. How do you seek for help?
        i. Do you verbally ask? Motion? Or they just help?
    c. What kind of help?
    d. Who do you seek help from?
        i. Besides family, is there anyone else who helps you?
17. When seeking or asking for help, how does it make you feel?
    a. Do you feel comfortable doing it?
18. What has stopped you, if anything, from seeking help?
19. Are there any instances when people help you when you don't need or want help?
    a. What happened?
    b. From who?
    c. How did that make you feel?
20. Has your _____ (type of mobility aid) helped you with these everyday tasks? OR How do you expect your _____ (type of mobility aid) will help you? (What do you need/want your aid to help you do?)
    a. In which ways?
    b. Do you believe you are more independent with the aid? OR Do you believe you will be more independent with the aid?
        i. What does independence mean to you?
21. Have you sought out any other support services for your disability?
    a. If yes: What services or NGO?
        i. Did you receive those services?
    b. If no: Why haven't you?
        i. Do you want to in the future?
    c. Are there any additional services that you wish to seek out to help you in everyday life?

B: BMVSS Professionals Interview Guides

1. What is your name?
    a. Age?
    b. Gender?
2. How long have you been working here (Jaipur Foot)?
3. How did you start working in this field?
    a. Why/what go you interested in disability services?
4. What is your job title?
    a. Tell me a little about what you do.
5. How would you define disability?
6. How are people with disabilities perceived in India?
    a. Is there any difference between the perception of physical and mental disabilities?
7. What are some possible barriers to service accessibility and help-seeking for people with disabilities?
    a. Does BMVSS work to bridge those barriers?
8. What do you see as the most common causes of these physical disabilities?
9. Do you think India is physically accessible for people with physical disabilities?
    a. Tell me more about that.

10. What would you say is the most challenging and rewarding part of your job?
11. Is there anything else you would like to add or ask me?

Additional questions for Mr. Mehta:

12. Why did you start this organization?
13. How many people work here?
14. Could you please tell me more about the international reach of this organization?
15. How is BMVSS able to create and supply aids free of cost?
16. Where do you see BMVSS in the future?

C: Sangath Professionals Interview Guide

1. What is your name?
2. What is your job title?
3. How long have you been working here (Sangath)?
4. How did you start working in mental health?
    a. Why/what got you interested in mental health?
5. How would you define disability?
6. How are people with disabilities perceived in India?
    a. Is there any difference between the perception of physical and mental disabilities?
7. Do you often see a comorbidity of mental health issues and disability?
    a. Why do you think this is?
8. What are some possible barriers to service accessibility and help-seeking behavior for people with disabilities?
    a. Specifically any mental or psychological barriers?
9. If any, what services does your organization provide for people with disabilities?
    a. Do you know of any additional support services (or NGOs) for people with disabilities?
10. What does an inclusive environment look like to you?

