

# International Training and Research on the Impact of Assistive Technologies for People with Disabilities in India

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*ABSTRACT: A team of two graduate research students from the University of Pittsburgh conducted three research studies at the Indian Spinal Injuries Centre (ISIC) in New Delhi, India. Two of the studies focused on the impact of assistive technology on quality of life for people with disabilities, and the wheelchair skills of users of different types of wheelchairs. These studies were part of an ongoing collaborative relationship between the University of Pittsburgh and ISIC, in the interest of improving the effectiveness of assistive technology (AT) provision in India. The first study involved the collection of the PART survey, which includes both objective and subjective measures of an individual's quality of life. The PART was asked of recent recipients of new AT, and the study is ongoing, with scheduled follow-ups at 6, 12, and 18 months. The second study, which is complete, involved the use of the Wheelchair Skills Test to investigate the effect of wheelchair type on the mobility skills of individuals. Participants were first tested while they used hospital wheelchairs, and then again after they had received a prescribed wheelchair from ISIC's AT department. After each test, participants were also asked the QUEST survey to assess their satisfaction with each type of wheelchair. The third study sought factors motivating the choice of driver cessation and unique characteristics shaping the market for vehicle modification and need for driver rehabilitation services. The impact of the research will be to improve the quality of life of people with disabilities by providing evidence to donors, providers and designers on which AT makes the most impact on the people who use it. ISIC's goal is to become a world-class research institution, and so this host of the ISSICON conference benefits from collaboration with international universities and organizations. In turn, the University of Pittsburgh researchers were exposed to specific challenges of service provision at the host institution that would be difficult to understand from afar. They developed an understanding of Indian perceptions of disability and its place in the country's overall socioeconomic conditions.*

## INTRODUCTION

The Department of Rehabilitation Science and Technology at the University of Pittsburgh School of Health and Rehabilitation Science received the International Research and Education in Engineering (IREE) supplement to a Research Experiences for Undergraduates (REU) award. (EEC 0552351, American Student Placements and Internships in Rehabilitation Engineering: ASPIRE-REU). Under this grant, a team of graduate research students conducted two research protocols. The first protocol focused on the impact of assistive technology on the quality of life for people with disabilities. The second study investigated differences between hospital style wheelchairs and active user configured wheelchairs in terms of skilled mobility, satisfaction, and effort. While the first protocol is longitudinal and ongoing, the later study has been completed. Both studies took place within the Department of Assistive Technology at the Indian Spinal Injuries Centre (ISIC) in New Delhi, India.

Faculty and Staff in the Department of Rehabilitation Sciences and Technology at the University of Pittsburgh have maintained a five-year, ongoing relationship with ISIC. This collaboration fosters research into the impact of AT on people with disabilities in India. There are two main benefits: increased opportunities to address the overwhelming need for low-cost, high quality AT in the developing world, and unrestricted studies on the impact of AT external to the boundaries imposed by funding structures in the United States.

The primary outcome of these studies has been the development of international research skills and collaborations for the graduate research students. The students will use this experience as a platform for future studies in international rehabilitation research. Additionally, these research studies have furthered the university's collaborations with ISIC towards a joint objective to advance the study of rehabilitation sciences. The three research studies will be among the first to provide vital outcome data to help improve AT provision in India, and they will help establish a model for comparable research in other developing nations. The studies evaluated the impact of AT on the quality of life of wheelchair users treated at ISIC. The importance of evaluating the outcomes of AT provision was recently emphasized by the United Nations and the World Health Organization.

ISIC is a national leader in medical care and rehabilitation of spinal cord injuries as the most advanced specialty hospital and rehabilitation center in South Asia. In addition to treating disorders of the spine, it is equipped for complete health care services. To complement the treatment services of the hospital, ISIC offers training programs for medical doctors and therapists. They have also developed comprehensive graduate and post-graduate courses in Disability Management and Rehabilitation, Orthotics, and Prosthetics. The Institute of Rehabilitation Sciences provides courses at the master trainer level, including Masters in physiotherapy, orthopaedics, spine surgery, and rheumatology. An institutional review board (IRB) has been set up to process human subject research proposals. Beyond standard treatment and health care services, several research studies are ongoing to investigate issues related to spinal cord surgery, drug treatments, and rehabilitation outcomes. The most recent addition to ISIC is the Department of Assistive Technology (DAT), which is involved in collaboration between ISIC and the University of Pittsburgh. The director of the DAT, Nekram Upadhyay, is a Ford Fellow (2004-2006) and Rehabilitation Engineering Technologist with an MS in AT from the University of Illinois at Chicago. The DAT's programme manager, Jyoti Vidhani, is a Heinz Fellow (2005-2006) who studied rehabilitation counseling at the University of Pittsburgh.

