THE IMPACT OF ASSISTIVE TECHNOLOGY IN INDIA: SURVEYS, A WHEELCHAIR SKILLS TEST, AND A RESEARCH METHODS DELPHI

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Current assistive technology (AT) provision efforts in less-resourced environments rely on heuristic methods to monitor and improve service provision, instead of evidence-based practice (EBP) which has become standard in well-resourced regions. To introduce EBP methods, and evaluate the impact of technology on the lives of people with disabilities, we collaborated with clinicians at the Indian Spinal Injuries Centre (ISIC). Two studies were conducted using ISIC quality assurance data collected with our assistance. Based on our experience at ISIC, a third study was performed to investigate the challenges to international AT research, and develop strategies to overcome these challenges.

The first study was conducted with individuals receiving new AT from ISIC. The data consisted of a baseline PART survey and 6-month and 12-month follow-ups taken with a majority (92%) outpatient population. Thirteen clients completed all three questionnaires. Results showed trends toward increased community participation and life satisfaction over the 12-month period. ISIC is planning to expand its implementation of the PART survey, perhaps online.

The second study was conducted with individuals (69% inpatient) who received new wheelchairs from ISIC. The Wheelchair Skills Test and QUEST were administered before and after personal wheelchair provision. Seven clients completed a full set of pre-

and post-tests. Trends toward increased skill completion rates, increased skill attempt rates, and slightly increased safety scores were found. QUEST scores increased in the post-test, bringing scores close to values reported in literature.

The third study, conducted using a three-round Delphi method online, involved the participation of 13 experts in AT and rehabilitation research with experience working in low- and middle-income countries. During the first questionnaire round, participants were asked to identify domains of research that they considered the most challenging. In the second round, they were asked to rank and categorize the challenges as being either ethical or logistical, and also to suggest strategies to address them. In the final round, participants were asked to critique each strategy on its efficacy. Topics discussed included local collaboration, appropriate tools and techniques, translation, retention, compensation, and funding. Verifying the efficacy of suggested strategies could be the subject of future research.

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ACKNOWLEDGMENT

1.0 INTRODUCTION

The United Nations World Health Organization (WHO) recognizes that disability lies not solely within an individual's body, but in the way that that individual interacts with the environment ("UN Enable - Frequently Asked Questions," 2007). By that definition, the WHO estimates that 10% of the worldwide population has some type of disability, though in some less-resourced countries, this figure is estimated to be as high as 20%. Because disabilities can involve a number of bodily functions, wheelchair users and potential wheelchair users represent a subset of these figures. Existing wheelchairs are often inappropriate for the environments where they are used (Saha, Dey, Hatoj, & Poddar, 1990), and the provision of these chairs does not meet the needs of users (Mukherjee & Samanta, 2005). Obstacles to the worldwide provision of appropriate wheelchairs include lack of funding, lack of prescription and repair expertise, and government subsidies of inferior technologies (Kim & Mulholland, 1999). There is no easy solution to this problem of providing wheeled mobility to the estimated 20-150 million individuals worldwide (Deffner, n.d.; Hotchkiss & Knezevich, 1990) who do not currently have it.

1.1 WHEELCHAIR PROVISION

1.1.1 Provision models

Several approaches have been taken to providing wheelchairs in less-resourced countries. These include the "charitable model," "workshop model," "manufacturing model," "globalization model," and a fifth model that integrates aspects of the other four

according to the needs of local people (Pearlman, Cooper, Zipfel, Cooper, & McCartney, 2006).

In the charitable model, organizations donate wheelchairs in mass numbers to people in lower income countries. Some charities provide used wheelchairs with or without custom fitting and local repair efforts. The Free Wheelchair Mission (FWM) donates a proprietary wheelchair model that is mass produced in China and shipped throughout the world. The wheelchair, which can be distributed for about $52 USD, has a seat made from a plastic lawn chair. In recent years, a thin foam seat cushion has been included, though concerns about potential complications such as pressure ulcers remain. One study reported modest benefits to participation, pain, and skin health among recipients of FWM wheelchairs in India and Peru; however, this study was retrospective rather than longitudinal (surveys were not conducted before the wheelchair was received). The study found that only 11.7% of individuals used their wheelchair more than 8 hours/day (Shore, 2008). This is in contrast to American wheelchair users who have been found to spend an average of over 12 hours/day in their wheelchairs (Fitzgerald, et al., 2005).

Charitable donations of used wheelchairs have been criticized for providing technology that cannot be maintained locally, undercutting efforts to develop sustainable sources of wheelchair provision (Kim & Mulholland, 1999). Donated wheelchairs have been shown to be quickly abandoned or rarely used due to poor fit and comfort, rapid breakdown of chairs, and inaccessibility of the local environment (Mukherjee & Samanta, 2005).

Workshop and manufacturing model enterprises involve the establishment of local wheelchair fabrication facilities. They have the potential to be sustainable, produce wheelchairs that are less expensive than imported equipment, and provide employment for local wheelchair users (Kim & Mulholland, 1999; Pearlman, Cooper, et al., 2006). However, they are subject to local economic influences, including competition from charitable wheelchair donations. Individuals assisting with the establishment of these shops must be prepared to teach wheelchair building and seating skills using methods that effectively convey knowledge to members of the local community (Kim & Mulholland, 1999).

Under the globalization model, an established wheelchair manufacturer builds or imports wheelchairs in an emerging market. This model can be sustainable and effective provided the product and sale cost are appropriate for the local community (Pearlman, Cooper, et al., 2006). Finally, a "multi-modal" model combines various strategies according to what works in a particular region, and allows efforts to be scaled as is feasible. Under this model, the need for wheelchairs in a region may be addressed by a number of different providers using diverse approaches (Pearlman, Cooper, et al., 2006).

In addition to these models for technology distribution, there is the concept of universal design, the "design of products, environments, and services to be used by persons with a wide range of abilities, without needing adaptation or specialized design" (Williams, 2009). Personal mobility technology itself (such as wheelchairs) generally does not fall into this category, given that people without disabilities rarely have a use for it. However, the majority of technologies that people with disabilities (PWD) use or would like to use, such as public transportation, computers, and cell phones, are designed

for the general market. With proper design, mainstream technologies can serve individuals with varying abilities. Though universal design is not the focus of this thesis, it is an important way that technologies can become more useful to PWD.

1.1.2 Design efforts

There have been numerous efforts by researchers to design mobility technology appropriate for less-resourced environments. It is unknown how many have been successful over the years. We are most familiar with organizations and technologies that have a large presence in rehabilitation literature or on the internet. These include a ground level mobility device (Lysack, Wyss, Packer, Mulholland, & Panchal, 1999; Mulholland, et al., 2000; Mulholland, Packer, Laschinger, Olney, & Panchal, 1998; Mulholland & Wyss, 2001), a manual wheelchair (Zipfel, Cooper, Pearlman, Cooper, & McCartney, 2007), a pediatric tilt-in-space wheelchair (Zipfel, 2007), and a low-cost electric powered wheelchair (Pearlman, 2007), which were all designed with a focus on India. The ground level mobility device was turned over to local developers after the initial research (Susan J. Mulholland, MSc, BScOT, Faculty of Rehabilitation Medicine, University of Alberta, personal communication, Jun. 7, 2009). Freely available designs have made it obtainable in India and other countries such as Nepal, where it is produced (Joy Wee, MSc, MD, FRCPC, Queen's University, Providence Care, personal communication, Jun. 27, 2009). Several wheelchair designs appear in the book *Disabled Village Children* (Werner, 1987) and can be built with simple materials and techniques. Hope Haven's KidsChair wheelchair incorporates seating supports for individuals with varying postural needs ("Wheelchairs designed to fit each individual need," 2007).

Whirlwind Wheelchair International (for whom the author has worked in a limited volunteer capacity) has established itself as a network of independent wheelchair shops around the globe. Whirlwind's staff serves to integrate design concepts gathered from innovators throughout the network. The result has been a series of wheelchair designs intended for regions in Latin America, Africa, and Asia ("About Whirlwind: Mission Statement," 2004). A study to evaluate a wheelchair specifically designed for people in Afghanistan found that users ranked the study wheelchair significantly higher than their original wheelchair in ease of propulsion, stability, transportability, seating comfort, and appearance (Armstrong, Reisinger, & Smith, 2007). For many years, Whirlwind has offered a wheelchair construction class at San Francisco State University ("Engineering 699: Wheelchair Design & Development," 2006). Similarly, a class at MIT, "Wheelchair Design in Developing Countries" (SP.784), addresses the improvement of appropriate wheelchairs and mobility tricycles.

Motivation Charitable Trust, based in the United Kingdom (for whom the author has also worked in a limited volunteer capacity), contributes in mobility technology, advocacy, community employment programs, and training ("Our work," 2009). Motivation has created the Worldmade brand, a wheelchair provision process that combines mass production, flat packing, and on-site fitting. These chairs, though mass produced, are designed such that their configuration can be customized upon assembly. The Worldmade three-wheel wheelchair, which was designed with rural areas in mind, has customizable seat width, seat depth, backrest height, footrest height, footrest position, and drive wheel axle position.

Freedom Technology, a wheelchair and tricycle shop based in the Philippines, offers a comprehensive line of everyday, sport, geriatric, and pediatric wheelchairs as well as tricycles. The company values quality and appropriateness of its technology and has conducted user research to assess its products ("Freedom Technology," 2008). This research came to the conclusion that a tricycle may best benefit someone with limited walking or crawling ability, that the tricycle should be able to be used easily over rough terrain, that it should support the user and be ergonomic, that it should be configurable to be used with significant cargo, and that repair frequency and costs should be comparable to a standard bicycle (Mellin, 2007).

In Nicaragua, Mobility Builders focuses particularly on children with complex seating needs, many of whom come from the poorest of families. They use a combination of clinical evaluation, computer-aided design, and local wheelchair fabrication to bring mobility to these children. Mobility Builders is an offshoot of The Wheelchair Project, a broader organization that raises funds to buy wheelchairs for those in need, trains therapists, and advocates for children's medical care ("Mobility Builders," 2009).

1.2 USER RESEARCH

Many similarities exist between the needs of wheelchair users worldwide, such as the need for access, appropriate seating and mobility, and employment opportunities. However, the specifics are not universal. Infrastructure accessibility and employment opportunities vary widely, and the appropriateness of technology depends on the environment and aspects of local culture (e.g. where cooking is done). Thus, to properly serve PWD in a given location, it is important to understand the specific needs of individuals. The UN Convention on the Rights of Persons with Disabilities, which has

been ratified by 59 countries including India, mandates the provision of affordable, quality technologies and services to PWD, as well as the collection of statistics necessary support policies toward this population ("Convention on the rights of persons with disabilities," 2006).

Although proponents of the various provision models believe in the effectiveness of their own efforts, there exists little reliable evidence to indicate that one strategy is superior to another. Certainly, we have read praise for one type of wheelchair and complaints about another, but these are anecdotes and may not represent the totality of wheelchair provision outcomes. Stronger evidence would come in the form of quantitative data that evaluates many outcomes in a region over a period of time. Ideally, this evidence would be collected using a standard survey tool appropriate for widespread use, so that results could be compared across regions and service delivery techniques.

The thesis work presented here represents both an example of applying these evidence based practice (EBP) research methods to less-resourced environments, and a guide on how to streamline future EBP efforts. We performed this research in collaboration with clinicians at the Indian Spinal Injuries Centre (ISIC), with whom we have collaborated in the past on both research and technology development projects (Jefferds, Pearlman, & Cooper, 2007; Pearlman, 2007; Pearlman, Jefferds, Nagai, Chhabra, & Cooper, 2006; Zipfel, 2007; Zipfel, et al., 2007).

ISIC is one of a few locations in India where the clinical prescription of wheelchairs occurs. The Department of Assistive Technology (DAT) has collaborated with our laboratories for several purposes: a) to assess the impact of AT in India, b) to

improve clinical provision at the ISIC DAT by evaluating the effectiveness of its practices, and c) to pilot the collection of such data in less-resourced environments.

Community participation, life satisfaction, wheelchair skills, and technology satisfaction were studied among clients of ISIC who received new AT. Following the work in India, a Delphi study of the international/cross-cultural research process was performed with individuals experienced in AT or rehabilitation research and development.

We aim to improve the level of evidence available to support appropriate mobility technology. With this evidence, providers such as the ISIC DAT should be able to improve their quality of care and inform donors, providers, and designers about which AT makes the most impact on the people who use it.

2.0 PARTICIPATION AND LIFE SATISFACTION OF INDIAN WHEELCHAIR USERS

The purpose of this study was to investigate the community participation and life satisfaction of ISIC clients who use AT (primarily wheelchairs). We sought to determine whether a change in these metrics occurred in the year after an individual received a new piece of AT from ISIC.

2.1 INTRODUCTION

The World Health Organization (WHO) has taken a lead in promoting a holistic approach toward disability. The WHO's International Classification of International Classification of Functioning, Disability and Health (ICF) considers disability to be a result of the interaction between a person's body and the environment. Body functions, body structure, activity, and participation are taken into account. Because "an individual's functioning and disability occurs in a context" ("International Classification of Functioning, Disability and Health (ICF)," 2008), a person with a particular impairment will live a unique life depending on socioeconomic status, educational work opportunities available, perception of the impairment by others, and any number of other factors. Furthermore, the ICF recognizes the concept of *parity*, in which the repercussions of an impairment are largely independent of the cause of that impairment (e.g., limb losses due to landmines and illness have similar consequences) (Üstün, Chatterji, Kostansjek, & Bickenbach, 2003). The ICF was designed to complement the International Classification of Disease (ICD) system, which classifies health conditions without addressing the repercussions of those conditions.

Recently the WHO, in collaboration with a number of other international agencies, published a best practices guidebook for manual wheelchair provision (Armstrong, et al., 2008). The book emphasizes the effects of appropriate technology on the health and happiness of wheelchair users, supplementing provision information with profiles of individuals who have benefited from wheelchairs. The message of many of these anecdotes is that appropriate technology benefits participation in one's community.

In addition to the best practice evidence, substantial research has been done in the area of participation. Vissers et al. (2008) investigated barriers to physical activity after spinal cord injury (SCI). This study found evidence that the logistical needs of individuals with SCI dominate immediately following injury, while social, economic, and health maintenance issues dominate in the long-term. In other words, depending on the time since disability onset, different issues may predominantly influence physical activity. After self-care challenges become routine, physical and social public barriers seem most limiting. Similarly, Chaves et al. (2004) found that wheelchair users with SCI in two US cities identified mobility technology as the most limiting factor to overall participation, even above the physical impairment. Participants in this study were an average 14±9 years post-injury. Chaves' findings agree with those of Vissers, in that individuals accepted their physical impairments in time and became more frustrated with the inadequacies of available technology (the wheelchair) and infrastructure (concerning environmental accessibility, or that which the wheelchair cannot traverse). Other studies (Chan & Chan, 2007; Meyers, Anderson, Miller, Shipp, & Hoenig, 2002) have also identified AT and adaptations as facilitators to participation. Shoulder pain has been shown to correlate with decreased participation among men with SCI (Ballinger, Rintala,

& Hart, 2000) and standard practice guidelines recommend a customizable wheelchair that is as lightweight as possible to reduce the risk of upper extremity pain and injury (Armstrong, et al., 2008; Boninger, et al., 2005). Thus, there is an established influence of pain and barriers on participation, with technology as a known mediating factor.

To benefit the Indian population, with and for whom we have developed a number of wheelchairs, it is important to understand the influence of such technology on their lives. Though we suspect that appropriate technology has similar effects worldwide, factors such as the wheelchair user's physical environment, and the social role of the person with the disability, will likely influence what defines "appropriate" technology. A first step in gathering this information is to assess whether current AT provision practices in India have a positive benefit in the lives of consumers. Little data of this type has been collected to date due to the nascent state of clinical provision in India, though even if provision were commonplace, the data would not necessarily exist. Rehabilitation specialists working to establish quality care practices and technologies can improve their effectiveness by assessing their current strengths and weaknesses.

The PART questionnaire (Appendix B), used in this study, is an update to the CHART (Whiteneck, Charlifue, Gerhart, Overholser, & Richardson, 1992). The objective section collects information such as the frequency that the individual does certain activities (such as childrearing and involvement in community religious activities), while the subjective section asks people to rank the importance of and their satisfaction with certain aspects of their life (such as family relationships). The PART is currently in active development. The developers are currently exploring multiple scoring methods (Marcel Dijkers, Ph.D, Mount Sinai School of Medicine, NY, personal communication, May 15,

2009). A comparison of the PART (24 questions) and CHART (32 questions), seen in

Appendix C, revealed 7 questions that were identical or nearly identical in wording and

format, and could potentially be compared directly. There was also a set of 9 PART

questions that appeared similar to a set of 10 CHART questions (not all were one-to-one

linkages).

2.2 METHODS

A longitudinal repeated measures survey study was conducted through the analysis of

medical records of clients of ISIC who were new recipients of AT. We assisted with an

ISIC project to assess the quality of its AT provision services, and records from this

project were ultimately transferred to the University of Pittsburgh as de-identified

existing medical data (IRB#: PRO08030465). This project had originally been

conceptualized as a formal research study. However, difficulties securing Institutional

Review Board (IRB) approval, primarily due to concern about the written translation of

study materials, led to a restructuring of the project. US researchers and ISIC staff agreed

to implement the PART survey (this section), as well as the Wheelchair Skills Test and

QUEST survey (section 3.0) measures as a quality assurance project. Hospital clients

were enrolled in the project as they utilized the DAT's services (typically wheelchair

evaluation), though if they did not have time to complete the measures or were suspected

to not understand the questions, they were not included in the transferred dataset.

DAT clients were asked to complete intake forms (Appendix A) on demographic

data (sex, age, diagnosis/injury level, inpatient/outpatient status, and AT currently

owned). Contact information was collected directly into ISIC records as part of the

standard hospital intake. Upon completion of these documents, the clients provided

responses to questions in the PART questionnaire. Follow-up interviews (repeated PART questionnaires) were conducted by ISIC staff at 6 and 12 months after the baseline. The purpose of these follow-ups was to determine whether community participation and life satisfaction had changed in the year since technology was received from the DAT.

The PART scoring method used involved assigning a numerical value to each response using a scoring key, and then taking a numerical average of the objective and subjective sections. A multiple regression model was used to evaluate the influence of gender and rural/urban location on responses. Data normality was verified using Q-Q plots of the baseline, 6-month, and 12-month objective and subjective scores. These plots allowed for assessment of data normality with a low sample size. Regression models were built, controlling for gender, semi-urban vs. rural (S-R), and urban vs. rural (U-R).

2.3 RESULTS

Data were transferred for 24 clients who completed the baseline questionnaire, 14 who completed the 6-month follow-up, and 13 who completed the 12-month follow-up. This decrease in available data points was due to ISIC's lack of current contact information to contact some individuals for follow-up. All but one of the included clients had received a new wheelchair close to the time of the baseline survey. The remaining client had recently acquired an accessible vehicle. Seventeen (71%) clients were male. Their ages ranged between 19 and 67 (mean 36.4±14.8). Twelve (50%) had paraplegia due to SCI, 5 (21%) had tetraplegia due to SCI, and 7 (29%) had other conditions such as poliomyelitis and syringomyelia. The majority (92%) were outpatients, though some had been recently discharged from the hospital. Demographic information can be seen in Table 1. Scores

for the objective and subjective sections at the baseline, 6 months, and 12 months are

presented in Table 2.

Table 1. ISIC client PART survey demographic information.

		Number	Percent
All		24	
Sex	**M**	17	71%
	F	7	29%
Age	**18-29**	12	50%
	30-39	6	25%
	40-49	1	4%
	50-59	4	17%
	60+	2	8%
Diagnosis	**SCI (Para)**	12	50%
	SCI (Tetra)	5	21%
	Other	7	29%
Status at baseline	**Inpatient**	2	8%
	Outpatient	22	92%

Table 2. Mean PART scores at the baseline and follow-ups.

	n	Objective	Subjective
Baseline	24	1.91 (0.62)	6.99 (1.91)
6-month	14	2.38 (0.66)	6.52 (1.46)
12-month	13	2.45 (0.58)	7.07 (1.07)

R square values were higher (≈ 0.50) for the objective regression models than for

the subjective models (≈ 0.27). The best significance (values <0.1) could be found in the

objective urban-rural comparison coefficient (Table 3). For this calculation, there were 10

urban dwellers, 1 semi-urban dweller, and 2 rural dwellers.