D: Sample Population Graphics

Figure 1: Gender v. Type of Interviewee

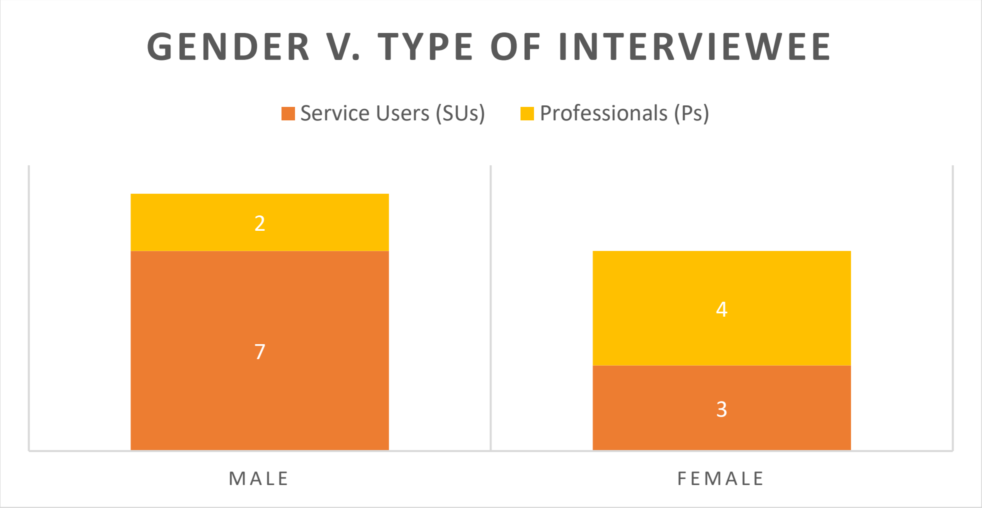

Figure 2: Current Employment Status of Service Users

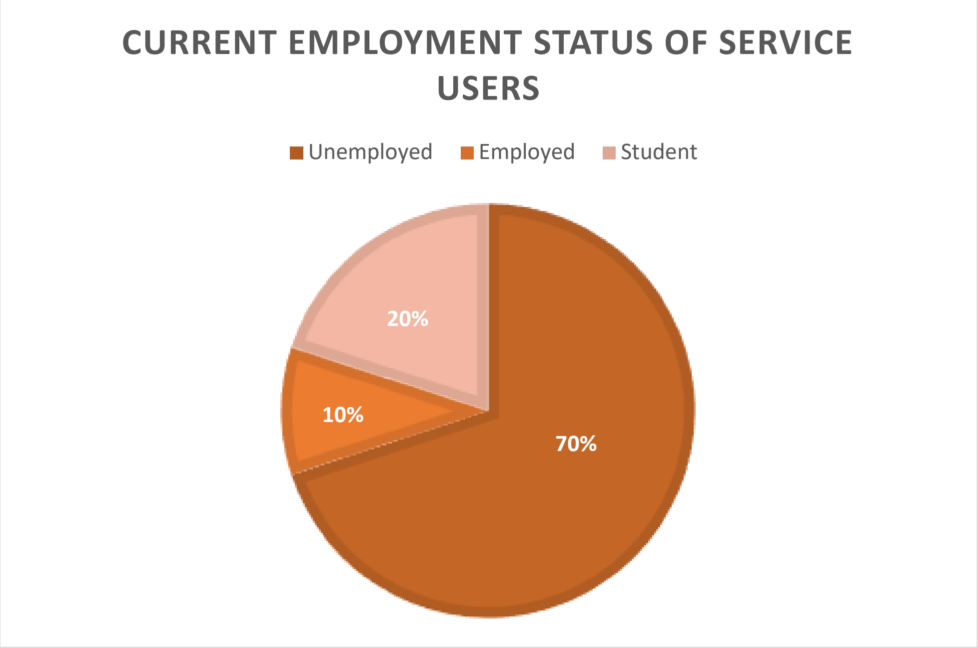

Figure 3: Indian State v. Setting (among SUs)

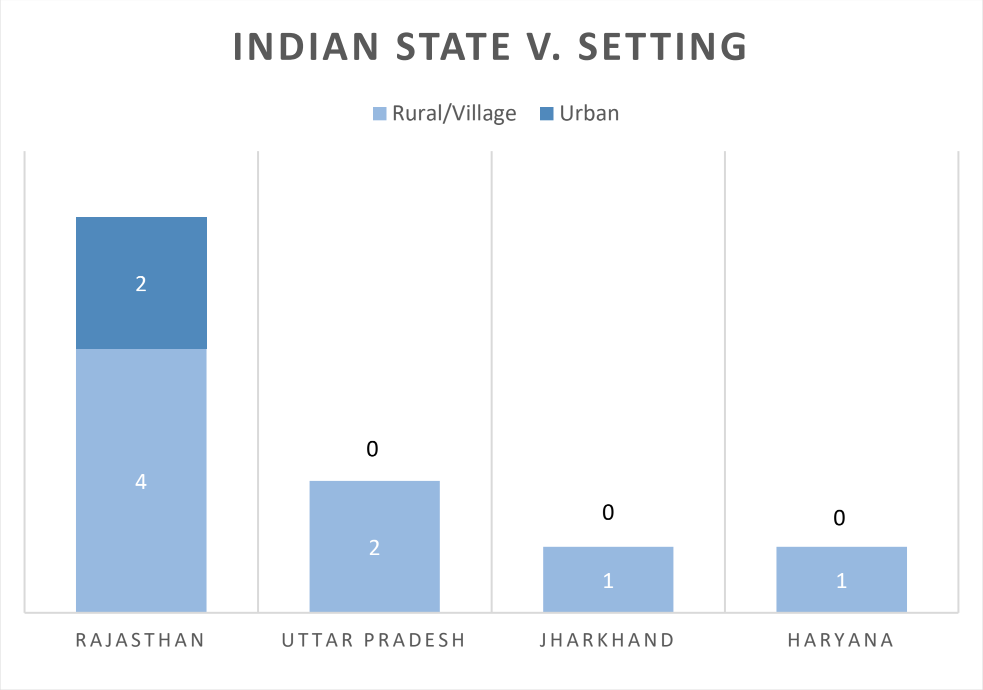

Figure 4: Cause of Impairment (among SUs)

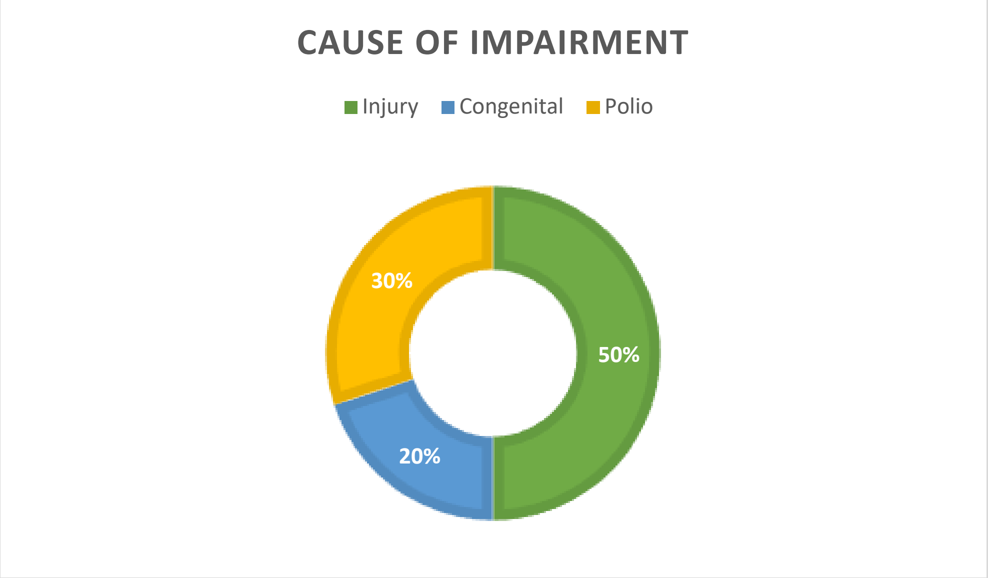

Figure 5: Type of Mobility Aids Used