The research studies conducted at ISIC took place between Jan. 9 and May 1 of 2008. During this time frame, Dr. Pearlman accompanied two graduate research students to New Delhi, India for the first two weeks and facilitated the start up preparations and familiarization with living in New Delhi. The first student researcher was Nahom Beyene, a first-year graduate student in the PhD program in Rehabilitation Sciences. The second student researcher was Alexandra Jefferds, a graduate student in the Masters program in Rehabilitation Sciences. The research team members were selected based on their interest and history of international research and travel. Mr. Beyene's effort to compile a list of disability services in Ethiopia has given him familiarity with the resources available to people with disabilities in developing countries. Ms. Jefferds has experience designing and building wheelchairs for India.

## **RESEARCH ACTIVITIES AND ACCOMPLISHMENTS OF THE INTERNATIONAL COOPERATION (LIMIT: 1-1/2 PAGES)**

The first research study involved the collection of the PART [1] questionnaire for AT recipients. The goal of the study was to introduce a standardized method to assess several aspects of the life of a person with a disability before and after they received AT. The expected outcomes of the longitudinal study are to (1) gather informative profiles of AT users serviced at ISIC, (2) gather longitudinal outcome data to evaluate the impact AT has on the lives of people with disabilities, and (3) set precedence for collecting outcome data in less-resourced countries. The impact of the research will be to improve the quality of life of people with disabilities by providing evidence to donors, providers and designers on which AT makes the most impact on the people who use it. The research team asked all study participants to complete intake forms asking for demographics and contact information. Upon completion of the intake form and subject recruitment records, the participants provided responses to questions listed in the PART questionnaire. For the follow-up interviews, the research team prepared a subject scheduling worksheet in Microsoft Excel. The scheduling worksheet calculated future dates corresponding to 6, 12, and 18 months post the initial, baseline test date. The follow up interview documents the status of the AT acquired during the baseline interview and whether or not the participant acquired any other AT products or services since the initial interview. Research findings thus far include the survey results from the baseline and the 6-month follow-up. There appear to be trends toward increased scores in the objective section (frequency of home and community participation) and decreased scores in the subjective section (satisfaction with participation).

The second research study involved the comparison between standard, hospital-style (depot/ward) wheelchairs and appropriately fit and designed wheelchairs. This comparison took place with the aim of understanding how wheelchair design impacts the functional mobility of users in the built and un-built environments of developing countries. Wheelchair users, designers, manufacturers, and providers in these regions will receive important guidance through evidence in this study linking design elements (eg. adjustability or reduced weight) to increases in mobility of wheelchair users. The wheelchair comparison study began with a general intake form for the study participants. After having completed the intake and documentation of subject recruitment records, the research team administered the Wheelchair Skills Test Program to the wheelchair user in their hospital-style wheelchair. The user was asked to select the representative numerical value (between 6-20) reflecting their level of exertion and effort to complete the skills test. Results indicate that participants were able to complete more activities in their new wheelchairs, though safety scores decreased. These were trends only because the number of participants recruited resulted in low statistical power.

In addition to the Wheelchair Skills Test, the researchers asked the same participants to complete the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) [2,3] for feedback on the individual's satisfaction with their current wheelchair and its service provision. All participants who received new wheelchairs (through ISIC's standard prescription practices) were allowed a week to familiarize themselves with the new AT product before repeating all of the previously mentioned steps in the study. Findings include a definite trend toward increased satisfaction with new, fitted wheelchairs as compared to the hospital wheelchairs. Post-prescription scores were comparable to other QUEST values found in the literature.

The third study was performed to investigate factors contributing to driver cessation and alternatives to independent transportation in New Delhi, India. This study evolved as an extension of the Quality of Life Technologies Engineering Research Center (QoLT ERC) driver capabilities (DriveCap) project. Using the international opportunity for research, this study showcased the QoLT Core Assessment Battery [4] in combination with two sections on driver cessation and barriers and limitations to community participation [5,6] for a total of 70 questions. Study participants included people with disabilities (physical or sensory) and senior citizens.

The mission of the Indian Spinal Injuries Centre is to reach the lives of thousands of newly spinal injured people every year by providing medical excellence through both scientific expertise and respect for the patient as an individual. The new Department of Assistive Technology furthers the success of ISIC in fulfilling this mission by implementing the highest standards for patient assessment, AT provision, and user evaluation. Through their efforts to serve AT clients through proper assessment and evaluation, the Department of Assistive Technology at ISIC closely mirrors the intent and purpose of the research work supported under the current NSF award.

The staff at ISIC provided a warm welcome to the research team and provided dedicated work space within their researcher's room. Through the workshop facility, researchers were able to benefit from experiential learning by designing and fabricating AT components. Additionally, occasional lunch outings provided informal opportunities to reflect upon and share cultural experiences.