Table 3. Analysis of regression models for B-6 (baseline to 6-month) and B-12 (baseline to 12-month) scores.

		R square	Gender Sig	SemiUrban-Urban Sig	Urban-Rural Sig
Objective					
	B-6	0.449	0.475	0.961	0.079
	B-12	0.520	0.875	0.881	0.032
Subjective					
	B-6	0.271	0.719	0.175	0.366
	B-12	0.275	0.208	0.887	0.197

Information about AT owned was collected at the baseline and the 6-month follow-up, but not at the 12-month. On average (mean and median), individuals owned more AT at 6 months than they had at the baseline. At the baseline, there was a trend toward higher objective scores with greater numbers of AT devices, and a marked higher subjective score with the individual who owned more than 10. At 6 months, there were slightly higher objective scores for individuals who owned more than 10 devices, and a trend toward higher subjective scores with greater number of devices (Table 4).

Table 4. Number of assistive technology devices owned, relative to PART scores.

# Devices		Baseline			6-month	
	n	Objective	Subjective	n	Objective	Subjective
<6	7	1.72	6.04	7	2.29	6.10
6 to 10	6	2.17	6.51	6	2.28	6.25
>10	1	2.65	9.25	2	2.93	7.70

2.4 DISCUSSION

Statistical analysis of the PART data indicates that urban/rural location partially accounted for variation in scores. In the objective section, those living in rural environments had higher participation scores. It is possible that some feature of rural environments, such as housing structure or availability of social supports, may be more conducive to participation. However, this apparent rural favor may also be due to participation bias; the two rural dwellers with whom the DAT staff was able to follow up may have a social or economic advantage that others lack. The rural/urban distribution present in this study was not representative of India as a whole, where the majority live in rural areas ("India Statistics (Demographics)," 2005) (a limitation of this study). However, the male majority was consistent with existing statistics on people with locomotors disabilities in India (Patel, 2009; Sarvekshana, 1991).

Modest increases in the objective scores indicated a trend that community participation increased. On the other hand, subjective scores decreased at 6 months and then returned approximately to baseline. Because the vast majority of clients were outpatients at the baseline, this cannot be attributed to the influence of a hospital stay. Overall, both objective and subjective scores improved over the course of 12 months, suggesting that the intervention of new AT may have improved their participation and life satisfaction. An analysis of the PART data suggests a population size of 32 would be required to achieve 90% power. The effect size at 6 months was calculated to be 0.6. Given that data for only 13 individuals were available at 12 months, the need for further quality assurance study of ISIC clients by DAT staff is indicated.

At baseline, most clients were outpatients who had been living in a community setting prior to their interactions with the DAT for this intervention. Some were outpatients recently discharged from ISIC and may still have been primarily concerned with self-care, as discussed by Vissers et al. (2008). By the 12-month follow-up, however, all had experience living in the community rather than the hospital. Average participation scores may have increased due to this shift of environment and client acclimation to life with a disability. Future research should record and explore the influence of time since disability onset on PART survey results.

A comparison of the number of AT devices owned with PART scores yielded a number of trends. There appears to be a correlation between higher scores and owning more AT, an effect which is most apparent when over 10 devices are owned. AT ownership appears to correlate more strongly with subjective scores (life satisfaction) than with objective scores (participation). Overall, these relationships may be due to a

positive impact that the AT has on the lives of those who own it (an influence indicated by existing literature). It may also be that individuals on a stronger financial footing may enjoy higher life satisfaction due to their economic status while simultaneously having the capability of purchasing more equipment.

Clients unavailable for follow-up were mainly from rural areas, indicating that it was more difficult for ISIC staff to contact this population. Some clients were reported to have no contact information in ISIC records, while the information of others may have changed. In India, mobile phone numbers are associated with the SIM card purchased, and a lapse in minute purchasing can result in loss of the number. If there were a way to provide participants of studies with prepaid cell phones guaranteed to last the duration of a study, this could place contact information changes more in the control of the researchers. Attrition and the resulting data biases are a problem in developed countries as well, where employed individuals are often reluctant to miss work for a study and unemployed individuals may have trouble accessing transportation to reach the study site (Bell, et al., 2008). In those cases, creative scheduling and electronic communication can improve recruitment and retention, again emphasizing the importance of reliable technology.

The PART questionnaire used in this study is a measure currently in development, and use of an established survey such as the CHART would have better facilitated comparisons to existing data. However, communications with Dr. Dijkers indicate that the PART has been formulated after careful analysis of the advantages and disadvantages of existing measures, and an understanding of the biopsychosocial influences on participation. It is likely that when the PART is validated and documented in literature, it

will be considered an improvement over current measures. Alternatively, the

Participation Scale (van Brakel, et al., 2006) could have been used, as it was developed in

India and other low-resource countries, and has been validated.

During use of the PART, we came to be aware of the fact that in the version of the

survey we had there, the PART answers were scaled to a key, and there was the potential

for an individual filling in the survey independently to misinterpret the scale. Consider

the following question:

> How many days in a week do you get out of the house?
>   1.   1-2 days
>   2.   3-4 days
>   3.   5-6 days
>   4.   7+ days

A person independently filling out the survey, who gets out of the house three

days a week, might write "3" as the answer, when in fact he or she answer might intend

"2," meaning "3-4 days." With concern for ISIC's ability to use the PART survey

efficiently, we experimented by giving two clients a reformatted PART that asked for

straight numerical answers (Appendix D). Both clients completed standard follow-ups.

Uncertainty about the validity of this reformat led to a deeper investigation about

the overall PART format. According to Dr. Dijkers, primary developer, the survey used

in India was in fact not properly formatted to begin with. The correct version used an

answer key categorized using letters, as below:

> How many days in a week do you get out of the house?
>   a)   1-2 days
>   b)   3-4 days
>   c)   5-6 days
>   d)   7+ days

It appeared that our concern about the format of the PART was warranted, but the

developer's solution differed from ours. As will be discussed in more depth in section

4.4, the use of survey tools and research methods appropriate for the studied population is crucial to the collection of valid data.

Since the original implementation of the PART at ISIC, the DAT staff have not continued its use with new clients due to time constraints in the provision process, but the staff are exploring alternate methods of deploying a participation survey (perhaps online) that would allow data to be collected efficiently among India's general disabled population. Such a survey could be publicized using the SCI-India Yahoo group ("SCI India - SCI Info Forum," 2009), which serves as an information and networking site for individuals in India with SCI. The use of online methods would introduce a socioeconomic bias to the data, but it would reach individuals who could not be reached in person as well as reduce the administrative load on ISIC DAT staff. Until the PART survey is validated, the CHART may be a better instrument with which to collect the needed data. CHART data could be directly compared with existing literature and provide a clearer overall picture of the impact of AT on the lives of users.

2.5 CONCLUSION

At ISIC, we assisted with the collection of PART data in a program intended to assess the DAT's effectiveness and pilot the collection of similar data in India and other countries. Logistical challenges experienced during the implementation of this study suggest that work is needed to reach more individuals and efficiently collect data. Electronic methods of communication (phones, internet) may prove useful in contacting populations difficult to reach in person.

Perceived difficulties such as those described above led the author to identify the need for a set of guidelines and strategies to assist individuals conducting AT research in

less-resourced countries. This was the motivation for the Challenges to International

Research Delphi described in section 4.0.

3.0 WHEELCHAIR SKILLS AND SATISFACTION OF INDIAN WHEELCHAIR USERS

The purpose of this study was to determine whether there is an immediate observable change in wheelchair skill and technology satisfaction in an individual who has received a custom-fitted wheelchair from ISIC, as compared to when he or she used a hospital-style wheelchair.

3.1 INTRODUCTION

The prescription of customized wheelchairs has become a practice, albeit uncommon, in India in the last 5-10 years. Most wheelchairs in India are acquired through vendors, government agencies, or charitable foundations without clinician input. They tend to be heavy, poorly designed, prone to mechanical failure, and do not allow their users to be independent or to move about efficiently with assistance (Mukherjee & Samanta, 2005; Saha, et al., 1990). Such wheelchairs are often inappropriate for the terrains within India. Many are manufactured locally, but chairs of similarly poor quality are also donated (Mukherjee & Samanta, 2005). Because the built environment of India is more challenging to wheelchair users than in western countries, and because many people live in undeveloped areas, wheelchair durability and stability are much more important than some charities and manufacturers may realize. In a recent study of Indian home accessibility by Pearlman et al., unstable surfaces, narrow doorways, steps, steep ramps, and inaccessible bathrooms were found to be some of the most frequent and challenging obstacles (Pearlman, Jefferds, Nagai, Chhabra, & Cooper, 2006). Several of these correspond with "community" skills described by developers of the Wheelchair Skills

Test (Kirby, 2008). Wheelchair skills performance (Kilkens, Post, Dallmeijer, van Asbeck, & van der Woude, 2005) and mobility level (Dijkers, Yavuzer, Ergin, Weitzenkamp, & Whiteneck, 2002) have been shown to increase participation, possibly due to individuals' increased ability to traverse physical barriers within the home and community. Though accessibility in India may be slowly improving, a much more immediate impact on participation could come through the provision of wheelchairs that allow the user to exercise better skills. Given the documented failings of poor quality wheelchairs, we hypothesized that individuals would demonstrate better proficiency using clinician-evaluated wheelchairs than they did using hospital-style wheelchairs. In this project, wheelchairs were categorized as being either "old/heavy/hospital" ($\approx$50 lbs., not fitted by a clinician, frequently inappropriate for user) or "active/fitted" (<35 lbs., fitted by a clinician, an educated guess at appropriate technology provision). Pictures of these two types of wheelchairs can be seen in Figure 1. If results support our hypothesis that custom-fitted wheelchairs provide users with increased independent mobility and technology satisfaction, this will provide evidence in favor of wheelchair distribution models that incorporate fitted chairs.

Figure 1. Top row: A hospital style wheelchair. Bottom row: Two types of wheelchairs available through the ISIC DAT.

The Wheelchair Skills Test (WST) was developed to fill a need for a standardized wheelchair proficiency instrument in research and rehabilitation (Kirby, Swuste, Dupuis, MacLeod, & Monroe, 2002). Version 4.1 consists of 32 skills ranging in difficulty from rolling the wheelchair and applying the brakes to ascending stairs. Participants are spotted on all skills. A rater judges whether the participant has passed or failed each skill, and whether failures occur safely or unsafely. It is not possible to pass a skill unsafely.

According to the manual (Kirby, 2008), several different percentage scores can be calculated. The Total Performance Score measures how many skills out of the total were passed, the Total Attempted Score measures how many skills out of the total were attempted, and the Total Safety Score measures how many skills out of the total attempted were awarded a safe score. Higher scores indicate more success at completing skills, attempting skills, and safely attempting skills, respectively. Formulas for these calculations can be seen in Equations 1-3. Additionally, the WST can be evaluated in the context of skills that a therapist believes are particularly relevant to an individual participant's rehabilitation goals.

Equation 1. Calculation of the Total Performance Score.
$$TotalPerformanceScore = \frac{TotalSkillsPassed}{TotalSkills} * 100$$

Equation 2. Calculation of the Total Attempted Score.
$$TotalAttemptedScore = \frac{TotalSkillsAttempted}{TotalSkills} * 100$$

Equation 3. Calculation of the Total Safety Score.
$$TotalSafetyScore = \frac{TotalSkillsSafe}{TotalSkillsAttempted} * 100$$

The Quebec User Evaluation of Satisfaction with assistive Technology (QUEST) 2.0 consists of 12 questions that are scored on a scale of 1-5, where 5 indicates highest satisfaction. There are two principal sub-sections: device, which contains 8 questions and addresses user satisfaction with the physical properties and utility of the wheelchair; and services, which contains 4 questions and addresses user satisfaction with the sale, information, and maintenance of the wheelchair. In addition, there is a third section that asks users to select from a list the three wheelchair characteristics that they consider most important. The contents of the list correspond to topics of questions in the device and

satisfaction subsections. The original QUEST 1.0 was found to be adequately sampled at the test level but with questionable line-item reliability (Demers, Wessels, Weiss-Lambrou, Ska, & De Witte, 1999). The revised QUEST 2.0 has been demonstrated to have good test-retest stability and to have fair to moderate correlation with the PIADS (Demers, Monette, Lapierre, Arnold, & Wolfson, 2002).

A selection of the literature suggests there are multiple strategies for scoring the QUEST. In a validation of the QUEST with a population of adults with multiple sclerosis, mean sub-scores for satisfaction with the device and for its services were calculated (Demers, et al., 2002). Other studies (Bergstrom & Samuelsson, 2006; Goodacre & Turner, 2005; Wessels & De Witte, 2003) used this technique as well. Typical scores from these sources were approximately in the 4.0-4.5 range for European AT users (Figure 11, Appendix E). Alternatively or in addition, a number of studies (Bergstrom & Samuelsson, 2006; Goodacre & Turner, 2005; Wressle & Samuelsson, 2004) calculated the mean of each individual question. These line-by-line scores ranged from approximately 3.5-4.5 for European AT users (Table 12, Appendix E). A third technique (Kirby, MacDonald, Smith, MacLeod, & Webber, 2008) was to calculate a summed score of survey responses, though scoring techniques were not described in detail and results did not appear comparable to other articles.

3.2 METHODS

The WST and QUEST were administered to clients of ISIC receiving new wheelchairs from the DAT. In addition to the client, three personnel were involved in each test: an evaluator, a spotter, and a translator (English and Hindi). After the WST was completed, the QUEST survey was conducted. If an individual was unable to respond to a question,

it was left blank. The WST and QUEST were administered to clients in their old personal (outpatients) or hospital-provided (inpatients) wheelchair. These measures were then repeated in the new wheelchair. No specific wheelchair training was given to the clients in the interim, though it was provided afterward if a client's schedule permitted.

WST evaluation and course setup were conducted as outlined in the WST manual (Kirby, 2008).The obstacle course was set throughout the physiotherapy department, hospital hallways, and on the ISIC grounds. Obstacles such as ramps, cross-slopes, and thresholds were identified in existing hospital terrain features. Others (steep ramp, pothole, etc.) consisted of wheelchair skills training equipment already at the hospital. Some, such as maneuvering paths (Figure 2), were constructed temporarily using small traffic cones placed on the floor.
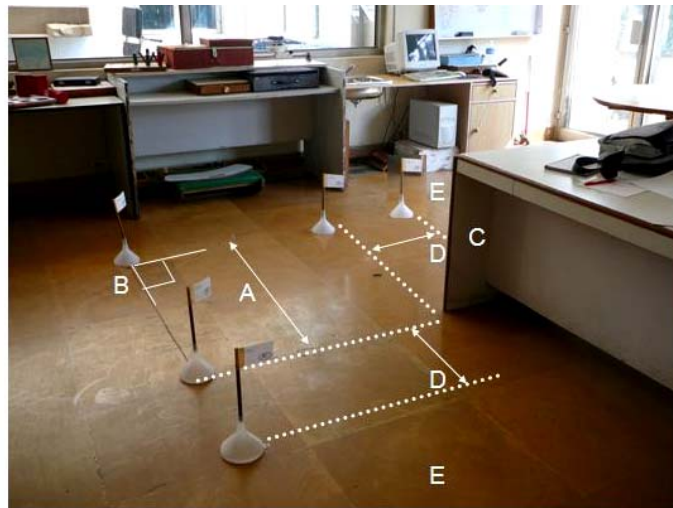
A. 1.2 m wide, smooth surface (marble tile)
B. 90 degree turns
C. Solid barrier
D. Start and finish line 0.5 m from corner
E. 1.5 m space before/after start and finish lines

Figure 2. The 90 degree corner turning obstacle, set up using cones on the floor.

Several different WST scores were calculated: 1) The Total Performance Score, documenting how many skills out of the total were passed; 2) the Total Attempted Score,

indicating how many skills out of those attempted were passed; and 3) the Total Safety

Score, indicating how many skills out of the total attempted were awarded a safe score

(Kirby, 2008). Both the subsection (Bergstrom & Samuelsson, 2006; Demers, et al.,

2002; Goodacre & Turner, 2005; Wessels & De Witte, 2003) and line-by-line (Bergstrom

& Samuelsson, 2006; Goodacre & Turner, 2005; Wressle & Samuelsson, 2004) methods

were used to score the QUEST. The first scoring method was used to compare pre- and

post-test scores, while the second method was used to identify the individual factors

which contributed to the overall differences between time points. These approaches were

taken based on an understanding of the purposes of each scoring method; the subsection

method allows for general comparisons of technology satisfaction between time points or

groups, while the line-by-line method can be used to examine responses in individual

domains such as safety and wheelchair effectiveness.

3.3 RESULTS

Of the 34 clients who received a new wheelchair from ISIC during March and April, 13

completed at least one set of WST and QUEST. Eight (62%) clients were male. Their

ages ranged between 21 and 60 (mean 33.0±12.2). Eight (62%) had paraplegia due to

SCI, 2 (15%) had tetraplegia due to SCI, and 3 (23%) had other conditions such as a

combination of SCI and traumatic brain injury (TBI). The majority (69%) were

inpatients. Client demographics can be seen in Table 5.

Table 5. WST/QUEST demographics.

		Number	Percent
All		13	
Sex	M	8	62%
	F	5	38%
Age	18-29	7	54%
	30-39	3	23%
	40-49	2	15%
	50-59	0	0%
	60+	1	8%
Diagnosis	SCI (Para)	8	62%
	SCI (Tetra)	2	15%
	Other	3	23%
Status	Inpatient	9	69%
	Outpatient	4	31%

At the time that data were transferred, 7 clients had successfully completed a full set of pre- and post-tests. Of these 7 individuals, 5 (71%) were male. Their ages ranged between 21 and 60 (mean 35.1±14.5). Five (71%) had paraplegia due to SCI, one (14%) had tetraplegia due to SCI, and one (14%) had both paraplegia due to SCI and a TBI. Most (5, 71%) were inpatients. Demographics of these clients can be seen in Table 6.

Table 6. WST/QUEST demographics for complete client data.

		Number	Percent
Complete		7	
Sex	M	5	71%
	F	2	29%
Age	18-29	4	57%
	30-39	1	14%
	40-49	2	29%
	50-59	0	0%
	60+	0	0%
Diagnosis	SCI (Para)	5	71%
	SCI (Tetra)	1	14%
	Other	1	14%
Status	Inpatient	5	71%
	Outpatient	2	29%

Interval time between the initial and final data collection was determined by client schedule and date of wheelchair receipt, and ranged from 7-19 days (mean 12). Data from the seven clients with complete data formed the basis for the direct pre-post comparison. Clients with less than the complete set of data were analyzed according to the category of wheelchair used (old/heavy/hospital or active/fitted).

Total Performance Score (TPS), the Total Attempted Score (TAS), and Total Safety Score (TSS) averages for the seven pre/post clients can be seen in Table 7 and Figure 3. TPS scores increased in all cases, as did TAS scores. TSS scores increased on average but decreased in the case of two individuals.

Table 7. Total Performance Score, the Total Attempted Score, and Total Safety Score averages for the Wheelchair Skills Test.

	TPS Pre	TPS Post	TAS Pre	TAS Post	TSS Pre	TSS Post
1	50.00	59.38	53.13	65.63	53.13	62.50
2	68.75	62.50	71.88	75.00	71.88	65.63
3	68.75	71.88	75.00	81.25	75.00	78.13
4	34.38	53.13	46.88	62.50	43.75	53.13
5	59.38	62.50	71.88	68.75	68.75	65.63
6	18.75	25.00	46.88	53.13	46.88	53.13
7	65.63	78.13	75.00	84.38	75.00	81.25
Mean	52.23 (19.24)	58.93 (17.06)	62.95 (13.31)	70.09 (10.95)	62.05 (13.67)	65.63 (10.97)
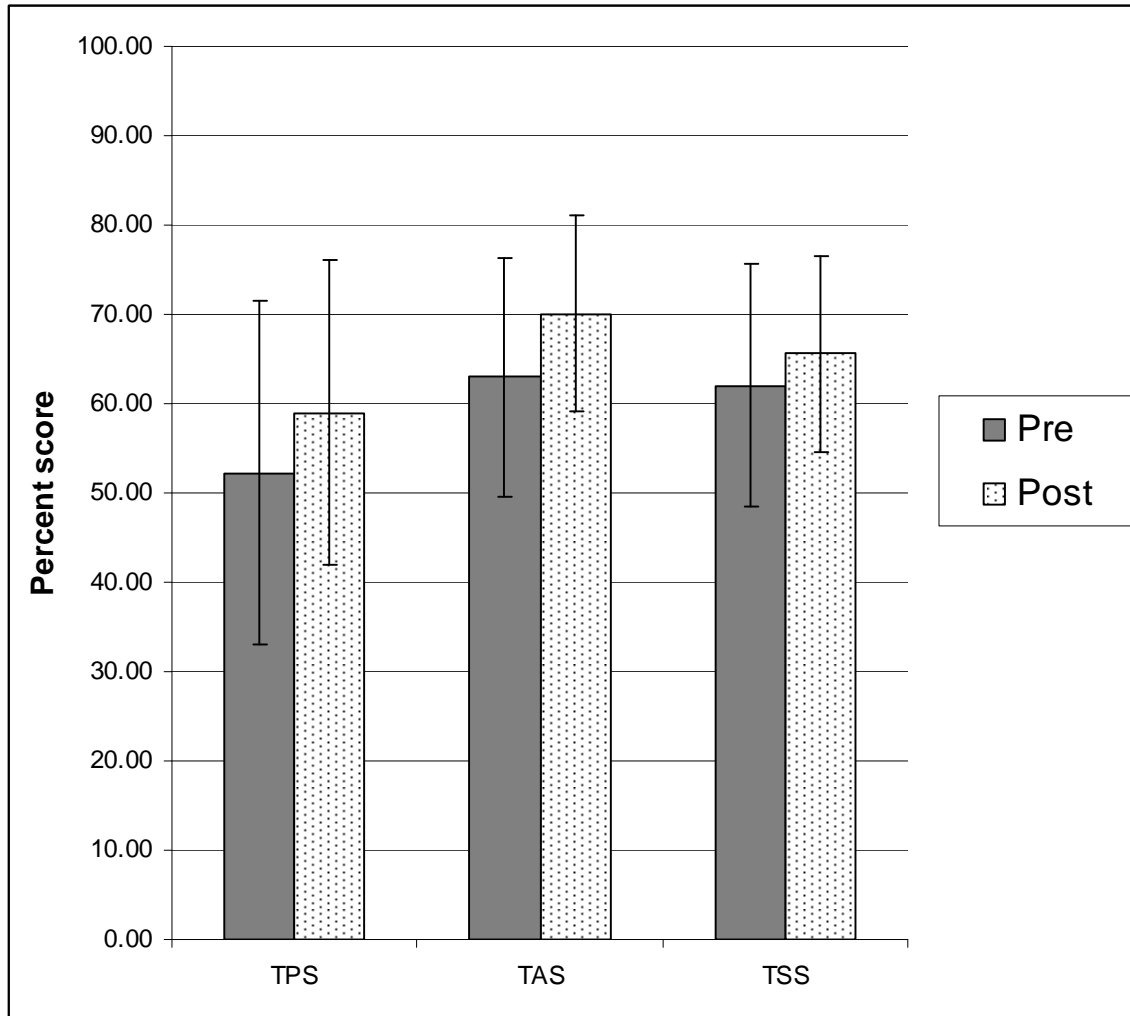
Figure 3. Total Performance Score (TPS), the Total Attempted Score (TAS), and Total Safety Score (TSS) averages for the Wheelchair Skills Test.

The scored results of the post-test wheelchair skills as clinical goals can be seen in Figure 4. Successful completion of these participation-relevant skills became less frequent as the skills increased in difficulty. All individuals were able to roll across a soft surface. Most could traverse a door, a threshold, and a cross slope, and perform a level transfer. Some could descend a 5cm level change and a pothole. None were able to traverse a 15 cm level change or ascend a 5cm level change.
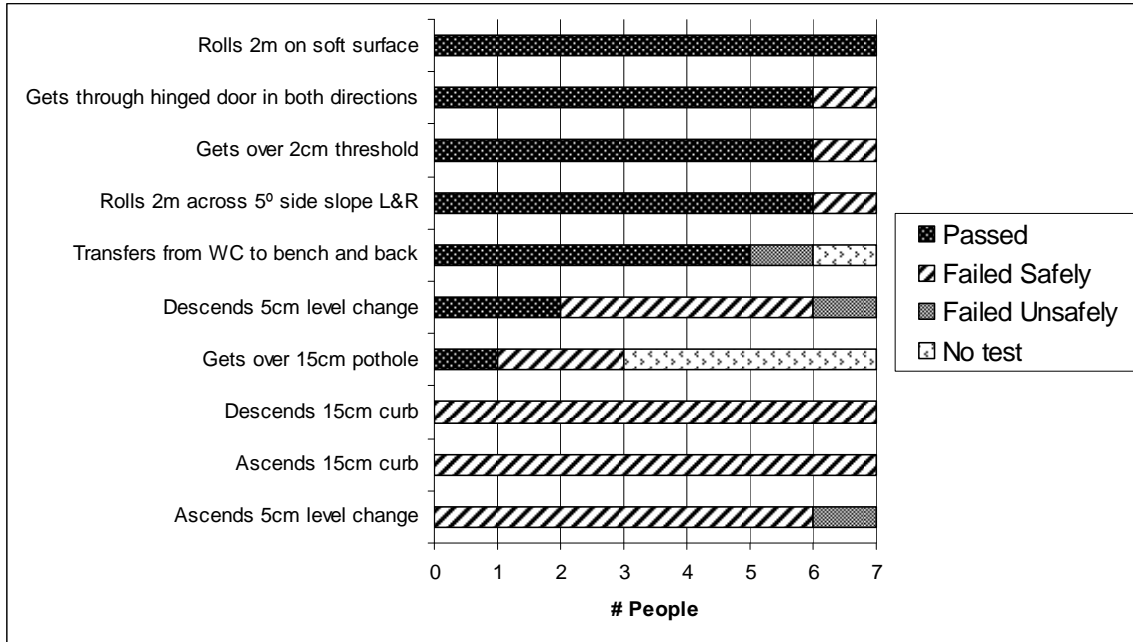
Figure 4. Scored results of individual wheelchair skills, as clinical goals.

Respective device and service subsection scores for the QUEST can be seen in Table 8. Pre-test scores averaged approximately 2.7 (out of 5) for both the device and services subsections, although other users of hospital-style wheelchairs rated them higher. Post-test scores averaged 3.44 in the device domain and 2.93 in the services domain; other users of fitted wheelchairs provided higher scores.

Table 8. QUEST subsection results for complete data points as well as incomplete old/heavy/hospital (O/H/H) and active/fitted (A/F) points.

	Device	Services
Pre-Test (O/H/H)	2.72 (1.02)	2.69 (0.63)
Post-Test (A/F)	3.95 (0.77)	4.21 (0.83)
O/H/H (incomplete)	3.44 (0.92)	2.93 (1.59)
A/F (incomplete)	4.44 (0.44)	4.00 (0.45)

In addition, the line-by-line scores of the pre- and post-prescription QUEST surveys can be seen in Table 9. Fewer service-related questions were completed, though this trend was diminished in the post-test. There appeared to be little correlation between

the line-by-line scores and wheelchair characteristics that the clients identified as most

important (Table 10).

Table 9. QUEST line-by-line results.

	Pre-test				Post-test			
	n	Mean	Min	Max	n	Mean	Min	Max
Dimensions	7	2.71 ± (1.70)	1	5	7	4.00 ± (1.41)	1	5
Weight	7	2 ± (1.00)	1	3	7	4.00 ± (1.15)	2	5
Adjustability	5	2.2 ± (1.30)	1	4	6	3.67 ± (1.03)	2	5
Safety	7	3.29 ± (1.25)	2	5	7	4.14 ± (0.90)	3	5
Durability	5	3.2 ± (1.48)	1	5	6	4.00 ± (0.63)	3	5
Easy to Use	7	2.43 ± (1.40)	1	5	7	4.29 ± (0.76)	3	5
Comfort	7	2.71 ± (1.25)	1	5	7	3.86 ± (1.07)	2	5
Effectiveness	6	3.17 ± (1.72)	1	5	7	3.86 ± (1.07)	3	5
Service Delivery	5	3.6 ± (1.34)	2	5	7	4.23 ± (0.79)	3	5
Repairs/ Servicing	4	3.25 ± (1.50)	2	5	6	4.33 ± (1.03)	3	5
Professional Service	4	3.5 ± (1.29)	2	5	7	4.00 ± (1.00)	3	5
Follow-up Service	4	3 ± (1.63)	1	5	3	4.33 ± (1.15)	3	5

Table 10. Reported frequency of preferred wheelchair properties, and the mean scores of the corresponding questions.

	Frequency (Pre-test)	Mean (Pre-test)	Frequency (Post-test)	Mean (Post-test)
Easy to use	22	2.43	6	4.29
Comfort	15	2.71	6	3.86
Safety	14	3.29	3	4.14
Effectiveness	10	3.17	2	3.86
Weight	8	2.00	1	4.00
Dimensions	7	2.71	2	4.00
Adjustments	2	2.20	1	3.67
Durability	2	3.20	0	4.00
Follow-up services	1	3.00	0	4.33
Service delivery	0	3.60	0	4.23
Repairs/servicing	0	3.25	0	4.33
Professional service	0	3.50	0	4.00

3.4 DISCUSSION

Though the results were not significant, there was a trend toward better scores on the

WST after the wheelchair prescription. On average, clients successfully completed more

skills in the post-test, as demonstrated by the 6.7% increased mean Total Performance Score[1]. In addition, individuals attempted more skills in their new wheelchairs (7.1%). The fact that individuals were willing to attempt more skills speaks to the immediate benefits of a fitted wheelchair; even though clients were not necessarily capable of performing more skills, they recognized that they were now in wheelchairs that permitted such skills. Safety scores increased overall by 3.6%, though the scores of some individuals decreased. Skills that most commonly became unsafe in the post-test were those that involved ascending ramps and curbs (rear tipping). This is not unexpected because fitted wheelchairs are often less stable than hospital wheelchairs due to a more forward axle position which shifts the user center of gravity relatively further back. The lightweight wheelchairs provided by ISIC typically come with anti-tippers, but the ultralight models do not. Larger safety increases might have been observed if the post-tests had been conducted later, after clients had become accustomed to their new wheelchairs. An examination of the construct validity of the WST indicated that wheelchair users with more than 21 days' experience performed significantly better than those with less than this amount (Kirby, et al., 2004). ISIC clients who fell within this 21-day window might demonstrate a learning effect between pre- and post-tests in addition to the effect of the wheelchair, while long-term wheelchair users would probably only demonstrate an effect due to differences in wheelchair characteristics.

A wheelchair skills training program (WSTP) for hospital clients would allow a user to make the most use of the maneuverability benefits of the fitted wheelchair while optimizing safety. Such a program exists and was trialed at ISIC prior to this study (Kirby & Cooper, 2007), and infrequent training sessions continue to occur. However, the DAT

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[1] Percentages reported are absolute and refer to values calculated using Equations 1-3.

at ISIC is small and staff members have very full schedules. Greater implementation of the WST and WSTP would likely require the addition of staff whose primary job tasks involved the application of these tools. Currently, there is one wheelchair skills trainer who volunteers at ISIC for several months of the year but who lives abroad for the remainder of the time. The QUEST, because it is a survey rather than a test or program, might be more easily integrated into the DAT program without staff increases.

In addition to the work load imposed by the WST and WSTP on DAT staff, we observed that clients did not remain in the hospital with their fitted wheelchairs long enough to have attended many training sessions. If wheelchair training was given to clients, it usually occurred only after they had received their new wheelchairs. Frequently, however, clients were discharged from the hospital shortly after fitting of the new wheelchair. In general, ISIC inpatients might benefit from receiving their own wheelchairs earlier rather than later, though such a modification of practice would have to be considered in the context of other factors such as changing user needs during the rehabilitation process.

The accessibility-related skills (Figure 4) were scored using the post-tests, because these were indicative of the skills that the clients went home with (and were therefore relevant to individuals' interactions with the home environment). An analysis of these skills suggests that clients were more competent wheeling on flat ground than they were on level changes (e.g. thresholds, curbs, steps). Most could traverse soft ground, a 2cm threshold, and a side slope, but successful completion of skills such as curb ascent and descent was much less common. Transfer skills might allow for the use of western style toilets, while skills in traversing tight spaces might allow more use of available

environments. However, Indian-style floor toilets remain challenging or impossible for wheelchair users, and doors are often simply too narrow for the wheelchair to fit through.

The QUEST results show a trend toward increased satisfaction with new wheelchairs. Each line-by-line score was higher in the post-test than in the pre-test, and post-test scores were in similar ranges to scores reported in existing literature for European populations (Appendix E). These increases indicate that participants were more satisfied with the technology and corresponding services associated with their new, fitted wheelchairs.

In addition, response frequency increased with the new wheelchairs, especially in the services subsection, possibly reflecting optimism and confidence in the services that would be provided for their own wheelchairs. Clients rated the service-related skills no higher in importance than they had in the pre-test, perhaps reflecting the reality that little wheelchair service is available throughout India. Use of the QUEST with community-based Indian populations might yield low service subsection responses such as the ones observed in the pre-tests presented here.

The wheelchair characteristics most frequently preferred by clients were "easy to use," "comfort," and "safety," followed by "effectiveness," "weight," and "dimensions." There appears to be a slight de-emphasis on wheelchair utility, as effectiveness was fourth in the list. This list may reflect the fact that the majority of inpatient clients completed the QUEST before discharge from the hospital (where accessibility is not an issue, and assistance is available from hospital employees). Thus, clients did not anticipate that "repairs/servicing" or "durability" would be high priorities, although these attributes were considered highly important by content experts (Demers, et al., 1999). If a

follow-up QUEST were conducted after individuals had lived with their wheelchair at home for some time, rankings might differ. A change in social role due to the acquired disability, or an improved understanding of accessibility and the need for wheelchair repair, could adjust an individual's preferences. Needs may become apparent as consumers become more familiar with the benefits and drawbacks of different types of wheelchairs. In addition, peer counseling and exposure of users to various types of wheelchairs could influence preferences.

An analysis of the WST data suggests a population size of 33 would be required to achieve 90% power, while the QUEST data suggests a population of 13 would be necessary to achieve 90% power. Due to the small sample size in this study, it was not possible to account for the numerous confounding factors that may have influenced the results of both the PART and WST/QUEST studies: gender, rural/urban location, follow-up losses, time lived in the community, and types of AT acquired at ISIC.

The results of this study suggest that the use of an individually fitted wheelchair may immediately improve the skills and satisfaction of Indian users. If evidence such as this were collected and applied across India toward more widespread availability of active/fitted wheelchairs, users might gain improved skills, satisfaction, and potentially, community participation.

Evidence collected at ISIC may already have benefited the people of India. The Ministry of Social Justice and Empowerment's ADIP Scheme has granted ISIC funds to distribute clinician-evaluated wheelchairs to PWD. Each individual is allocated the equivalent of approximately $125 USD for a wheelchair, orthosis, or other piece of AT, and there is some leeway to justify shifting funds from one person's less expensive item

to pay for another's more expensive one. ISIC has begun holding three-day distribution camps each month, and will try to extend the ADIP scheme's support when the current six month term expires. Individual outcomes of this distribution are not being tracked due to time constraints during the camps. Upon ISIC's recommendations (supported by the findings presented here), wheelchair recipients under this program will receive foreign-purchased wheelchairs rather than the ones currently manufactured by the government agency ALIMCO, which cannot be custom-fitted. The Ministry of Social Justice and Empowerment appears to regard ISIC as an expert resource for rehabilitation and is receptive of the hospital's advice with regard to its disability policies (Nekram Upadhyay, MS, New Delhi, India, personal communication, July 1, 2009). This positive relationship could serve as an important channel for implementing future research findings in India, and thus improving the lives of PWD there.

3.5 CONCLUSION

The provision of custom-fitted wheelchairs to clients of ISIC appears to immediately increase the wheelchairs skills of those individuals. Clients attempted more skills in their new wheelchairs and consequently safety scores decreased among some individuals. To allow clients to make optimal use of their fitted wheelchairs, provision should be coupled with more extensive wheelchair skills training than they currently receive. Inpatients may therefore benefit from receiving their personal wheelchairs earlier in the rehabilitation process. Post-test QUEST scores were comparable to those in European literature, suggesting that the wheelchairs and associated services provided by ISIC were perceived as an improvement over what clients had previously received.

We were able to conduct this assessment of the impact of ISIC's wheelchair provision by assisting the hospital implement the WST and QUEST. The structure of the completed project differed from its original conceptualization as U.S.-based research with hospital collaboration. This change occurred due to difficulties securing IRB approval for it and the PART project. The Challenges to International Research Delphi (section 4.0) was formulated to explore the challenges others had encountered while conducting international AT research.

4.0 CHALLENGES TO INTERNATIONAL RESEARCH DELPHI

The purpose of this research study was to survey individuals with experience conducting AT research in low- to middle-income countries, to determine the most challenging aspects of this type of research and collect strategies to address these challenges.

4.1 INTRODUCTION

Evidence-based practice (EBP) incorporates the best evidence currently available in a healthcare field for the purpose of improving patient care. Strout et al. (2009) describes a "synergy" between research findings, clinician expertise, and client values. Often the motivation for improving practice using these resources is to save on healthcare costs (Brauer & Bozic, 2009). AT professionals in North America have incorporated best evidence into position papers on certain wheelchair technologies (Arva, et al., 2007; Arva, Schmeler, Lange, & Lipka, 2005; Dicianno, et al., 2008). In addition to having educational purposes, these papers are intended to help clinicians obtain approval from funding sources (Arva & Schmeler, 2006).

A large disparity exists between the developed and the developing worlds in terms of access to the health information necessary for good EBP. According to Godlee et al. (2004), to close this gap, less-resourced countries must "pull" information rather than rely on others to "push" it at them. In other words, the development of sustainable, growing health resources within a country is the best way to encourage information flow there. Hence, researchers from the developed world who participate in projects elsewhere can have a large impact by involving in-country collaborators, with the intention of building local sustainability.

However, differences in values, culture, or research practices between visiting researchers and the local population can introduce challenges to the effective collection of data. According to Dawson and Kass (2005), research methods may need adaptation to be effective and ethical in non-western cultures, a fact which research practice guidelines and ethics committees are sometimes slow to acknowledge. Informed consent, which is a *process*, may need to be adapted to fit various contexts. For example, illiteracy impedes the understanding and signing of consent forms. Even literate individuals may find consent forms too wordy, technical, or overwhelming (Dawson & Kass, 2005; McIntosh, et al., 2008). In the Dominican Republic, a signature represents a much stronger contractual agreement than is intended by a consent form (McIntosh, et al., 2008). In settings where privacy of the individual is considered less important than community decision-making, values held by a far-off IRB could come into conflict with values held by the local community. According to Paz & Blair (2006), a culturally-sensitive consenting process is the only way to ensure that consent is "truly informed."

Study methodology and measures must be appropriate for the local research environment. The universality of Likert scales has been questioned (Dévieux, et al., 2005; J. W. Lee, Jones, Mineyama, & Zhang, 2002; Weech-Maldonado, Elliott, Oluwole, Schiller, & Hays, 2008), and it is challenging to achieve survey equivalence during translation (Schmidt & Bullinger, 2003; Sperber, Devellis, & Boehlecke, 1994); Cha, Kim, & Erlen (2007) developed a method of translation that is practical with a limited number of translators. Other types of observation must also be attuned to local culture. For example, developers of AT should explore whether the primary purpose of AT ought

to be independence of the user (a western value), or quality of life in the context of a communal living dynamic (Mulholland, et al., 1998).

The resources available to local populations can also impact studies. Retention can be affected when migrant individuals lack contact information (Prabhaka & Thakker, 2003). As discussed in section 2.3, a similar experience influenced our data, with ISIC clients who could not be contacted via house location, phone number, or email address. Additionally, the skills of local mechanics and the availability of parts can affect the appropriateness of an AT device (Mulholland, et al., 1998). Government and infrastructure also play a role. Lack of adequate health care in a region can make care for those with disabilities of low priority (Boone, 1995). Limited storage space in small clinics can compromise data confidentiality, and the remoteness of some research sites can make it difficult for researchers to include certain populations (Paz & Blair, 2006).