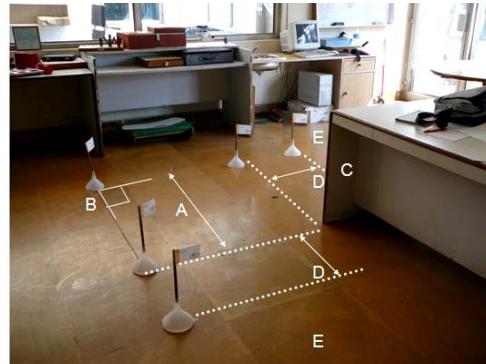
Nahom Beyene contributed to the research achievements by serving as a spotter for the standardized wheelchair skills test and developing a document (see Figure 2) to specify the test course layout at ISIC. Mr. Beyene also created a follow-up scheduling system for the PART study. For responsibilities as a graduate research assistant, he also managed and conducted the study on driver cessation and alternatives to independent transportation with the support of a research assistant from ISIC. Mr. Beyene's contribution to the Department of Assistive Technology was a template to develop a catalogue of AT products available through the department at ISIC.

Alexandra Jefferds worked in the Department of Assistive Technology as an intern in addition to performing research work at ISIC. As an intern, Ms. Jefferds contributed to the modification and customization of many wheelchairs by the request of hospital patients and outpatient clients. She also developed skills within the Prosthetics and Orthotics department while assisting on the development of computer access devices. Ms. Jefferds was the lead researcher for the PART study and the dedicated test conductor for the wheelchair skills test.

Both students provided support for the International Spine and Spinal Injuries Conference (ISSICON) by assisting workshops and making presentations. Mr. Beyene provided a presentation on wheelchair transportation safety during the main conference and Ms. Jefferds helped develop a presentation about wheelchair seating technologies.



**Figure 1: Picture of wheelchair skills test course trial and evaluation**



- A. 1.2 m wide, smooth surface (marble tile)
- B. 90 degree turns
- C. Solid barrier
- D. Start and finish line 0.5 m from corner
- E. 1.5 m space before/after start and finish lines

**Figure 2: Sample course setup diagram for 90° turns forwards and backwards, to the left and right**

The University of Pittsburgh's collaboration with ISIC offered the researchers a unique opportunity to initiate outcome studies research with individuals with spinal cord injury in an unstudied region. Outcome studies play an important role in determining how to design and provide AT that will have the most positive impact on the quality of life of people with disabilities. Results from these studies will help increase social participation, which has several positive effects in society as a whole. From the clinical perspective, outcome research can provide guidance on how to be more effective when providing AT to users. From an engineering perspective, the studies give important guidance on design for mobility and independence.

### **BROADER IMPACTS OF THE INTERNATIONAL COOPERATION (LIMIT: 1-1/2 PAGES)**

The experience of conducting research at ISIC presented many benefits due to the diversity of people who were present at the hospital over the duration of the study. In the beginning, a team from Motivation's Worldmade Wheelchairs was present for a trial study to obtain feedback on the value of their wheelchair to potential users in New Delhi. The technician came from Sri Lanka and the therapist came from Madagascar. Also, a group of individuals from the US came to ISIC to implement a wheelchair rugby team. Lastly, the ISSICON conference provided the research team with exposure to experts from throughout South and East Asia, Australia, and parts of Africa with experience in hospitals and clinics that serve people with spinal cord injuries.

The IREE supplement extends the mission of the REU in two ways: including graduate student participation and exploring international research topics. Through this combination, the IREE supplement helps to increase the global community of international researchers in academia.

The opportunity for international travel accommodates long term sustainability and continuous improvement of the Department of Assistive Technology at ISIC. A physical presence also allows the awardee research team to understand and internalize underexposed challenges to service provision at the host institution, which may not be communicated equally by annual or periodic reports.

Visiting ISIC in New Delhi presented many lessons for the research team including language differences that impact understanding and technology development trends developed by the provisions available for workshop equipment. Translation services provided the means to develop survey tools in Hindi. In certain situations, the official Hindi vocabulary was less effective than using English words. Direct translation from English to Hindi required impromptu assistance with a layperson's definition of proper Hindi vocabulary terms. At the same time, the use of Likert scales as discrete variables for response to questions presented some problems for study participants. The researchers concluded that this may be due to a reduced use of superlatives (eg. good, better, best) in the common communication of people in New Delhi. While performing wheelchair modifications, there were many instances where products

commonly available in US stores had to be hand-built within the workshop. Further, the tools available for shop work mostly required manual labor for cutting, applying bolts and fasteners, and detailing. In the absence of power tools and mass produced parts, great skill was required to improvise quality, functional modifications for assistive technology.