Though not a study of international research, an article by Mann, Hoke, and Williams (2005) reported on challenges to research among Mexican-American women, a group whose culture differed from that of the researchers. The article describes communication of the value researchers place on participation, respect for the difficulties of maintaining confidentiality in a tight-knit community, extensive recruitment and retention concerns, cultural aspects of translation, accommodation of the children who frequently accompany women participants, and the anticipation of technical difficulties with research equipment. The depth of the discussion suggests a thorough understanding of the target population with whom the research strategies were employed. This article may be of particular importance to those attempting to include women in research, a

process that can be difficult even for those who intend to recruit a representative study population (Armstrong, et al., 2007).

The literature above explores numerous ethical and logistical challenges to international and cross-cultural research. Although many of these are likely relevant to AT and rehabilitation, no study has been published which identifies the challenges most urgently problematic in this field. Such a prioritization could drive formal study and impact EBP. Currently, the best source of knowledge about the challenges to this type of research may be the individuals who have experience conducting it. Though information collected from this population would be anecdotal, more controlled research studies could follow to confirm results.

The Delphi method was used to gather such information from individuals with expertise in international mobility technology research. In healthcare, Delphi studies have been used to identify core sets of the International Classification of Functioning, Disability and Health for various health conditions (Bauernfeind, et al., 2009; Finger, Cieza, Stoll, Stucki, & Huber, 2006; Hoppestad, 2006), determine predictors of whiplash-related pain and disability (Miró, Nieto, & Huguet, 2008), compile a list of effective self-help treatments for depression (Morgan & Jorm, 2009), and strategize to improve communication between general practitioners and rehabilitation specialists (Beaumont, 2003). Thus, there is a record of the Delphi method being used to gather information from healthcare professionals and consumers.

The Delphi method was developed as a means to integrate the insights of a group to form a prediction more accurate than could be developed by an individual (Stewart, 1987). A Delphi study is an anonymous focus group that takes place in the form of a

number of surveys. The same participants contribute to all rounds. Because participants are mutually anonymous, issues of ego and reputation may be avoided, theoretically yielding more honest answers. There is no consensus about ideal panel size. Powell (2003) suggests that Delphi benefits most from quality (expertise and commitment of participants) regardless of quantity. Additionally, Delphi literature does not define a standard level of consensus (Hoppestad, 2006; Hung, Altschuld, & Lee, 2008). Values of 75%-80% (within a response bracket such as the interquartile range or above a particular Likert rating) appear typical in medical literature (Finger, et al., 2006; Miró, et al., 2008; Morgan & Jorm, 2009).

Each survey round is based on responses from the previous round, and participants are shown interim results to contextualize the current task. Using this method, the researcher can direct the flow of ideas toward a specific goal. In our case, the goal was to identify significant challenges to international AT and rehabilitation research practice, and identify potentially beneficial strategies to address these challenges.

4.2 METHODS

The research was approved by the University of Pittsburgh IRB as an exempt study (PRO08080282). It was conducted entirely online (http://www.surveymonkey.com), which allowed us to quickly recruit and enroll participants worldwide. No compensation was provided. Individuals with experience conducting AT-related research or technology development internationally (particularly in low- and middle-income countries) were identified for recruitment. Some were authors of papers that were found through a literature search; terms included "disability," "research," "cross-cultural," "less-resourced," "international," "developing countries," "challenges," "obstacles," and

"barriers." From the articles found, 9 authors were identified. Other participants were selected based on the researchers' knowledge of colleagues in the AT field.

In the first round (Appendix F) of the study, participants were presented with twelve domains of international AT research and were asked to choose the five that they considered most challenging. These twelve domains were based on challenges identified in the literature search and researchers' understanding of the research process. They included: participant recruitment; collection of informed consent; retention and follow-ups; communication with participants; collaboration with local researchers; working with local business, craftspeople, and infrastructure; use of appropriate research tools and techniques; protection of participant privacy; time management; daily living in the locale; and funding. An "other" category was included. "Seeding" a consensus study from literature has been done previously to focus and eliminate redundancy in the questionnaires (Spaar, Frey, Turk, Karrer, & Puhan, 2009; Tran, et al., 2008). Doing so reduces the work load on both participants and researchers.

The most frequently chosen domains were used to form the second round (Appendix G). In this round, participants were asked to rank the domains from least to most challenging. Participants were also asked to classify each challenge as either an ethical or a logistical issue, and to suggest strategies they had used to overcome them. The suggested strategies were analyzed using qualitative research software.

The third round (Appendix H) asked participants to respond to a selection of previously suggested strategies chosen by the researcher for their specific potential for discussion or contention (in contrast to sentiments that the researcher had observed to be expressed by the majority of participants). Participants were asked whether they had used

a particular strategy, whether the strategy had helped, and whether they believed that the strategy would help in general.

Participation in this study lasted approximately 2 months. A flowchart of the rounds can be seen in Figure 5.
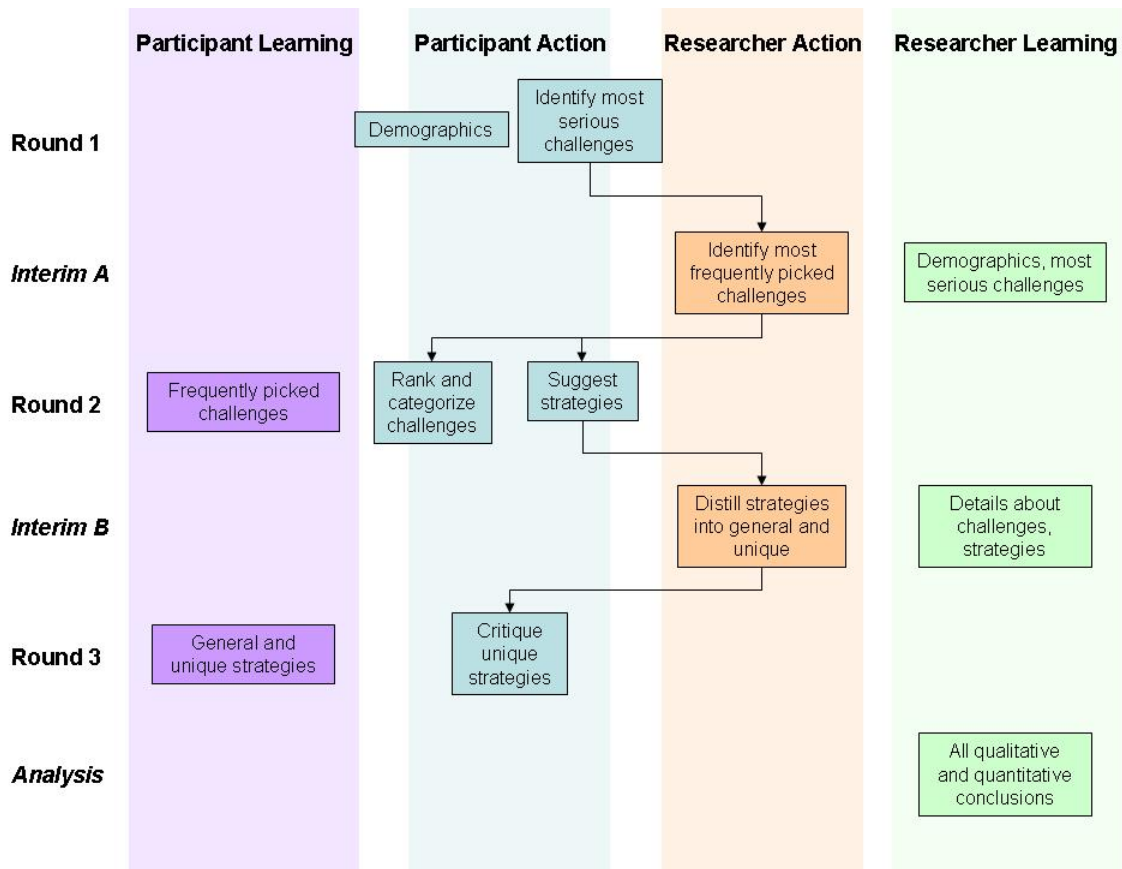
Figure 5. Flowchart of the three rounds of the Delphi survey.

4.3 RESULTS

During recruitment, the 32 individuals sent invitation emails were expected to be eligible due to their reputations, publications, or personal connections to researchers. Sixteen individuals responded to the email; two declined because they deemed themselves unqualified, and one agreed to participate but never completed the first round survey. Ultimately, 13 individuals participated in all three survey rounds. The participants lived

in the USA (6), India (2), South Africa (2), Canada (1), China (1), and Norway (1), and frequently had experience researching in countries other than their own. Eight (62%) reported at least 6 years of research experience, and 3 (23%) reported at least 11 years of experience. The majority (62%) had performed at least 40% of all their AT research in less-resourced countries. They reported various internal and public uses for their research findings.

In the first round of the study, each participant chose five domains of research that he or she found challenging. Domains were binned according to response frequency, with the median of 6 the cutoff (Figure 6). The low response bin ($n<=3$) included the domains of participant recruitment; collection of informed consent; working with local business, craftspeople, and infrastructure; protection of participant privacy; and daily living in the locale. The high response bin ($n>=6$) included retention and follow-ups; communication with participants; collaboration with local researchers; use of appropriate research tools and techniques; time management; and funding. At least 60% (3 of 5) of each participant's chosen domains were in this high bin. On average, participants were 74% in agreement with the high bin domains, though the percentage varied according to several demographic characteristics (Table 11).

Table 11. Percent agreement with the high bin in round 1, according to demographic variables. Percentages consider the "other" category a low bin domain.

		n in category	% high bin agreement
Overall		13	74%
Country of origin	Western	8	83%
	Non-western	5	64%
Experience conducting AT research in less-resourced countries	0-5 years	5	64%
	6-10 years	5	76%
	11-20 years	1	80%
	21-30 years	2	90%
% research done in less-resourced countries	0-20%	2	80%
	21-40%	3	80%
	41-60%	3	73%
	61-80%	1	80%
	81-100%	4	65%
Purpose of research	Keep for internal use	2	90%
	Publish	3	60%
	Both	4	70%
	Other	4	80%
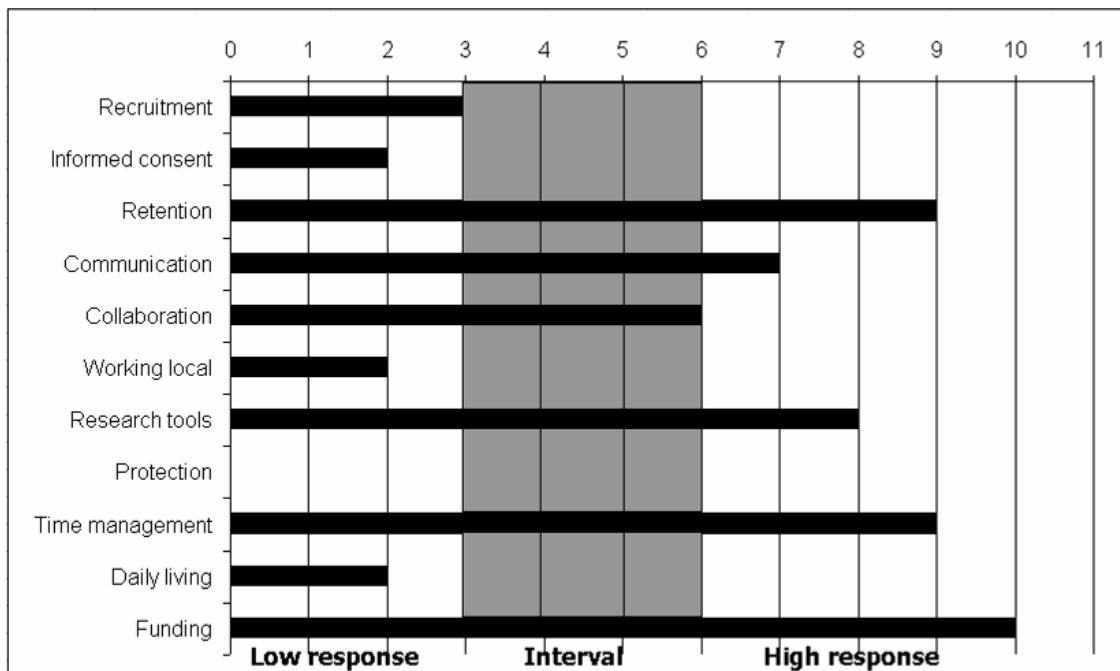
Figure 6. Research domain response frequencies in round 1. The gray area depicts a distinct interval between the low and high response bins.

This second group of six domains was carried over to round 2. Participant rankings of their relative challenge can be seen in Figure 7. Based on median responses, funding scored the lowest (most challenging) while time management scored the highest (least challenging).
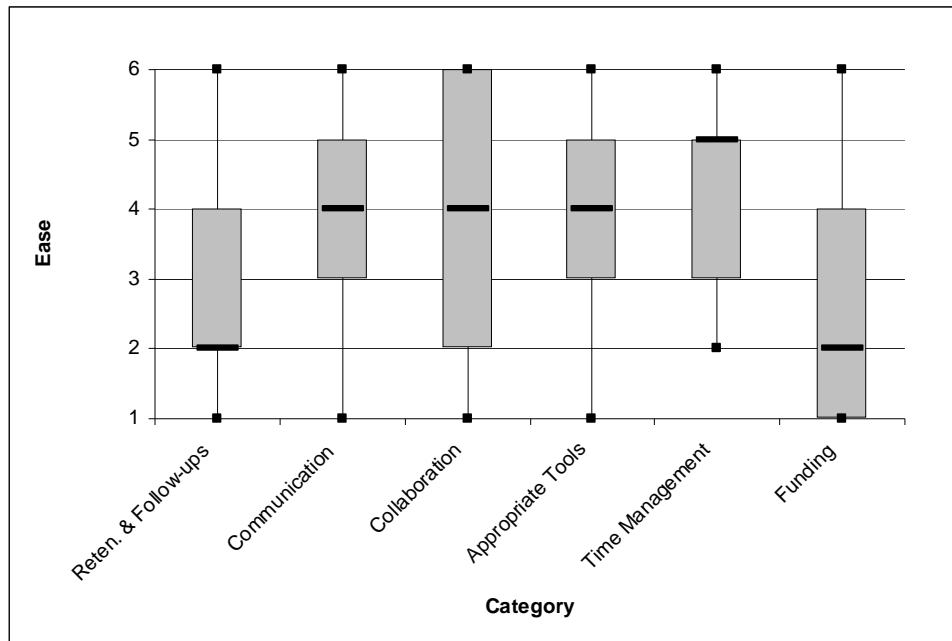
Figure 7. Round 2 rankings of high bin domains. A 1 represented "most challenging," and a 6 represented "least challenging."

Participants categorized the challenges as being either ethical ("affecting participant rights, health, or safety") or logistical ("making the work harder than it should be or affecting ability to get good [interpretable] results"). These responses can be seen in Figure 8. Though the choice was posed as being for one or the other, some individuals qualified their answer with a comment that the challenge was both ethical *and* logistical. Those responses are listed as Log-Both or Eth-Both. Most challenges were categorized as primarily logistical, with "collaboration with local researchers" and "use of appropriate research tools and techniques" rated the most ethical.
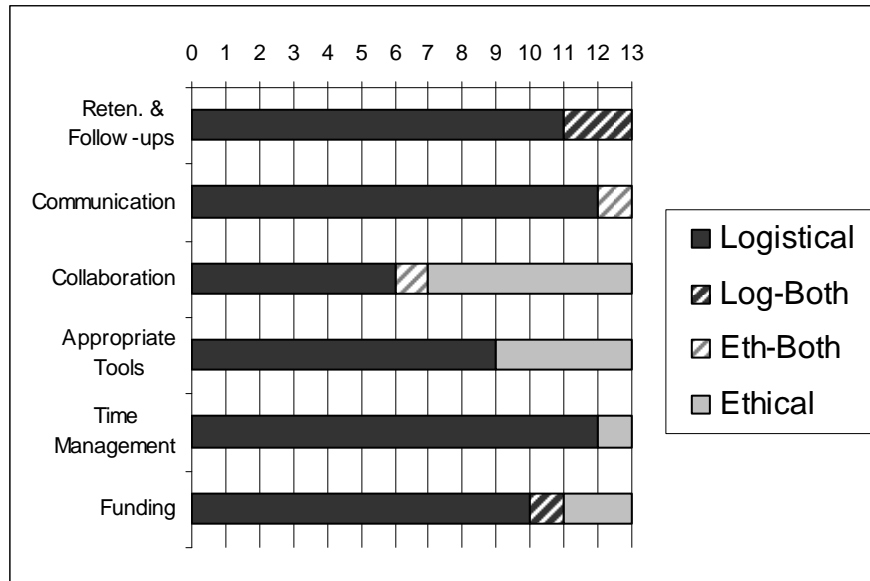
Figure 8. Participant categorization of challenges as ethical or logistical.

The qualitative examination of second round comments led to an aggregation of the following majority opinions (these were presented to participants at the beginning of round 3):

- Qualified local collaborators can help with networking, learning local customs, and making sure research is important to local people.

- Funding can be difficult to acquire, so know the requirements of the grant you are applying to.

- Survey tools must make sense to participants. The best formats involve straightforward "yes/no" or "good/bad" questions, or focus groups. Likert scales are not universally understood and should be avoided.

- Long before data collection starts, make sure the research is worthwhile. Work with the target population to learn their priorities.

- Respect local punctuality conventions. If necessary, allow more time for tasks.

Some participants also wrote (paraphrased):

- Dialects and cultural differences make translation tricky. A qualified translator who understands the research intent is necessary.

- Participants must give informed consent. The skill of translators or local collaborators can impact how well this occurs.

- Appropriate compensation can improve participant retention.

Suggestions carried through to part 3 for criticism (due to their apparent representation of a minority opinion, potential for contention, or potential to clarify a group position) included:

- Participants should keep a log/diary of daily events, mainly to improve retention.

- Organize studies into small projects that can be funded with smaller grants.

- Be very critical of motives for doing the research. Make sure the research will benefit participants or their community.

- To keep participants in the study, pay them a 'transport allowance' incentive that is actually more than transportation costs.

- Identify a participant who enjoys translation, and use him/her as the translator.

- Pay for some study expenses out of your own pocket.

- As an incentive to improve follow-up, leave an instant camera with each end user. Develop the film at the follow-up.

- Have a good written translation of study materials.

According to the results of round 3, these strategies had been tried by differing numbers of participants; almost all had tried using a written translation of study measures, while very few had given participants a diary for the purpose of improving retention. With the exception of dividing research into small projects to aid with funding (2 instances), and employing a participant as a translator (3), all attempts at using the various strategies had been considered helpful by participants (Figure 9). Furthermore, the majority of people who had benefited from a strategy in the past, or had not attempted it, responded that they believed it would help.
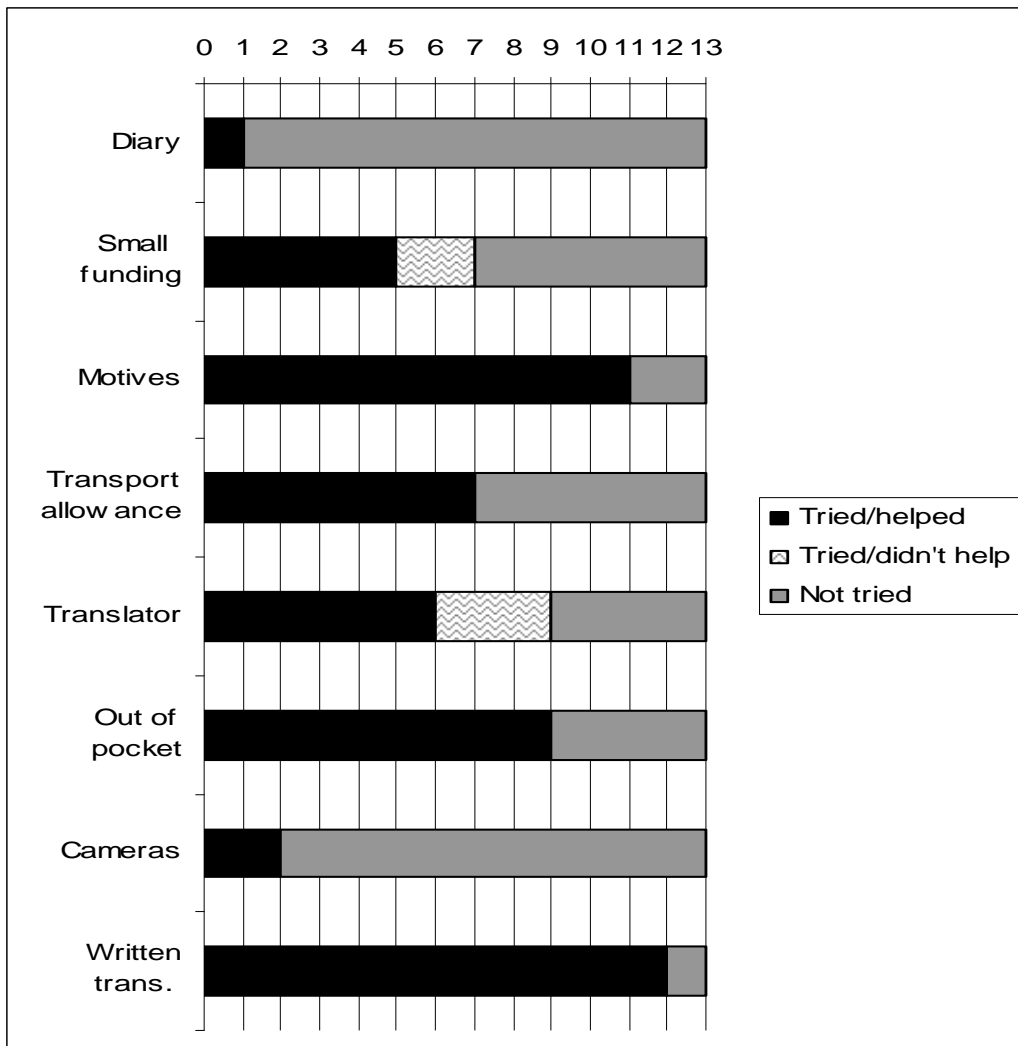
Figure 9. Attempt and success rates of participants using the unique strategies.

Participants also expressed their opinion of whether these strategies would work in general around the world. The majority of people who had benefited from a strategy in the past, or had not attempted it, responded that they believed it would help. In Figure 10, responses from Figure 9 (first term) have been merged with this additional response (second term). For example, the "No/Yes" category represents people whose attempt at using the strategy had not been successful ("No") but who believed the strategy might be beneficial in general ("Yes"). Cool colors (diagonal bars) represent a positive response to the general application of the strategy, while warm colors (orthogonal bars) represent a negative response.
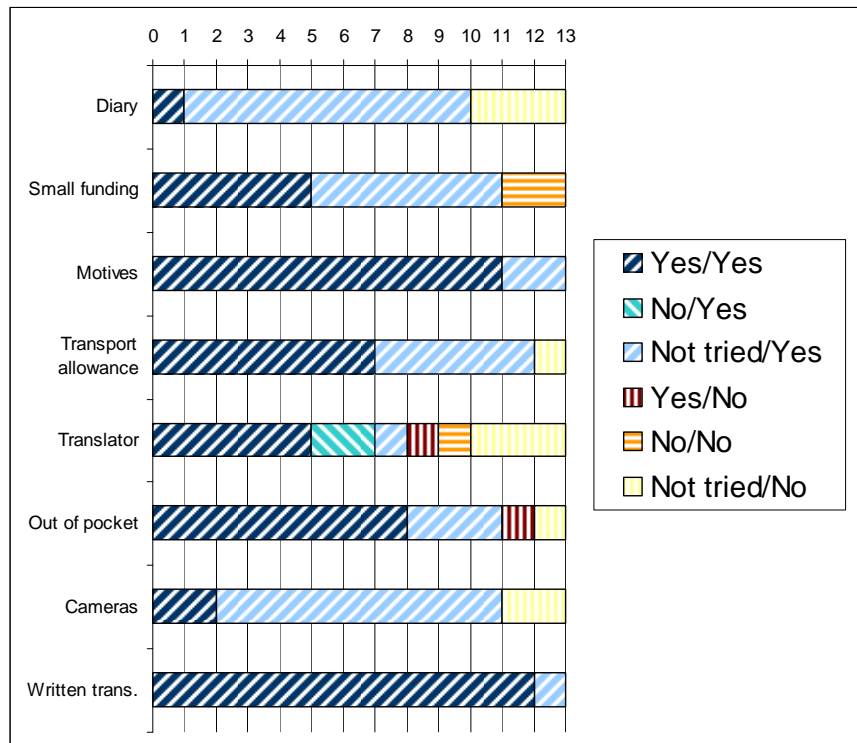
Figure 10. Merged responses to the questions "has this strategy helped you?" and "would it help in general?"

In addition to perfect retention, the participants unanimously indicated that they would like to see the final results of the study. When given the opportunity to give

general comments at the end of the final round, participants wrote, "I look forward to seeing the results," "I feel I have benefited already," "Great questions... and learning opportunity," "Nice job," "Thanks for looking into this. Your results could be very useful," and "Thanks." All participants gave thoughtful, in-depth responses throughout the study.

Table 13 (Appendix I) contains a paraphrase of the challenges, strategies, and caveats given by participants. The full set of participant comments from all three rounds can be seen in Appendix J.

4.4 DISCUSSION

Participants had experienced particular challenge with research domains including funding (rated most difficult), retention and follow-ups (second most difficult), communication with participants, collaboration with local researchers, use of appropriate research tools and techniques, and time management. Domains less frequently identified as challenging were recruitment, informed consent, working local, protection of participants, and daily living. These encompass some of the more complex ethical issues that have been discussed in the literature, and are still important even though participants in this study did not identify them as relatively challenging. It is possible that some of the participants do not adhere to strict subject protections such as informed consent, and this may have led to a de-emphasis of ethical concerns in the round 1 quantitative data. Nonetheless, challenges not carried from the first to the second round still entered later discussion. For example, informed consent was mentioned in discussions of translation logistics, and a few participants indicated that it was difficult to secure IRB approval for international studies. Protection of participants was frequently a theme in translation and

compensation comments. Many of the "logistical" challenges were discussed in terms of ethical concerns.

This study was not a comprehensive exploration of all domains of the research process, but rather it focused on areas that participants deemed particularly challenging. In several cases, these areas were not the same as those discussed heavily in the ethics literature (consenting and IRB approval, participant protection, local resources). An informal examination of participant demographics suggests that residence in a western country, more years of international AT research experience, and internal or "other" data use were indicators of choosing more high response bin domains. However, binning the participant population (Table 11) resulted in small groups (n of 1 or 2 in some cases), and a larger population would be needed to reliably determine the degree to which the demographics influenced responses. Responses according to demographics were not analyzed during the formulation of the round 2 survey, but future research might want to consider the interests of the target population (inexperienced researchers, perhaps) and the source of best experience (those with 21-30 years in the field). In the case of this study, it does not appear that any participants felt (or were) damagingly excluded through the disregard of domains important to them, given the strong retention rate and the fact that all participants chose a majority of high bin domains in round 1.

The challenges of using appropriate survey tools were frequently mentioned. Two individuals commented on the lack of universal understanding of measures such as Likert scales. One participant wrote that concrete questions such as "which do you like better, A or B?" may be more likely to yield valid responses from peoples worldwide. Another suggested rescaling questions from "0 to 10" to "-5 to +5" to more transparently

communicate negative and positive sentiments. This process was used during the development of the PIADS to allow a tool to more easily detect the drawbacks of AT (Day, Jutai, & Campbell, 2002). Sources from literature indicate that the use of appropriate survey tools is also a concern in western countries as well, where focus is on the content validity of measures as they pertain to the effective characterization of disability in a population (Hoenig, Giacobbi, & Levy, 2007; Wade, 2003).

Comments addressed the need to communicate with local collaborators to determine the tools and techniques most appropriate for the particular setting. Because choice of tools can greatly affect data quality, this is a step that should be given care. Participants cited the essential need to involve qualified local collaborators throughout the study (7) to ensure that the needs of the studied community are met. These local collaborators should include PWD, as Kewman (2001) indicates that "relevance and social value of research programs" improve when they are involved in study development. Consultation with local collaborators could also help determine the amount and form of compensation appropriate for a population, to ensure that compensation did not become coercion (2). The nature of cross-cultural collaboration is such that different parties may employ dissimilar concepts of time and punctuality. In some cases, this can mean participants arrive two hours late for appointments, or consider it polite to not inform of a cancellation rather than call with bad news (Mann, et al., 2005). Participants suggested that researchers anticipate loose scheduling (4) and that they should plan better or allocate more time for planned activities (8).

Participants also commented on the challenges of translation. Not merely the act of exchanging words, translation requires an understanding of the topic to be conveyed.

Though it occurs most frequently during international research, it can also be necessary among minority populations within the U.S. (C.-C. Lee, Li, Arai, & Puntillo, 2009; Mann, et al., 2005; Simon, Zyzanski, Durand, Jimenez, & Kodish, 2006; Unger, Soto, & Thomas, 2008). Sentiments expressed by participants were that the efficacy of written translation can be affected by participant literacy (4), that the translation must be done properly (2) and that it must be coupled with oral translation (2). One participant described a written translation as "absolutely necessary." While participants did not believe that written translation can stand alone, losses of meaning can occur during oral translation as well (Hunt & de Voogd, 2007; Mann, et al., 2005; Simon, et al., 2006). Given that semantically equivalent terminology may not exist between two languages (Cha, et al., 2007), individuals with expertise in both rehabilitation and translation might provide a valuable service to researchers in need of translators who understand what one participant referred to as the "needs of both the people who are listening and those that are talking." This sentiment was similar to one expressed by Mann et al. (2005), who noted that even if a translator is present, he or she must be familiar with the "vernacular of the region." Translators versed in rehabilitation and AT would also be valuable in the production of back-translations (often required by IRBs and specifically suggested by one participant in this study).

Because participants generally agreed that financial incentives should be avoided (9), and because no IRB will approve incentives, it falls to a researcher to find other strategies to encourage retention. The suggested strategy of having participants keep a diary (to improve retention) was received with the caveat that the diary must collect useful data (1), the assumption that all diary use is employed for the purpose of collecting

data (4), or doubts about the ability of diaries to provide useful data (3). The participant who suggested diary use "not as much for data collection as they are lead to believe, but to keep the goals of the study fresh in the participants mind daily" was of a minority opinion.

Responses (5) to the camera strategy contained skepticism about cost-effectiveness (inexpensive digital cameras were recommended), but it was noted that cameras can provide an excellent window into the lives of participants (3). In fact, this strategy has been successfully used in our efforts to understand wheelchair accessibility in India (Jefferds, Pearlman, & Cooper, 2007; Pearlman, Jefferds, Nagai, Chhabra, & Cooper, 2007). Retention, a major concern of medical research in general, has not been studied deeply with a rehabilitation focus; however, PWD may have "cognitive impairment, financial stress, and difficulty in accessing transportation" that pose unique challenges to rehabilitation research (Bell, et al., 2008). Thus, creative solutions such as using cameras and diaries should be experimented with further. Retention strategies such as those suggested by Bell et al. (2008) for mainstream American participants and by Mann et al. (2005) for Mexican-American women, might also warrant future evaluation and use.

Funding was discussed with respect to grants and incidental expenses. Participants wrote that it was difficult to secure funding (3), particularly if the project did not fit the funding source's criteria of worthwhile research. Some funding sources "may be biased towards pharmacological and basic science research" and therefore tend to exclude rehabilitation studies (Wade, 2003), which often must address "the person, the device, and the environment" (Hoenig, et al., 2007). Funding specifically for PWD is

available through the Leahy War Victims fund of USAID, which has allocated between $339,000 and $13,351,885 USD for various projects throughout the world (USAID, 2009). In 2002, the World Bank's Small Grants contributed 9% (approximately $207,000) of its $2.3M funding toward aid for PWD (Levinger & Mulroy, 2003). In contrast to these figures, global HIV funding rose from $300M to $13.7B between 1996 and 2008 (*The Global HIV/AIDS Epidemic: Fact Sheet*, 2009). Multiple participants in this study (3) suggested that researchers plan carefully to ensure strong justification exists for the intended project. Doing so can aid the acquisition of funds and also ensure on a more fundamental level that the project is worthwhile. Responses suggested that the success of smaller (rather than larger) projects depended on whether the overall research goal lent itself to this format (2). Participants said that paying study expenses out of pocket does help (if the researcher can afford it) (4), but suggested alternatives (5) such as reimbursement by grants if at all possible.

Many of the positive quantitative responses were tempered by caveats involving situations that could compromise participant rights, result in wasted effort, or require additional strategies to ensure successful research. For example, support for written translation was very positive quantitatively, yet participants still qualified their responses.

4.5 CONCLUSION

The challenges identified in this study appear to be relevant, to one degree or another, in both less- and more-resourced countries. The specific strategies to address these challenges may differ, however. For example, the specific resources available to participants in a given locale may influence researchers' ability to effectively follow up. The content of a Likert scale may need to be validated for a study in a western country,

but in a non-western country, it is also necessary to ensure that the very use of such a scale is culturally appropriate (and given the results of this study, it is likely not). Among the challenges identified—funding, retention and follow-ups, communication with participants, collaboration with local researchers, use of appropriate research tools and techniques, and time management—none appear to be exclusively relevant to international research. This includes "collaboration with local researchers" if this is taken in the broader sense of collaborating with individuals with expertise in the topic at hand (notably PWD).

It is likely that a set of specific strategies guaranteed to make international AT research straightforward and quick does not exist. The results of this study suggest that time, cultural sensitivity, collaboration, and careful planning are a researcher's best allies. Participants in this study stressed the importance of making the studied individuals the primary beneficiaries of all research done with them. So that the benefit to local populations may be optimized, future studies should explore helpful research strategies in greater depth, with a larger population of international AT researchers weighing in. A future Delphi could begin with a petition for strategies and conclude with a list of the ones believed to be most helpful, as Morgan and Jorm (2009) did with self-help strategies for depression. Such a study would provide a resource that AT researchers could use to improve research success.

5.0 FUTURE WORK

The first two studies described in this thesis were based on collaboration work at ISIC, with the intention to assess and improve the fitting of AT (particularly wheelchairs) there, as a pilot for similar work in other clinics in low- and middle-income countries. The author's experiences working in this cross-cultural dynamic led to the formulation of the Delphi study.

Studies derived from the pilot work presented in the PART and WST/QUEST chapters would likely benefit from analyzing larger sample sizes than were used here. This would improve the statistical significance of any observed changes and allow for control of numerous variables. Only the PART study contained follow-up data, though both participation-focused and skills-focused studies could potentially be conducted with a longitudinal design. The wheelchair skill and technology satisfaction study could have been better informed if skill levels long before and long after wheelchair prescription had been assessed (this would have allowed us to gauge the skills improvement imparted by the change of technology only). Future research could also investigate the effects of the wheelchair skills training program available at ISIC, or potentially integrate the WST with a participation measure to explore the relationship between wheelchair skills and community participation.

Staff at the ISIC DAT are currently considering a project to expand the collection of participation data (using the PART or perhaps the CHART) to the broader population of individuals with disabilities. Such a project would move focus away from ISIC's provision efforts and toward India as a whole. Given the Ministry of Social Justice and Empowerment's current concern for PWD, the time is ripe for ISIC and others to conduct

research that will shed light on this population. Doing so would be consistent with the mandate of the UN Convention on the Rights of Persons with Disabilities for the collection of statistical data that facilitates the convention's policies. The research will require careful planning to ensure that as representative a sample is collected from India's diverse ethnic and socioeconomic groups. The use of an online survey shows promise as a method to collect data from large numbers of people, but additional efforts may be necessary to reach individuals who are not literate or do not have access to the internet. The collection of a broad sample of participation is likely a worthwhile project, because it would generate baseline data to which the data of ISIC and other providers could then be compared. Through an improved understanding of the impact of technology and service provision, another UN Convention mandate could be realized: that of providing quality care and technology to preserve and advance the rights of PWD.

As the work in India continues, the results of the Delphi study can potentially provide guidance. Participants in this study commented on collaboration with local researchers and community, the use of appropriate tools and techniques, satisfactory translation, the "do's and don'ts" of retention and compensation, time management, and funding. More work is needed in verifying the effectiveness of the strategies—respecting time and punctuality conventions of the local culture, providing non-financial incentives such as cameras to improve retention, organizing research to fit available funding; and obtaining a written translation of study materials—suggested by the Delphi participants.

An important task for future investigation appears to be identify, evaluate, and compile a collection of strategies international researchers may turn to for guidance. The

suggestions made by participants here, as well as those made by others (e.g. Bell, et al.,

2008; Mann, et al., 2005) may serve as a starting point.

ISIC INTAKE FORMS

<u>Subject Linkage Sheet</u>
For ISIC use only – Cannot be transported to the U.S.

Subject name: _____

Ward/bed: _____/_____

Subject ID(s):

      PART-O_____

      WST/QUEST_____

Assessor name(s):

_____

Therapist(s):

_____

Tests scheduled:

_____
_____
_____
_____
_____

Tests completed:

      ☐ PART-O

          Date(s): _____/_____/_____ , _____/_____/_____

                   _____/_____/_____ , _____/_____/_____

      ☐ Wheelchair Skills Test – Old Wheelchair

          Date: _____/_____/_____

      ☐ Wheelchair Skills Test – New Wheelchair

          Date: _____/_____/_____

      ☐ QUEST – Old Wheelchair

          Date: _____/_____/_____

      ☐ QUEST – New Wheelchair

          Date: _____/_____/_____

Subject Intake Sheet
Can be transported to the U.S.

What are you currently using as your primary mobility assistive technology:

☐ Manual Wheelchair ☐ Power Wheelchair ☐ Scooter   ☐ Crutches ☐ none

Make: _____ Model:_____

What types and numbers of assistive technology are you using:

Bathing/Showering (shower seat, hand grips, special shower head, etc.)
Total # _____ ; List of devices _____

Bowel and Bladder Management (catheter, leg bag, etc.)
Total # _____ ; List of devices _____

Dressing (splint for buttoning, etc.)
Total # _____ ; List of devices _____

Eating (adapted table, silverware, plates)
Total # _____ ; List of devices _____

Functional Mobility (wheelchair, scooter, crutches, rollater, walker, prosthetic limb, tricycle.)
Total # _____ ; List of devices _____

Personal device care (hearing aides, glasses, prosthetics, adaptive equipment (eg., automobiles))
Total # _____ ; List of devices _____

Personal Hygiene and Grooming
Total # _____ ; List of devices _____

Sexual Activity
Total # _____ ; List of devices _____

Sleep/rest (adapted bed, pillows, transfer board)
Total # _____ ; List of devices _____

Toilet Hygiene (commode seat, handles)
Total # _____ ; List of devices _____

Home Modifications (ramps, door handles, rails in bathroom)
Total # _____ ; List of devices _____

Computer Access (adapted mouse, voice recognition software)
Total # _____ ; List of devices _____

APPENDIX B

PART SURVEY
(Version used in India—see notes in section 2.4)

PART: OBJECTIVE ITEMS
I am going to begin this interview with questions about your typical activities. So, first . . .
O1. In a typical <u>week</u>, how many <u>hours</u> do you spend in active homemaking, including cleaning, cooking and raising children?
O2. In a typical week, how many hours do you spend in home maintenance activities, such as home repairs, home improvements and gardening?
O3. In a typical week, how many hours do you spend in school working toward a degree or in an accredited technical training program, including hours in class and studying?
O4. In a typical week, how many hours do you spend working for money, whether in a job or self-employed?
O5. In a typical week, how many hours do you ride in trains, buses, taxis and other public transportation? This includes public transportation for people with disabilities.
O6. In a typical week, how many hours do you drive or ride in a car? This includes all types of private transportation.
0   None
1   1-4 hours
2   5-9 hours
3   10-19 hours
4   20-34 hours
5   35 or more hours

So far, I've asked questions about the <u>amount of time</u> you engage in activities. Now, I will ask you about <u>how often</u> you do things. So . . .
O7. In a typical week, how many <u>times</u> do you socialize with friends, in person or by phone? Please do not include socializing with family members.
O8. In a typical week, how many times do you socialize with family and relatives, in person or by phone?
O9. In a typical week, how many times do you give emotional support to other people, that is, listen to their problems or help them with their troubles?
O10. In a typical week, how many times do you use the Internet for communication, such as for e-mail, visiting chat rooms or instant messaging?
0   None
1   1-4 times
2   5-9 times
3   10-19 times
4   20-34 times
5   35 or more times

O11. In a typical week, <u>how many days</u> do you get out of your house and go somewhere? It could be anywhere – it doesn't have to be anyplace "special".
0   None
1   1-2 days
2   3-4 days
3   5-6 days
4   7 days

Now, I'd like you to think about a typical month . . .
O12. What best describes how you spend your days in a typical month?
0   I rarely leave my bed
1   I rarely leave my room - but I do get out of bed
2   I rarely leave my house - but I do get out of my room
3   I rarely leave my block or neighborhood - but I do get out of the house
4   I travel beyond my block or neighborhood

Now I have questions on how often you do various things in a typical month.
O13. In a typical month, how many times do you eat in a restaurant?
O14. In a typical month, how many times do you go shopping? Include grocery shopping, as well as
        shopping for household necessities, or just for fun.
O15. In a typical month, how many times do you engage in sports or exercise outside your home? Include
        activities like running, bowling, going to the gym, swimming, walking for exercise and the like.
0   None
1   1-4 times
2   5-9 times
3   10-19 times
4   20-34 times
5   35 or more times

I have more questions on how a typical month looks like, but please note that the answer categories are
different.
O16. In a typical <u>month</u>, how many <u>times</u> do you do volunteer work?
O17. In a typical month, how many times do you go to the movies?
O18. In a typical month, how many times do you attend sports events in person, as a spectator?
O19. In a typical month, how many times do you attend religious or spiritual services? Include places like
        churches, temples and mosques.
0   None
1   One time
2   Two times
3   Three times
4   Four times
5   Five or more times

O20. In a typical month, how many times do you participate in a club or organization, such as the PTA, a
choir, sorority, hobby group, neighborhood organization, brain injury or other support group?
0   None
1   One time
2   Two times
3   Three times
4   Four times
5   Five or more times

O21. <u>Now, I'd like you to think about the last three months</u>. In that time, have you taken adult education
classes, GED classes, continuing education, special courses, or used other opportunities for learning, for
instance, seminars or conferences?
1   Yes
2   No

O22. <u>Switching, now, to a somewhat different kind of question</u> . . . Do you live with your spouse or significant other?
1   Yes [SKIP TO QUESTION O24]
2   No

O23. Are you currently involved in an ongoing <u>intimate</u>, that is, romantic or sexual, relationship?
O24. [Not including your spouse or significant other], do you have a close friend in whom you confide?
1   Yes
2   No

PART: SUBJECTIVE ITEMS

IMPORTANCE: So far, we have talked about your typical activities. Now, I'd like to try to get a sense of which of your activities and relationships are important to you. I'm going to read a list of areas of activity and then ask you how important each is to you. .