In addition, the researchers were exposed to Indian perceptions of disability. In many cases, patients and their families had no exposure to people with severe disabilities or assistive technology before the accident that introduced them. For poorer families, the sudden disability of a family member, particular a bread-winner, can result in complete financial ruin. Consequently, the concept of a person with a disability as an enabled, capable, contributing member of society is very underdeveloped. The staff at ISIC attempts to guide patients toward opportunities that are still available to them, and to educate them about their remaining capabilities. However, India as a whole is still in the early stages of empowerment for people with disabilities, and so at times even the ISIC staff was not familiar with progressive expectations for patients, particularly individuals with quadriplegia. India is changing, though, and now that lightweight wheelchairs have become available to those who can afford them, it is possible to find individuals with severe disabilities leading completely independent lives. As is typical in many aspects of Indian society, the “haves” are finding ways to flourish in a global economy, while the “have-nots” are still caught in deep poverty where survival of the family is often the most pressing concern. The ideal outcome in this situation is when a disabled individual finds a way to continue contributing to his or her family’s wellbeing.

### **DISCUSSION AND SUMMARY (LIMIT: 1 PAGE)**

The researchers had the privilege of contributing to an international collaboration of researchers and assistive technology practitioners. They attended and contributed to the ISSICON conference, attended hospital rounds, participated in assistive technology evaluations, interacted with patients, and collaborated with AT department staff to ensure the sustainability of the services offered. They were able to observe the complexities of life in India in a way that would not have been possible had they not visited.

Preliminary research results indicate that while trends have been detected in user participation, wheelchair skill, and technology satisfaction, future research with a larger study population would be ideal. The WST/QUEST findings suggest that in India, wheelchair skills and user satisfaction with technology increase with the fitting of an appropriate wheelchair. Data collection for the PART study is ongoing, and trends may become more apparent as more follow-up surveys are collected.

The IREE’s intent is to support international research conducted by “early-career” researchers. The researchers on this project believe that such support should not just be financial, but that the IREE should promote researcher confidence and professional practice by providing applicants with networking and communication resources to discuss international research funding, trends, and priority areas of work. This would allow researchers to better understand their obligations, identify areas for potential collaborative studies, and appreciate their role in the scope of international research. Our research team returned to the US only 24 hours prior to the IREE conference. As a result, the team was unable to attend and an opportunity was lost to share experiences and materials with other scholars engaged with international research.

The experience in India provided the researchers with the experience of working in a foreign culture, and they believe that overall, research practices should be tailored to the local environment. Special attention should be paid to time management; a researcher should be patient and prepared to take advantage of opportunities for productivity. In places like India, where crowded infrastructure can make it difficult to complete tasks, efficiency may come more easily if the study measures are coherent with the sensibilities of participants. Self-reported surveys allow the researcher to administer many simultaneously, but care must be taken that any translations make linguistic and cultural sense. As we improve our tools for surveys and assessments, the quality of participant responses and research results will increase. These efforts will better assure that our questions are measuring what we intend them too, by reducing confusions or misunderstandings among study participants. As a result, international research may advance the techniques of research methodology across spoken languages.

### **ACKNOWLEDGEMENTS**

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## BRIEF BIOGRAPHIES OF RESEARCHERS

**Nahom Beyene** received his BS in mechanical engineering from the University of Texas at Austin in 2002. He received an M.S. in Engineering: Biomechanical Engineering from Stanford University in 2004, and is currently a first-year student in the Rehabilitation Science PhD program at the University of Pittsburgh. Mr. Beyene has over five years of work experience with the NASA-Johnson Space Center in exercise hardware design and development. In addition to providing engineering and human factors support, he led a NASA team with collaboration from academia to conduct a study on the Advanced Resistive Exercise Device, which simulated skeletal loading in zero gravity.

**Alexandra Jefferds** received her Bachelor of Science in BioEngineering from the University of Pittsburgh. During her undergraduate term she worked on several research projects at the Human Engineering Research Laboratory. She collaborated on a project to research the long-term impacts of transfers on the upper extremities of manual wheelchair users with Dr. Alicia Koontz. More recently, she developed a web survey system to serve as a research tool for the collaborative development of a power wheelchair appropriate for India. Additionally, she continues to aid in the design of the Indian power wheelchair under Dr. Rory Cooper and Jon Pearlman as she pursues her master's degree in Rehabilitation Science and Technology from the University of Pittsburgh's School of Health and Rehabilitation Science.

**Jon Pearlman** received his BS in Mechanical Engineering from the University of California at Berkeley, his M.Sc. in Mechanical Engineering from Cornell University with a focus in Biomechanics, and his PhD in Rehabilitation Science and Technology from the University of Pittsburgh School of Health and Rehabilitation Science. He currently works as a faculty researcher at the Human Engineering Research Laboratories. His research focus is on understanding and improving assistive technology transfer to developing nations.