I'm sure some of these areas are very important, while others are less important. As I read the list I would like you to tell me if an area is of high, medium or low importance to you at this time IF THE PERSON RATES AN AREA AS BEING OF LOW IMPORTANCE, ASK THE FOLLOWING: Did you rate this area as of low importance only because it is not part of your life right now, while in reality it **is** important to you and you would like to **have** it in your life? IF YES, Would you want to change your mind and call it of medium or high importance?

	Importance			Satisfaction	
	3	2	1	0 - 10	**Areas of Activity**
S1	HI	MED	LO		Going to school and other opportunities for you to learn. Do not include school for your children – only think of yourself
S2	HI	MED	LO		Paid and unpaid work, in other words, having a job or volunteering
S3	HI	MED	LO		Having and raising children
S4	HI	MED	LO		Housekeeping and other activities to keep your home in good order
S5	HI	MED	LO		A relationship with a spouse or significant other
S6	HI	MED	LO		Relationships with family and relatives. This includes relationships with your adult children, if you have any.
S7	HI	MED	LO		Relationships with friends and acquaintances
S8	HI	MED	LO		Public and private transportation
S9	HI	MED	LO		Participation in religious services and functions
S10	HI	MED	LO		Activities in other organizations, or other parts of your community
S11	HI	MED	LO		Recreation and leisure, whether at home or elsewhere - the activities you do "for fun"

SATISFACTION: Now I would like you to tell me how happy or satisfied you are with each of the areas of life you said are of high importance to you. For each we will use a scale that runs from 0 to 10, where 0 means: you are **totally** dissatisfied with how things are, and 10 means: you are **completely** happy with how things are.

Let's start with the first one. How happy or satisfied are you with how things are in your life in the area of ___**?** Remember, use a number between 0 and 10.

APPENDIX C

CHART COMPARED TO PART

(Direct): Direct equivalence of question between CHART and PART
(Indirect): Indirect similarity of question between CHART and PART

WHAT ASSISTANCE DO YOU NEED?
People with disabilities often need assistance. We would like to differentiate between personal care for physical disabilities and supervision for cognitive problems. First, focus on physical "hands on" assistance: This includes help with eating, grooming, bathing, dressing, management of a ventilator or other equipment, transfers etc. Keeping in mind these daily activities...

1. How many hours in a typical 24-hour day do you have someone with you to provide physical assistance for personal care activities such as eating, bathing, dressing, toileting and mobility?
_____ hours paid assistance _____ hours unpaid (family, others)

2. Not including any regular care as reported above, how many hours in a typical month do you occasionally have assistance with such things as grocery shopping, laundry, housekeeping, or infrequent medical needs because of the disability?
_____ hours per month

3. Who takes responsibility for instructing and directing your attendants and/or caregivers?
_____ Self
_____ Someone Else
_____ Not applicable, does not use attendant care

Now, focus on supervision for cognitive problems instead of physical assistance. This includes remembering, decision making, judgment, etc..

4. How much time is someone with you in your home to assist you with activities that require remembering, decision making, or judgment?
_____ Someone else is always with me to observe or supervise.
_____ Someone else is always around, but they only check on me now and then.
_____ Sometimes I am left alone for an hour or two.
_____ Sometimes I am left alone for most of the day
_____ I have been left alone all day and all night, but someone checks in on me.
_____ I am left alone without anyone checking on me.

5. How much of the time is someone with you to help you with remembering, decision making, or judgment when you go away from your home?

_____ I am restricted from leaving, even with someone else.

_____ Someone is always with me to help with remembering, decision making or judgment when I go anywhere.

_____ I go to places on my own as long as they are familiar.

_____ I do not need help going anywhere.

6. How often do you have difficulty communicating with other people?

_____ I almost always have difficulty.

_____ I sometimes have difficulty.

_____ I almost never have difficulty.

7. How often do you have difficulty remembering important things that you must do?

_____ I almost always have difficulty.

_____ Sometimes I have difficulty.

_____ I almost never have difficulty.

8. How much of your money do you control?

_____ None, someone makes all money decisions for me.

_____ A small amount of spending money is given to me periodically.

_____ Most of my money, but someone does help me make major decisions.

_____ I make all my own money decisions (or if married, in joint participation with my partner).

Now, I have a series of questions about your typical activities.

ARE YOU UP AND ABOUT REGULARLY?

9. On a typical day, how many hours are you out of bed? _____ hours

(Indirect) PART-O12. What best describes how you spend your days in a typical month?

10. In a typical week, how many days do you get out of your house and go somewhere? ____days

(Direct) PART-O11. In a typical week, <u>how many days</u> do you get out of your house and go somewhere. It could be anywhere – it doesn't have to be anyplace "special".

11. In the last year, how many nights have you spent away from your home (excluding hospitalizations?) _____ none _____ 1-2 _____3-4 _____5 or more

12. Can you enter and exit your home without any assistance from someone?

yes_____ no_____

(Indirect) PART-O12. What best describes how you spend your days in a typical month?

13. In your home, do you have independent access to your sleeping area, kitchen, bathroom, telephone, and TV (or radio)? _____yes _____no
(Indirect) PART-O12. What best describes how you spend your days in a typical month?

IS YOUR TRANSPORTATION ADEQUATE?

14. Can you use your transportation independently?
_____yes _____no
(Indirect) PART-O5. In a typical week, how many hours do you ride in trains, buses, taxis and other public transportation? This includes public transportation for people with disabilities. / PART-O6. In a typical week, how many hours do you drive or ride in a car? This includes all types of private transportation.

15. Does your transportation allow you to get to all the places you would like to go?
_____ yes _____ no
(Indirect) PART-O5. In a typical week, how many hours do you ride in trains, buses, taxis and other public transportation? This includes public transportation for people with disabilities. / PART-O6. In a typical week, how many hours do you drive or ride in a car? This includes all types of private transportation.

16. Does your transportation let you get out whenever you want?
_____ yes _____ no
(Indirect) PART-O5. In a typical week, how many hours do you ride in trains, buses, taxis and other public transportation? This includes public transportation for people with disabilities. / PART-O6. In a typical week, how many hours do you drive or ride in a car? This includes all types of private transportation.

17. Can you use your transportation with little or no advance notice?
_____ yes _____ no
(Indirect) PART-O5. In a typical week, how many hours do you ride in trains, buses, taxis and other public transportation? This includes public transportation for people with disabilities. / PART-O6. In a typical week, how many hours do you drive or ride in a car? This includes all types of private transportation.

HOW DO YOU SPEND YOUR TIME?

18. How many hours per week do you spend working in a job for which you get paid?
hours _____ (occupation: _____)
(Direct) PART-O4. In a typical week, how many hours do you spend working for money, whether in a job or self-employed?

19. How many hours per week do you spend in school working toward a degree or in an accredited technical training program (including hours in class and studying)?
_____ hours

(Direct) PART-O3. In a typical week, how many hours do you spend in school working toward a degree or in an accredited technical training program, including hours in class and studying?

20. How many hours per week do you spend in active homemaking including parenting, housekeeping, and food preparation? _____ hours
(Direct) PART-O1. In a typical <u>week,</u> how many <u>hours</u> do you spend in active homemaking, including cleaning, cooking and raising children?

21. How many hours per week do you spend in home maintenance activities such as gardening, house repairs or home improvement? _____ hours
(Direct) PART-O2. In a typical week, how many hours do you spend in home maintenance activities, such as home repairs, home improvements and gardening?

22. How many hours per week do you spend in ongoing volunteer work for an organization?
_____ hours
(Indirect) PART-O16. In a typical <u>month,</u> how many <u>times</u> do you do volunteer work?

23. How many hours per week do you spend in recreational activities such as sports, exercise, playing cards, or going to movies? Please do not include time spent watching TV or listening to the radio. _____ hours
(Indirect) PART-O17. In a typical month, how many times do you go to the movies? / PART-O18. In a typical month, how many times do you attend sports events in person, as a spectator?

24. How many hours per week do you spend in other self-improvement activities such as hobbies or leisure reading? Please do not include time spent watching TV or listening to the radio. _____ hours

WITH WHOM DO YOU SPEND TIME?

25. Do you live alone? ____ Yes ____ No (If yes, skip to question 26.)

       25a. (If you don't live alone) do you live with a spouse or significant other?
       ____ Yes ____ No
(Direct) PART-O22. <u>Switching, now, to a somewhat different kind of question . . .</u> Do you live with your spouse or significant other?
       25b. How many children do you live with? _____
       25c. How many other relatives do you live with? _____
       25d. How many roommates do you live with? _____
       25e. How many attendants do you live with? _____

26. (If you don't live with a spouse or significant other) are you involved in a romantic relationship?
___ Yes ___ No ___ N/A (Subject lives with spouse or significant other)
(Direct) PART-O23. Are you currently involved in an ongoing <u>intimate</u>, that is, romantic or sexual, relationship?

27. How many relatives (not in your household) do you visit, phone, or write to at least once a month? _____ relatives
(Indirect) PART-O7. In a typical week, how many <u>times</u> do you socialize with friends, in person or by phone? Please do not include socializing with family members. / PART-O8. In a typical week, how many times do you socialize with family and relatives, in person or by phone? / PART-O9. In a typical week, how many times do you give emotional support to other people, that is, listen to their problems or help them with their troubles?

28. How many business or organizational associates do you visit, phone, or write to at least once a month? _____ associates

29. How many friends (non-relatives contacted outside business or organizational settings) do you visit, phone, or write to at least once a month? _____ friends

30. With how many strangers have you initiated a conversation in the last month (for example, to ask information or place an order)?
___ none ___ 1-2 ___ 3-5 ___ 6 or more

WHAT FINANCIAL RESOURCES DO YOU HAVE?

31. Approximately what was the combined annual income, in the last year, of **all family members in your household**? (consider all sources including wages and earnings, disability benefits, pensions and retirement income, income from court settlements, investments and trust funds, child support and alimony, contributions from relatives, and any other source.)
$ _____ .

32. Approximately how much did you pay last year for medical care expenses? (Consider any amounts paid by yourself or the family members in your household and **not reimbursed** by insurance or benefits.)
$ _____ .

PART MODIFIED FOR SELF-ADMINISTRATION IN INDIA

PART: OBJECTIVE ITEMS
Modified by Alexandra Jefferds for use in India

Weekly Activities

O1. In a typical <u>week</u>, how many <u>hours</u> do you spend in active homemaking, including cleaning, cooking and raising children? _____

O 2. In a typical week, how many hours do you spend in home maintenance activities, such as home repairs, home improvements and gardening? _____

O 3. In a typical week, how many hours do you spend in school working toward a degree or in an accredited technical training program, including hours in class and studying? _____

O 4. In a typical week, how many hours do you spend working for money, whether in a job or self-employed? _____

O 5. In a typical week, how many hours do you ride in trains, buses, taxis and other public transportation? This includes public transportation for people with disabilities and <u>does not</u> include a private vehicle. _____

O 6. In a typical week, how many hours do you drive or ride in a car? This includes all types of private transportation. _____

0   None
1   1-4 hours
2   5-9 hours
3   10-19 hours
4   20-34 hours
5   35 or more hours

So far, I've asked questions about the amount of time you engage in activities. Now, I will ask you about how often you do things. So . . .

In the questions below, a "time" means an individual instance that you do an activity. For example, if you eat 3 meals a day, you would say that you eat "3 <u>times</u> a day." This is different than asking how many hours (a length of time) you do one particular activity.

O 7. In a typical week, how many <u>times</u> do you socialize with friends, in person or by phone? Please do not include socializing with family members. _____

O 8. In a typical week, how many times do you socialize with family and relatives, in person or by phone? _____

O 9. In a typical week, how many times do you give emotional support to other people, that is, listen to their problems or help them with their troubles? _____

O 10. In a typical week, how many times do you use the Internet for communication, such as for e-mail, visiting chat rooms or instant messaging? _____

O 11. In a typical week, how many <u>days</u> do you get out of your house and go somewhere? It could be anywhere – it doesn't have to be anyplace "special". _____

Now I have questions on how often you do various things in a typical month.

Monthly Activities

~~0~~ 12. In a typical month, what best describes how you spend your days in a typical month? Circle the best answer below.
0   I rarely leave my bed
1   I rarely leave my room - but I do get out of bed
2   I rarely leave my house - but I do get out of my room
3   I rarely leave my block or neighborhood - but I do get out of the house
4   I travel beyond my block or neighborhood

~~0~~ 13. In a typical month, how many <u>times</u> do you eat in a restaurant? _____
~~0~~ 14. In a typical month, how many times do you go shopping? Include grocery shopping, as well as
        shopping for household necessities, or just for fun. _____
~~0~~ 15. In a typical month, how many times do you engage in sports or exercise outside your home? Include
        activities like running, bowling, going to the gym, swimming, walking for exercise and the like.
        _____
~~0   None~~
~~1   1-4 times~~
~~2   5-9 times~~
~~3   10-19 times~~
~~4   20-34 times~~
~~5   35 or more times~~

~~I have more questions on how a typical month looks like, but please note that the answer categories are different.~~
~~0~~ 16. In a typical month, how many <u>times</u> do you do volunteer work? _____
~~0~~ 17. In a typical month, how many times do you go to the movies? _____
~~0~~ 18. In a typical month, how many times do you attend sports events in person, as a spectator? _____
~~0~~ 19. In a typical month, how many times do you attend religious or spiritual services? Include places like
        churches, temples and mosques. _____
~~0   None~~
~~1   One time~~
~~2   Two times~~
~~3   Three times~~
~~4   Four times~~
~~5   Five or more times~~

~~0~~ 20. In a typical month, how many times do you participate in a club or organization, such as the PTA, a
        choir, sorority, hobby group, neighborhood organization, brain injury or other support group?
        _____
~~0   None~~
~~1   One time~~
~~2   Two times~~
~~3   Three times~~
~~4   Four times~~
~~5   Five or more times~~

Last Three Months

O 21. ~~Now, I'd like you to think about the last three months.~~ In the last 3 months, have you taken adult education classes, GED classes, continuing education, special courses, or used other opportunities for learning, for instance, seminars or conferences? Circle the best answer below.
1   Yes
2   No

Now

O 22. Do you live with your spouse or significant other? Circle the best answer below.
1   Yes ~~[SKIP TO QUESTION O24]~~
2   No

O 23. If you answered "No" to question 22, are you currently involved in an ongoing <u>intimate</u>, that is, romantic or sexual, relationship? Circle the best answer below.
1   Yes
2   No

O 24. [Not including your spouse or significant other], do you have a close friend in whom you confide? Circle the best answer below.
1   Yes
2   No

PART: SUBJECTIVE ITEMS

IMPORTANCE: So far, we have talked about your typical activities. Now, I'd like to try to get a sense of which of your activities and relationships are important to you. I'm going to read a list of areas of activity and then ask you how important each is to you. .

I'm sure some of these areas are very important, while others are less important. As I read the list I would like you to tell me if an area is of high, medium or low importance to you at this time IF THE PERSON RATES AN AREA AS BEING OF LOW IMPORTANCE, ASK THE FOLLOWING: Did you rate this area as of low importance only because it is not part of your life right now, while in reality it **is** important to you and you would like to **have** it in your life? IF YES, Would you want to change your mind and call it of medium or high importance?

	Importance			Satisfaction	
	3	2	1	0 - 10	**Areas of Activity**
S1	HI	MED	LO		Going to school and other opportunities for you to learn. Do not include school for your children – only think of yourself
S2	HI	MED	LO		Paid and unpaid work, in other words, having a job or volunteering
S3	HI	MED	LO		Having and raising children
S4	HI	MED	LO		Housekeeping and other activities to keep your home in good order
S5	HI	MED	LO		A relationship with a spouse or significant other
S6	HI	MED	LO		Relationships with family and relatives. This includes relationships with your adult children, if you have any.
S7	HI	MED	LO		Relationships with friends and acquaintances
S8	HI	MED	LO		Public and private transportation
S9	HI	MED	LO		Participation in religious services and functions
S10	HI	MED	LO		Activities in other organizations, or other parts of your community
S11	HI	MED	LO		Recreation and leisure, whether at home or elsewhere - the activities you do "for fun"

SATISFACTION: Now I would like you to tell me how happy or satisfied you are with each of the areas of life you said are of high importance to you. For each we will use a scale that runs from 0 to 10, where 0 means: you are **totally** dissatisfied with how things are, and 10 means: you are **completely** happy with how things are.

For example, if having a job is of high importance to you and you love the job you have now, you might rate that as a 10 (completely satisfied). However, if having a job is very important but you don't have one, and this makes you worry a lot, you might rate that as a 0. You are rating how happy (or not) you are about how that area of your life is right now, not how important or unimportant that area is. You can use any number from 0 to 10.

Let's start with the first one. How happy or satisfied are you with how things are in your life in the area of ___**?** Remember, use a number between 0 and 10.

COMPARISON OF QUEST RESULTS TO EUROPEAN LITERATURE
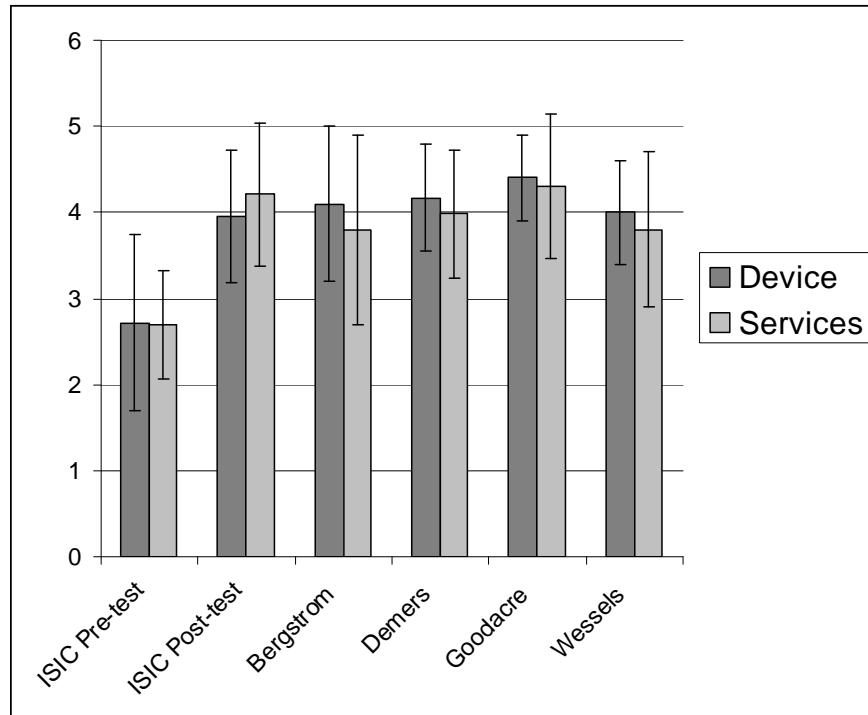
Figure 11. ISIC pre- and post-test section scores compared to existing literature for European AT users (Bergstrom & Samuelsson, 2006; Demers, et al., 2002; Goodacre & Turner, 2005; Wessels & De Witte, 2003).

Table 12. ISIC line-by-line scores compared to existing literature for European AT users (Bergstrom & Samuelsson, 2006; Goodacre & Turner, 2005; Wressle & Samuelsson, 2004).

	ISIC Pre-test	ISIC Post-test	Bergstrom	Goodacre	Wressle
n	≈7	≈7	≈120	55	44
Dimensions	2.71	4.00	4.27	4.7	4.26
Weight	2.00	4.00	4.15	4.6	3.94
Adjustment	2.20	3.67	3.8	4.6	4.15
Safety	3.29	4.14	4.21	4.5	4.27
Durability	3.20	4.00	4.08	4.5	4.31
Ease of use	2.43	4.29	4.42	4.7	4
Comfort	2.71	3.86	3.77	4.5	4.11
Effectiveness	3.17	3.86	4.16	4.7	4.33
Service delivery	3.60	4.43	3.74	3.9	4.24
Repairs & services	3.25	4.33	3.97	4.5	3.86
Professional services	3.50	4.00	3.9	4.6	3.63
Follow-up	3.00	4.33	3.43	4.6	3.45

APPENDIX F

DELPHI STUDY ROUND 1

International Research Strategies -- Round I

1. International Assistive Technology Research Strategies - Round 1 of 3

The Human Engineering Research Laboratories welcome you to round 1 of 3 of the International AT Research Strategies study. The purpose of this study is to determine the key difficulties of international/cross-cultural research, and what the best strategies are to address these difficulties.

You have been invited to participate in this study because you have experience conducting assistive technology (AT) related research or technology development in less-resourced environments such as developing countries.

DEFINITIONS:
• For the purposes of this study, we are defining "research" as an effort to collect information to get a better understanding of the influence of assistive technology on the lives of people with disabilities and their community of friends, family, and colleagues. It involves a process, method, and design.
• Assistive Technology (AT) is any technology that allows someone to do an activity they otherwise could not, or which allows them to do the activity more easily or safely. Categories of AT include mobility devices, communications devices, tools to assist with activities of daily living, adapted computer equipment, and home modifications. AT can be specially designed for people with disabilities, be a modified version of an existing device, or be an existing device used in a unique or unconventional way.

Thank you for your participation.

If you have a concern, please contact:
Alexandra Jefferds
412-954-5302 or anj9@pitt.edu

2. Consent and Contact Information

* **1. I certify that I agree to take part in this research study voluntarily, knowing that I may withdraw at any time. By checking the box below, I grant the Human Engineering Research Laboratories the authorization to use my survey responses for research purposes, and my contact information only to contact me.**

☐ This box represents my authorization.

* **2. Please enter your contact information.**

Full Name:

State/Province:

Country:

Email Address:

Phone Number:

3. General Information

3. In what country or countries...

... do you live?

... is your university or
organization
headquartered?

... do you do research?

4. How many years have you been doing research in the area of assistive technology (AT)?

◯ 0-5

◯ 6-10

◯ 11-20

◯ 21-30

◯ >30

5. What percentage of your AT research is conducted in less-resourced environments such as developing countries?

◯ 0-20%

◯ 21-40%

◯ 41-60%

◯ 61-80%

◯ 81-100%

6. How does your university or organization use your research results?

◯ Keep them, for internal use

◯ Publish them, in an effort to build an international knowledge base

◯ Both of the above

◯ Other

(please specify)

7. How knowledgeable are you about the World Health Organization's International Classification of Functioning, Disability and Health (ICF)?

◯ Have not heard of it

◯ Aware of it

◯ Somewhat knowledgeable

◯ Very knowledgeable

◯ Expert

4. Aspects of Research

* 8. Please select the 5 aspects of international/cross-cultural research that you have found to be most challenging.

☐ a) PARTICIPANT/SUBJECT RECRUITMENT

Finding qualified and willing participants for your study…

☐ b) COLLECTION OF INFORMED CONSENT

Making sure the participant understands study risks, has had all of their questions answered, is agreeing to participate of their own free will…

☐ c) RETENTION AND FOLLOW-UPS

Keeping participants in the study for the entire duration and not dropping out, contacting participants at a future date to collect more data…

☐ d) COMMUNICATION WITH PARTICIPANTS

Effective communication in spite of cultural and language differences between researchers and participants…

☐ e) COLLABORATION WITH LOCAL RESEARCHERS

Addressing cultural differences, determining research expectations, benefiting the professional interests of all involved organizations…

☐ f) WORKING WITH LOCAL BUSINESSES, CRAFTSPEOPLE, AND INFRASTRUCTURE

Buying and building study equipment locally, incorporating available resources and skills of local repair personnel…

☐ g) USE OF APPROPRIATE RESEARCH TOOLS AND TECHNIQUES

Cultural appropriateness of survey formats ("On a scale of 0-5, how would you rate…"), individual function is judged according to cultural norms (e.g. What would a similar non-disabled woman be expected to do with her time?)…

☐ h) PROTECTION OF PARTICIPANT PRIVACY

Data collection, data storage, information security (encryption, virus protection, etc.)…

☐ i) TIME MANAGEMENT

Making the best of your limited time in the locale, working with different concepts of time and punctuality around the world…

☐ j) DAILY LIVING IN THE LOCALE

Transportation, communication, purchasing food and other items, housing, personal safety, etc…

☐ k) FUNDING

Finding money for your research or project, spending the money in different ways…

☐ l) OTHER (please describe)

[ ]

APPENDIX G

DELPHI STUDY ROUND 2

International Research Strategies -- Round II

1. International Assistive Technology Research Strategies - Round 2 of 3

The Human Engineering Research Laboratories welcome you to round 2 of 3 of the International AT Research Strategies study. The purpose of this study is to determine the key difficulties of international/cross-cultural research, and what the best strategies are to address these difficulties.

Thank you for your continued participation.

If you have a concern, please contact:
Alexandra Jefferds
412-954-5302 or anj9@pitt.edu

International Research Strategies -- Round II

2. Item Ranking

* 1. Please enter your name so we can keep track of your continued participation.

Name:

In the first round, you and other participants in this study said that the following aspects of international/cross-cultural research were the most challenging:

- RETENTION AND FOLLOW-UPS

    Keeping participants in the study for the entire duration and not dropping out, contacting participants at a future date to collect more data

- COMMUNICATION WITH PARTICIPANTS

    Effective communication in spite of cultural and language differences between researchers and participants

- COLLABORATION WITH LOCAL RESEARCHERS

    Addressing cultural differences, determining research expectations, benefiting the professional interests of all involved organizations

- USE OF APPROPRIATE RESEARCH TOOLS AND TECHNIQUES

    Cultural appropriateness of survey formats ("On a scale of 0-5, how would you rate..."), individual function is judged according to cultural norms (e.g. What would a similar non-disabled woman be expected to do with her time?)

- TIME MANAGEMENT

    Making the best of your limited time in the locale, working with different concepts of time and punctuality around the world

- FUNDING

    Finding money for your research or project, spending the money in different ways

* 2. Now, please rank these items from 1-6, according to how challenging you think they are.

	1 (most challenging)	2	3	4	5	6 (least challenging)
Retention and follow-ups	○	○	○	○	○	○
Communication with participants	○	○	○	○	○	○
Collaboration with local researchers	○	○	○	○	○	○
Use of appropriate research tools and techniques	○	○	○	○	○	○
Time Management	○	○	○	○	○	○
Funding	○	○	○	○	○	○

3. Item Classification and Strategies

For each of the 6 difficulties, please state whether it is an ethical or logistical issue.

Also, please describe strategies (methods) that you or people on your research team have used to get around each difficulty.

* 3. RETENTION AND FOLLOW-UPS
Keeping participants in the study for the entire duration and not dropping out, contacting participants at a future date to collect more data

◯ This is an ethical issue (it affects the rights, health, or safety of people)

◯ This is a logistical issue (it makes your work harder than it should be, or keeps you from getting good results)

Strategies used to get around this difficulty:

* 4. COMMUNICATION WITH PARTICIPANTS
Effective communication in spite of cultural and language differences between researchers and participants

◯ This is an ethical issue (it affects the rights, health, or safety of people)

◯ This is a logistical issue (it makes your work harder than it should be, or keeps you from getting good results)

Strategies used to get around this difficulty:

* 5. COLLABORATION WITH LOCAL RESEARCHERS
Addressing cultural differences, determining research expectations, benefiting the professional interests of all involved organizations

◯ This is an ethical issue (it affects the rights, health, or safety of people)

◯ This is a logistical issue (it makes your work harder than it should be, or keeps you from getting good results)

Strategies used to get around this difficulty:

* 6. USE OF APPROPRIATE RESEARCH TOOLS AND TECHNIQUES

   Cultural appropriateness of survey formats ("On a scale of 0-5, how would you rate..."), individual function is judged according to cultural norms (e.g. What would a similar non-disabled woman be expected to do with her time?)

◯ This is an ethical issue (it affects the rights, health, or safety of people)

◯ This is a logistical issue (it makes your work harder than it should be, or keeps you from getting good results)

Strategies used to get around this difficulty:

* 7. TIME MANAGEMENT

   Making the best of your limited time in the locale, working with different concepts of time and punctuality around the world

◯ This is an ethical issue (it affects the rights, health, or safety of people)

◯ This is a logistical issue (it makes your work harder than it should be, or keeps you from getting good results)

Strategies used to get around this difficulty:

* 8. FUNDING

   Finding money for your research or project, spending the money in different ways

◯ This is an ethical issue (it affects the rights, health, or safety of people)

◯ This is a logistical issue (it makes your work harder than it should be, or keeps you from getting good results)

Strategies used to get around this difficulty:

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APPENDIX H

DELPHI STUDY ROUND 3

International Research Strategies -- Round III

1. International Assistive Technology Research Strategies - Round 3 of 3

The Human Engineering Research Laboratories welcome you to round 3 of 3 of the International AT Research Strategie study. The purpose of this study is to determine the key difficulties of international/cross-cultural research, and what the best strategies are to address these difficulties.

Thank you for your continued participation.

If you have a concern, please contact:
Alexandra Jefferds
412-954-5302 or anj9@pitt.edu

International Research Strategies -- Round III

2. Item Ranking

* 1. Please enter your name so we can keep track of your continued participation.

Full Name: _____

In the second round, you and other participants in this study suggested strategies for dealing with international/cross-cultural research challenges.

In general, you agreed that:

- ❑ It is very good to have qualified local collaborators help you with your research. They can help you with networking, learning local customs, communicating with participants, and making sure your research is important to local people.
- ❑ It is hard to get funding for your projects. Often, money is only available for certain purposes. It is very important to know the requirements of the grant you are applying to.
- ❑ Survey tools must make sense to participants. The best formats involve straightforward "yes/no" or "good/bad" questions, or focus groups. Complex rating systems such as Likert scales should be avoided because there is too much room for different interpretations.
- ❑ Long before you start data collection, make sure your research is worthwhile. Don't rush into a study because you think it is a good idea. A good approach is to work with local people in the area you want to study, to find out what really matters to them.
- ❑ Do not try to force your own ideas about time management on others. Learn about local punctuality customs, and if necessary, allow a lot more time to get things done.

Some of you also said:

- ❑ Translation is much trickier than it seems. Dialects and cultural differences can give you difficulties where you least expect them. It is very important to have a qualified translator who understands the purpose of your research.
- ❑ You must make sure that participants are fully informed when they give consent to participate. Your ability to do this may depend on the skill of your translator or local collaborators.
- ❑ Adequately paying or otherwise compensating participants can make the difference between them dropping out of the study and staying in.

Now, below are some of the more unique and specific suggestions that you and other participants made. Please say whether you have tried this strategy, whether it helped you reach your project goals, and whether you think it would help in general.

* 2. "Participants should keep a log/diary of daily events. The main purpose is not to collect data, but to keep them focused and reminded of the study."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts…		

Comments:

* 3. "Organize your studies into small projects that can be funded individually with smaller amounts of money."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts...		

Comments:

* 4. "Be very critical of your own motives for doing the research. Make sure the research will benefit your participants or their community, not just you."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts...		

Comments:

* 5. "To keep participants in the study, pay them a 'transport allowance' that is actually more than transportation costs (and therefore an incentive)."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts...		

Comments:

* 6. "Identify a participant who enjoys translation, and use him/her as your translator."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts...		

Comments:

* 7. "Pay for some study expenses out of your own pocket."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts...		

Comments:

* 8. "As an incentive to improve follow-up, leave an instant camera with each end user. Ask them to take pictures of themselves and their families during the test period, and then develop the film for them at the follow-up."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts...		

Comments:

* 9. "Have a good written translation of your study materials."

	Have you tried this? Did it help?	In general around the world, would it help?
Your thoughts...		

Comments:

* 10. Thank you for your participation. You have completed the study. Would you like to be sent an email when the results are published?

◯ Yes

◯ No

11. Any other comments?

PARAPHRASED DELPHI QUALITATIVE RESULTS

Table 13. Paraphrased challenges, strategies, and critiques offered by participants (ps).

Round 1 (Challenges)	Round 2 (Strategies)	Round 3 (Critiques)
Retention & Follow-ups	Involve local researchers and research assistants (4)	
	Pay ps. appropriately (3)	
	Ensure accurate translation and p. understanding of procedures (2)	
	Lots of planning, reminder calls, prep visits to ps. (2)	
	Get all data at one time (don't use follow-ups)	
	Have ps. keep a daily log for retention	Logs can improve accuracy of reporting (4)
		Doubts about compliance (2)
		Log could hinder organic development of ideas
		A log must collect data
	"Transport allowance" for retention or actual transport allowance	Give a real transport allowance (2), or food/snack (3)
		Give a reasonable amount (2)
		Don't introduce bias or obligation with excessive compensation (2)
		Token money always works for retention (2)
		Everything done to acknowledge a participant's time, effort, and sacrifice is appropriate
	Let ps. keep equipment after trial regardless of whether they like it	
	Network with other local service providers	
	Give ps. instant cameras	Cameras need resources to process (4)
		Collect great data, help with reporting (3)
		Has been done before
		Do it in addition to monetary compensation
		Use digital cameras
		Make sure it collects data
Round 1	**Round 2**	**Round 3**
Communication with participants	Find a good local interpreter (3), someone who understands the issues (2)	
	Written translation for studies (3)	Helps only when ps. are literate (4)
		Make sure it is properly done (2)
		Couple with oral translation (2)
		Absolutely necessary
		Difficult and costly to do properly
		Focus on what you are trying to say
		A tool to identify potential communication difficulties
		Include pictures
	Include local people with disabilities (2), as a translator	Avoid introduction of translator bias (3)
		A peer translator would be best (2)
		Hire a good translator (2)
		Find the best (2)
		Works in a pinch
		Need consistency in translators
	Work with good local partners (2)	
	Involve the family members or caregivers	
	Learn about dialects to anticipate difficulties	
	Exclude those with whom communication will be difficult	
	Avoid rating systems	

Table 13. Cont.

Round 1 (Challenges)	Round 2 (Strategies)	Round 3 (Critiques)
Collaboration with local researchers	Plan for enough time at the beginning of the study to discuss and agree on possible differences and different expectations (4)	
	Don't get lost in your own agenda (2)	Ps. are the purpose of research (4)
		Real user involvement is needed and very important (3)
		Working for interests of ps. can improve results (2)
		Application is the rationale (2)
		There is not necessarily a duty to help, only do no harm
	Share or collaborate on publication of research findings (2)	
	Partner with local organizations that are working on the same issue (2)	
	Demonstrate the potential benefit from the results of research to the local researchers and administrators	
	IRB approvals can be difficult to get, so try to get approval [here] in the U.S.	
Round 1	**Round 2**	**Round 3**
Use of appropriate research tools and techniques	Decide measures in planning phase with potential participants or staff (7)	
	Simple, concrete questions	
	Focus groups	
	COPM	
	Rescale Likert scales	
	Literature review to understand psychometrics	
Round 1	**Round 2**	**Round 3**
Time management	Anticipate loose scheduling (4) & allocate more time (5)	
	Plan better or more conservatively (3)	
	Learn how to communicate time concepts locally	
	Pick people up rather than meet them	
	Be comfortable with multiple means of transportation	
	Use a local coordinator	
Round 1	**Round 2**	**Round 3**
Funding	Funding is a problem! (3)	
	Make sure your study design is fundable (3)	
	Have a clear understanding of how the money will be used (2)	
	Design modular projects that allow you to start with a minimum of funding	Small funding steps can increase chances of research success (3)
		Can help if research lends itself to it (2)
		Easier to raise small than large sums of money (2)
		You lose if parts of the research go unfunded (2)
		It helps in grant writing success (2)
		Small projects can require extra reporting work
	Pay from your own pocket	If the researcher can afford it, it helps (4)
		Funding entity should pay (3)
		This should only be "plan B"
		Sometimes this is necessary
		Get reimbursement or tax credit

FULL DELPHI QUALITATIVE RESULTS

(Comments have been edited slightly for readability and anonymity.)

Delphi Round 1

Difficulties entered into the "other" category...

- Attitude of patients and clinicians towards needs for research on AT
- Getting approval from national authorities for the research
- Very difficult to find appropriate human ethics review committee to approve the research project. Many institutions we worked with do not have such service.
- Finding qualified local individuals to manage an on-going research project
- Participants are not willing to come to the institution from remote areas and in that situation researchers are going to their places. *Researcher has to pay the participants for their participation (in many situations).
- Participants often depend on charity for survival and are hyper aware of giving you the answer that makes you happy. Their survival is based on keeping the aid provider happy and they are not naive or unsophisticated in their dealings with you.
- Tools to effectively measure quality of life

Delphi Round 2

Strategies related to the difficulty of...

PARTICIPANT RETENTION
- Pay them in kind....
- Lots of planning, reminder calls, prep visits to participants, getting all data at one time if possible (not to rely on participants follow up). Subjects to keep a daily log of activities related to the study (not as much for data collection as they are lead to believe, but to keep the goals of the study fresh in the participants mind daily). To pay a "transport" allowance which is much more than what is required (As monetary incentive to stay involved and focused). Possible equipment benefits; "you can keep the trial wheelchair whether it works for you or not" (If stated that they can keep it only if it works for them, they may bias the answers toward positive in order to keep the chair for themselves as a back up chair or to sell.)
- Scheduling spreadsheet with partners in the country conducting follow-ups
- Involve local researchers and research assistants, in order to allow for closer follow up over a longer period of time

- This actually has elements of both ethics and logistics, having to choose only one item - I have selected logistics. Strategies: Having qualified local staff managing communications with participants is key. Ensuring that all local staff are trained (and certified as needed) regarding informed consent process and issues of participant confidentiality. Ensuring that all documents provided to participants are accurately translated to appropriate language/dialect. Maintenance of on-going communications with participants. Ensuring that any questions/concerns a participant has will be addressed in an appropriate, timely manner throughout the study. Use of reliable translators as needed. The provision of fair reimbursement for the participants' expenses.
- Compensate for continuing participation
- Networking and linking with other local service providers. Small trick that helped us was leaving an instant cameras with each end users and requesting that they take pictures of themselves and their families during the test period which we would collect on our next visit and process for them
- It's mostly a question of funding for transportation
- More thorough explanation to participants about the rationale of the study
- Engagement of qualified support personnel, maintaining motivation through encouragement and support
- It is both ethical and logistical. In my limited research I've been able to use people with whom I had some long-term relationship and could asses how likely they would be to stay in touch/complete the study. This only worked because I'd lived in the country for 2 years prior to study.

COMMUNICATION
- Interpreter and also involve the family members or caregivers
- Subtleties of the many local dialects can easily be missed by even a very good interpreter. Learn about the dialects that will be spoken by participants and how much of a barrier this will create. Use specific selection criteria to exclude participants that will have difficulty. Perhaps a screening question to test the language barrier before inclusion.
- Ensuring understanding is manageable for consenting, but for long durations of participation in a study (i.e. long questionnaires) it is beneficial to have a fully translated questionnaire for reference or used directly to improve accuracy of responses.
- Always include local people with disabilities and their local/national organizations as part of the research team.
- Again, this topic has both ethical and logistic issues. I have selected ethical here, in part because communication logistics were addressed in the previous question on participant retention. Regarding ethics: clear and accurate verbal and written communications are vital to the provision of informed consent and to ensure the rights, health and safety of participants. Accurate and timely 2-way communication is vital throughout the process. The research staff must be prepared to respond appropriately to any concerns/questions that the participant has regarding the study.

- Require to hire local coordinator to handle all logistic issues and follow up the research progress
- Finding a good local interpreter in advance or identifying one of the participants who enjoys translation is extremely valuable to ones project. somebody with insight into the issues being discussed is particularly valuable
- Have a really good local partner
- Prepare documents in different languages to communicate with participants
- Employment of people who speak indigenous language, allotting more time and patience to communications so complete understanding is achieved
- Work with a translator whom I know personally and trust, who knows the subject matter and understands the goal of the research (what we are trying to learn). Get questions in writing in the local language and have more than one person review the translation to make sure the gist of it is correct. with product design questions, avoid words and rating systems (ie 1-5) altogether if possible--present 3 physical prototypes and have them ranked best to worst in different contexts (indoor, outdoor, on a bus, in a toilet, etc)

COLLABORATION
- An international organization as well as a local organization can easily get lost in its own objectives and regardless of the rhetoric can overlook the interests and rights of users. On the other hand, end beneficiaries don't have a larger picture of the needs of the full community so if left to their own individual choices, may choose methods and solutions that don't accurately meet the needs of the larger group over time. Strategies: Based on little experience, start with very broad data collection regarding need before determining objectives. However, the "voice of the people" cannot always be the final word. Experience in the specific field must be a large factor as well.
- Share or collaborate on publication of research findings because research results and interpretation of results may have major impacts on the work of professionals and advocates in the county where the study takes place.
- Plan for enough time at the beginning of the study to discuss and agree on possible differences and different expectations.
- Patience, respect.
- Again this area has both issues of ethics and logistics. I have selected ethics here because most of the logistics are fairly straight forward. Ethically it is important to partner with local organizations that are working on the same issue. These partnerships can and should be mutually beneficial.
- Demonstrate the potential benefit from the results of research to the local researchers and administrators.
- Prevent negative student interventions taking place in projects. Too often visitors come and work on what they need from the host organizations rather than on what these host organizations or projects need themselves - there is a common perception in developing countries that people come from developed countries to take ideas and use their experiences to benefit themselves. Make sure that the projects invite you and ensure as much communication takes place before the visits and that the activities are appropriate for the users as well as for the visitors.

- IRB approvals can be difficult to get. Try to get approval here in the U.S. Also, establish relationships that pre-exist the study in question.
- Arrange meetings with involved parties in order to have research topics that meet both academic and practical aims
- Upfront clarification of goals, Sharing of finding and rewards
- I've never had to do this with "researchers" per se as I was never asked to produce publishable academic research. However collaborating with anyone means dealing with their goals which may not be your goals, and which may not be communicated to you clearly or honestly. Also it means dealing with their work habits. all that said, you often need people with language skills and community knowledge to make your work possible

TOOLS

- 1. Very, very simple questions with very concrete choices are best ("for this feature, which wheelchair is better, A or B?" rather than, "rate the effectiveness of this feature for wheelchair A from 1 to 10, 10 being the best"). Basically thumbs up or thumbs down for many questions is the clearest and in some cases the only way to get useable data. Focus groups are very good also. Groups with the same dialect, with a little guidance can debate nicely and produce conclusions that seem very well thought out with all angles weighed appropriately by the group. This can be recorded with a tape but simple conclusions are good to record on a form for easier analysis. 2. COPM (Canadian Occupational Performance Measure) is a good model and is validated. The questions are tailored to the individuals specific interest and need for improvement. Improvement is measured specifically for that individual but can be analyzed along with data from many others subjects. It's sort of like a combination of qualitative and quantitative.
- Explaining Likert scales as percentages of agreement and disagreement or redefining the scale of 0-10 as -5 to +5
- We are always meeting the people that we include in the studies and to choose the appropriate tools has not been a major challenge. But the methodology is always discussed during the planning phase because we have the strategy to involve the users.
- One must be very adept at understanding the local culture to develop survey tools. Cultural differences can easily change the meaning of a statement that may seem very simple. Survey tools should be reviewed by local staff to ensure that they are appropriate for their intended use in the specific environment.
- Need to communicate with local service providers to understand the needs for issues to be studied.
- Network, link, talk - make sure this is right - spend time researching locally before rushing into something which will be impossible to change - if you get this right you will be adding value to all concerned - if you are convinced you know better and don't listen well - you will be wasting everybody's time
- Have a good local partner who ensures cultural appropriateness
- To have more comprehensive literature review to understand the psychometric properties of the tools.
- Engage indigenous people in establishing formats,

- Brainstorm with local folks who understand the goal of your research. This isn't just a "cosmetic" issue about cleaning up the survey form it goes way deeper--if you can't explain to a sympathetic and knowledgeable local group why your questions will produce useful info, it may be because your research isn't very useful. If you can convince them why what you're asking is important--and for what you will use the info--they can help you get the info. If they don't understand the point, then they can't. Again, asking people to rank concrete examples best-worst seems to be clearer than scoring them on a scale.

TIME
- 1. Attitudes about punctuality vary. Find out how local people talk about time (i.e. in Tanzania 1:00 is one hour after sunrise in local speak, in Nicaragua you must say, "8 AM en punto" if you want to meet at 8:00 and not 8:30 or 9:00) 2. Picking people up rather than meeting them is best. 3. Take full control of all opportunities for lateness and/or plan for a much longer time than you would think. 4. Things just go wrong more often so plan extra time. 1/4 to 1/2 more time for everything. This is less stressful for everyone than forcing compliance to you idea of timeliness.
- Use more conservative scheduling techniques and be comfortable with multiple modes of transportation.
- We do not have a good answer except that we have to include extra time in our planning for unexpected events, and try to follow up closely.
- I see this primarily as a logistic issue. If possible, one should plan for anticipated delays that might be the cultural norm in a specific area (showing up for meetings 30 minutes late, not working on a particular day of the week, observing religious practices during the day, observing national, local or religious holidays, etc.).
- Require local coordinator to oversee the research project.
- "When in Rome do what the Romans do" - you will not find it easy to dictate and enforce your work ethics in another other persons work place. It will be counter productive. Allow time to fit in and embrace the different ways. prepare in advance , do extra work on your own time
- Where this is a problem, plan your meetings to actually start later than the times they are called for.
- To have a better advanced planning
- Extending initial perception of time needed for project to fit with local norms and lowering broad expectations so you can get simpler yet more definable results
- Allocate enough time for what you're trying to do, knowing that you won't be 100% efficient

FUNDING
- Some times you pay from your own pocket
- Funding seems to follow trends much more than proportion or importance of need. Programs for children seem to have better success than for adults. Those who write proposals should speak to practitioners/implementers more before setting the program objectives. This is very often overlooked and then those who

implement are left to conduct inappropriate or ill planned programs simply because the funding is for specific items and is not flexible.

- Ensure consistent communication regarding usage of funding and timely payment for research staff and compensation for study participants.
- Applying for money is the most difficult issue. Some times it is an ethical issue that unfortunately people do not put priority on funding projects for people with disabilities.
- It can become rather frustrating addressing the ever-changing priorities of funding agencies.
- Funding is always needed to hire local coordinator, to secure the commitment of the staff and administrator and to compensate the cost for subjects to participate in the study.
- Always a problem - I don't have any strategies for this = if you find some please share them!
- Design modular projects that allow you to start with a minimum of funding.
- To be more aware of funding availability and to write well-written proposals with good study rationales and designs
- Upfront definition of where dollars go & communication with funding source. Matching funds with flexibility to expedite when some sources fall through
- Both an ethical issue and logistical. Ethically: do you really need to know this info to solve a problem, or are you just curious, or do you need a thesis topic? All are legit reasons for research but you better be upfront with everyone which it is. logistically: it's fucking hard to get people to pay you to gather info, everyone's more interested in doing what they already believe to be right (distributing vast numbers of chairs, doing really thorough trainings) vs. the possibly uncomfortable process of examining assumptions and potentially finding out you've been barking up the wrong tree all these years

Delphi round 3 comments

Critiques of the suggested strategy...

HAVE PARTICIPANTS KEEP A DIARY TO IMPROVE RETENTION
- From my experience this has not been a relevant challenge.
- Participants in a study I was involved in were asked to provide ~monthly averages (3 times over the course of the study) regarding the distance they traveled in a wheelchair and the percentage of time spent engaged in particular activities. It's difficult for anyone to estimate averages like this, so it may have increased accuracy to have the participants work with a daily log
- The participants should be close and attentive in the daily events so that it reflect in their studies.
- Sounds like a good idea. Not sure about compliance.
- For demanding study requirements that involve daily actions....or for extra proof/evidence on questionnaires, this may help to reduce recall bias

- I made this comment. It's hard for participants to go home and remember to think about the effects of the intervention when it comes time to answer questions. A log helps them to provide more detailed and complete feedback when being questioned later. Not possible with participants who are not literate, except if they use a provided tape recorder. Checking in by phone periodically is also useful for participants who have phones or access to phones.
- Asking participants to keep diary or a log would be a big challenge since they would not be motivated to do so unless the purpose is well explained.
- It is difficult to tell if this would be of value to others but I don't feel it would assist me in any way - if anything it might hinder organic development and work flow
- Although it might help, if the data are not to be used, then the step adds work for participants.
- I have not tried logs, but had more collaborative meetings to help motivate, but a log would probably help also.

PLAN SMALL PROJECTS TO MAKE FUNDING EASIER
- Small projects require a lot of extra reporting and too much resources might be assigned to reporting that could be used for research.
- It might help if overall projects lent itself to segmented progress.
- Small study projects can be linked to different funding agencies according to the proposed outcome of the study.
- This is just like an entrepreneur venture where the individual can concentrate more in all steps.
- This is somewhat obvious as it's usually easier to raise small sums than large sums.
- Seems sometimes the opposite problem--grants only for big blocks of cash
- Less is more would be the summary of this point...and it is most likely that a smaller, more manageable and tightly focused study will yield more reliable results at a fundable price point. Additionally, recommendations from the study will be more implementable in the local environment if they are smaller scale and targeted efforts.
- One down side is that if you don't get the other funding, your data may not be useful without the unfunded parts. if you fund the whole thing at once, you can count on it getting done.
- In case of funding as a limiting factor, organizing a study into small parts is a plausible alternative as long as the plans still gives the stakeholders the full picture of the whole study.
- This makes it easy to let funders influence the outcomes of your work by dominating the funding criteria and not allowing for the core activities and long term objectives to be met or satisfied - when parts of the overall project are not funded the whole project is put at risk
- This is a good strategy for research in general -- you don't have to hit a home run to score.

- Yes, and it helps in grant writing success to break them down into smaller projects.

BE VERY CRITICAL OF YOUR MOTIVATIONS FOR DOING THE RESEARCH

- You always have to be critical and always involve the users in order to get their input and their comments on the importance of your research. Real user involvement is needed and very important.
- I think this is extremely important to do. If done honestly, it can result in greater benefit to the participants/community and will probably improve the research through the utilization of participants who have a greater interest in the research.
- As per my understanding primary benefits always go to the community.
- The object of research is to promote welfare to the society and not for individual interest.
- There can be only one motive: To improve the lives of our beneficiaries. I'm not really critical of my own motives as this has always been my only motive
- I absolutely agree with this, but I don't see it as no negative a thing to be honest about how you (the researcher) benefit. this is OK if no one is harmed. I think there is a definite duty not to harm but there is not necessarily a duty to help.   just be honest with everyone and provide compensation where appropriate.
- If you look into the community and imagine people asking "what's in it for me?", then it is likely that the research will be more accepted, partnerships will be easier to form, and recommendations will be better received.
- I have always researched only what I needed to for product development purposes. I think it's a good approach.
- Regardless of the level or type of research studies, the applications should the ultimate rationale.
- So often researchers and students come to Africa looking for material to improve their study experiences, this often drains local resources, disappoints the people they use as a source of information and creates barriers for future interactions. The people involved and those that give their time and resources to assist   these students or researchers get disillusioned as to the value of outside research ever assisting them positively in terms of long term sustainable activities and goals. they feel used and often abused by the process
- As above, a good strategy in general, not just for international work.

PAY PARTICIPANTS A "TRANSPORT ALLOWANCE" AS AN INCENTIVE

- We should not pay the participants to be in a research study. In a research study the incentive should not be the reason to participate. We cannot motivate the participants by extra allowances. I have some times used food (tea, suger, mili mil, soap, etc) to show our appreciation, after they have contributed and participated.
- I think it's important to check with local sources and maintain an amount that would easily cover the participants' expense, however over compensating can change the motivation and the reason why participants are participating. Monetary compensation aside, the participant(s) should also be benefiting in the short and/or long term from their actual participation in the research.

- Token money always keeps the subjects into research and it's just to honor them for their time and efforts.
- The idea is to keep the participants involved in studies, by allowing some incentives in the name of transport cost.
- Usually you need to pay for lunch as well as transport.
- This is analogous to the "per diems" most of us are receiving while in the field. I prefer to call salary salary, however this is a minor issue.
- Everything done to acknowledge a participant's time, effort, and sacrifice is appropriate
- It must be done in a way that it doesn't bias the data, make the participant feel obligated or build an expectation of positive feedback
- A reasonable amount of allowance is usually a good way for participants' involvements.
- This might help in some circumstances but we would rather be inclined to provide the transport and a meal as an incentive. I personally do not feel comfortable with bribery. If you want to pay them to take part in a project say so outright
- There is a fine line between reasonably compensating someone for time spent (OK) and creating a financial incentive to participation (could constitute exploitation of a vulnerable population).

USE A PARTICIPANT AS A TRANSLATOR
- In the one case in which I did this, it was out of necessity as our dedicated translator suddenly became unavailable. In this case it worked out great, however I think that in some cases it could easily go the other way. Translation should be done by a non-participant to ensure that one participant's viewpoint does not affect other participants.
- I think, a subject would always would better translator for his/her peer. which would be peer translator
- A good translator amongst the participants should be picked up and utilize his/her service.
- Pay for a good translator. There is no substitute.
- In general, take the time to find people with good attitude and aptitude. One very stupid thing people from developed countries do is arrive assuming the locals are idiots, and therefore hire some idiot because he meets this expectation, then leave with that expectation confirmed. Take the time to find good people, they exist.
- It is probably better to have a translator who is not a participant so that you don't risk questions being interpreted as the participant/translator's opinion (another bias)
- Best to have consistency in interpreters throughout so difficult to make sure the first participant becomes the interpreter for the rest.
- The translator for any validation studies should be a well trained one to ensure the translation quality. Simply enjoying the process might not suffice.
- People work best and commit to the process when they enjoy their participation and take pride in a job well done   i always choose translators who volunteer from the crowd or who are recommended by others in a group or an existing project -

quality translations is not always about grammar but about understanding the subject and needs of both the people who are listening and those that are talking
- Engaging the audience is good. Have to be careful that the person does not editorialize if he/she disagrees with what you have asked him/her to say.

PAY FOR SOME STUDY EXPENSES OUT OF POCKET
- Often you just have to pay some expenses out of your own pocket.
- Aside from occasional petty cash issues I think the primary funds should be provided by the funding entity. This helps to set parameters and determine the realistic scope of the project
- It would only happen when researcher have some money to spend. I know some people do that, which always works.
- It creates a sense of sympathy in the participants when they notice that the over-budgeted study expenses is integrated by the entrepreneur out of his own pocket.
- Of course this would help. But unless you have the money, why pay your own money? Go out and raise more money, instead.
- This should only be "plan B", it is usually the result of sloppy proposal writing. But yeah, do what it takes.
- It is good to not miss opportunities, or delay action, when in an international setting as long as the justification for a purchase is sound and budgeted. it is good to set up reimbursement or advances where receipts are used to justify/quantify expenses.
- The overall expenses should be projected before the commencement of a project. Any ad-hoc expenses may not be appropriate.
- "No pain no gain" personal commitment to projects is invaluable.
- There are some simple ways to get tax relief for donations like this, so your $$ goes further.

USE CAMERAS TO IMPROVE RETENTION
- Could be a good idea, but then you need facilities to process the photos. This might not be available out in the rural area.
- Great idea. I've seen other projects that have done this and it helps to portray the day-in-the-life aspect of the participant's experience. This also works well with wedding guests!
- It's a little hard to work like this but I know it has already been done in this area.
- I think the expense might be prohibitive as only a small percentage would actually take pictures, and unless they are digital pictures, cost of developing might be too much.
- I did it with a $50 digital camera and got some great info. Most people in the US can't be bothered to read your report, or won't trust your conclusions anyway even if you do. But everyone looks at pictures of not triedrd world and trusts the opinion they form from those pictures.
- It may well work, but I believe monetary compensation is a more widely desired method. the pictures would be nice, but it is in some respect an allocation of how

the participants allocation is spent....if this is done in ADDITION to compensation, then this is probably a good idea to increase follow-up success.
- Digital may be better. Prices are coming down. Be sure to ask for specific pictures and be consistent.
- Most of the participant might not be fond of the idea of taking pictures/video unless it is an essential part of the project.
- Outstanding results. No better way to creep into the lives of your end users and identify the real issues and impacts of your work - nothing better
- I foresee logistical challenges in getting the pictures to the participants.

USE A WRITTEN TRANSLATION OF YOUR STUDY MATERIALS
- It would help for those who can read/write, but many cannot read/write properly.
- Absolutely necessary. Have it translated to the foreign language(s) and then translated back to your language to ensure that it's accurate.
- Most of the translations are not appropriately match so it would be always helpful to have properly translated and written.
- As long as people can read, a good translation with lots of pictures is very good.
- Really helps hammer out just what you're trying to say, and makes translation easier.
- At the minimum, this process is an opportunity to find terms or concepts that may be confusing in another society (particularly important if a measurement tool is selected purely off of reliability and validity findings in the US, but is being applied internationally). The trick is to do this, if possible, before submitting the research protocol to the IRB....so changes can be rapidly included and approval can be obtained with a final version of the measurement tool.
- Helpful but some may need it explained. Some are reluctant to say that they don't read well. For consistency, I would read or explain all written material to all participants.
- Study materials with good translation are the key to success for a validation study/survey study
- If your end users can read otherwise use translators. Often the written word is not as powerful for the end user as practical training, demonstrations and assistance with doing it themselves. With other levels it is more appropriate. every project will have to be assessed separately for this and you might have different needs in one project - adapt to suit the situation
- Difficult and costly to do it properly (back-translation, etc).

FINAL COMMENTS
- Good luck! Looking forward to read the report and learn from your results.
- Thanks for the opportunity to participate. Look forward to seeing the results.
- This something that I have done for the first time, it looks very interesting. I would be waiting for the results and a summery of the outcomes.
- The positive outcome of the research should be communicated to the participants so that the beneficial effect and the importance of research is forwarded to the community. Such post period communication experience a fruitful response.

- This was cool. I feel I have benefited already (reading the suggestions of other researchers) and look forward to the results. I appreciate that you kept the survey so concise, it fits into a "just came back from lunch" window.
- Great questions....and learning opportunity to see other commonly faced challenges with recommendations on how to improve study integrity.
- Nice job.
- Warm regards to you and I hope the outcome provides positive reinforcement and guidance for future research which is so badly needed in so many parts of the developing world
- Thanks for looking into this. Your results could be very useful.
- Thanks

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