Measuring Environmental Factors in an International Context: A Social System Perspective for an Extended Question Set

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Introduction

People living with long-term functional limitations are very familiar with the influence of the environment, physical and economic structure, as well as cultural and social attitudes, on their lives. These factors can either restrict or support the individual's full participation in society or have a neutral impact. Our understanding of disability is difficult because of the influence of these environmental factors which can vary by participation area, by individual goals and choices, by type of action difficulty causing limitations and other characteristics of the person such as age, gender and race. Though these latter personal factors are seen as a separate area in the ICF (2001), the inclusion of attitudes in the environmental context does not necessarily allow for the separation of attitudes toward disability alone when the person's age, gender or race can confound social attitudes toward disability.

Many of the theoretical models of environmental impact on disability creation organize their approaches at two different levels, the individual and the societal levels. The immediate environment of the individual, including settings such as the home (reflecting the immediate family), the workplace (the specific job the person holds), the place of worship (the specific religious organization which the person chooses), and other similar settings which surround the individual, create micro systems in which the individual is personally involved. The person deals with the physical and material elements of the context as well as the attitudinal responses which are reflected in the interpersonal interaction that take place in these micro systems. The societal level of environment reflects the structure and organization of various systems in the community that provide services, protection, shelter, food and other products, entertainment, and health care for the total population including things like transportation systems, policing, building construction systems, grocery chains and other forms of product distribution and health care systems. The individual only comes in contact with a small portion of the larger systems, but the larger systems dictate the general approach to disability. While it is well recognized that both these environmental areas, individual and societal, can have a great affect on the disabled person's ability to participate in their chosen social roles, we have very little national or international data

on the patterns of environmental barriers or supports. Most of our information and understanding of these environment/person interactions are based on anecdotal stories of personal experience rather than organized data on the general environmental context. While rehabilitation organizations often explore the nature of the context their clients need to deal with and in many cases have developed questionnaires to collect extensive environmental information from their clients, the data collected in this manner, while detailed, is usually focused on one type of functional limitation or impairment and is not generalizable to differently impaired individuals or different geographic areas in the general society. It raises issues, but is not necessarily applicable for national policy purposes.

Considering Cross-Cultural Environment Issues

However, recent national and international legislation such as the American's with Disabilities Act (1990) and the International Convention on Persons with Disability (2006) establish a mandate for understanding the role of the environment in disability. Once the individual moves outside of the home to shop for food, visit a doctor, use public transportation, go to school, or work at a job or any of the more complicated activities associated with participation in a social system, the measurement of disability needs to be concerned with the interactive nature of the person and the environment, the real crux of disability. In most surveys today measurement of this interaction is associated with the activities that reflect ***actual social participation of the person(such as working at a job or going out for dinner)***, ***without an elaboration of the context within which the activity takes place***. While we may know from measuring basic functioning and simple task activities, what a person brings to the attempt to use their local environment such as public buildings and transportation, we know nothing about the buildings or the transportation system itself. The regularity of transportation schedules, the type of vehicles, the routes they travel, the fares they charge, or the experience the individual has with that system all can influence the usefulness of the system for the person. The same is true for the person without a basic action difficulty as well – we have nothing to help us understand what one has to negotiate in order to use the transportation system successfully, **nor** do we have the factors influencing the ***choices*** a person may or may not have about how to use what is available.

There are questions that have been developed, primarily by rehabilitation professionals, to try to get at these more complicated aspects of the environment on social integration and participation, but they are relatively simple and focused on the individual's personal evaluation of the difficulty of the experience or the frequency they have the experience rather than a description of the nature and extent of the problem encountered. While

the evaluation of the experience is very helpful, it focuses the resulting data on the disabling impact of the environment on the person (level of difficulty and frequency) rather than describing the scope of environmental barriers or supports in a locale. Generally, as well, the questions have been developed for a particular type of limitation, most frequently mobility limitations, and are not necessarily applicable to all types of functional limitations or in all cultures. Additionally they do not include anything about the element of choice. Using such measures gives us some clues about environment, but provides a false sense of having measured the environment when in actuality what has been measured is the impact of the environment on the individual (see Whiteneck, 2004).

Contemplating cross-cultural measurement of environmental facilitators and barriers for persons with limitations in basic activities creates a vision of wildly different images, from very modern high speed rail transportation in Japan to travel by donkey or mule in Tibet. It evokes images of one story mud huts in Rwanda to multi-story skyscrapers in Shanghai or steep mountains in Alpine regions to miles of plains in the Caucuses. Where does one begin? **One begins by recognizing that the issue is not the sophistication or simplicity of the transportation system or the variety of architectural styles or the various topographies of separate regions, but rather,** ***how what is available works to inhibit or facilitate the participation of the individual with a variety of functional limitations***. In a country where there are no curbs, there aren't any needs for curb cuts. Cross-cultural measurement requires creating an approach that is culturally neutral while at the same time recognizing that physical topography and weather, building structure, means of transportation and culturally approved methods for doing things are what create the barriers or supports we seek to identify. In other words, we **are not** examining the differences between transportation systems or home structures across cultures, **rather we want to know how *the* transportation system – whatever form it may take – works for the population with disabilities within each culture**.[1] Unlike the approach from the rehabilitation perspective which tries to understand the individual environmental experience and solve it or modify it, we are approaching this problem from a more general viewpoint by using what is experienced to try to identify the range of possible environmental problems from a population perspective, more similar to creating a profile of structural/cultural environments as they impact persons with physical, mental and emotional limitations. The question we are addressing does not focus on the differences among specific factor A (for example the specific types of building

[1] Ideally we would want to know that information for everyone in the culture since the social structure may provide barriers and supports for everyone in one way or another. However, our first concern is to identify the types of barriers and supports experienced by persons with disabilities.

structures) across cultures X, Y and Z. Rather it addresses the facilitation or restriction that the society has developed in a particular environmental element (the types of building structures or the type of transportation system) as experienced by the citizens with disabilities within that particular culture. In other words our objective is to create a profile of the range of accessibility in the various cultures as experienced by a representative sample of the population in that culture that report a variety of functional limitations as defined by the Washington Group short set of questions. However, since we are asking questions of individual respondents our data can serve two purposes, identifying the individual experience of person X as they attempt to move around and participate in their cultural environment and when aggregated the individual experiences will create a profile of the barriers/facilitators in the specific culture which will give us a more general picture of how the culture is accommodating its population with disabilities. Although a respondent will only be able to respond based on their own personal experience with the immediate types of environmental components with which they come in contact in their micro systems, aggregating the answers to the questions will reflect the more general representation of the cultural experience of everyone with any type of functional limitations. Such a description can then be examined in terms of whether or not the respondents are disabled, elderly or the type of functional difficulty they report. Certainly our expectation is that persons using wheelchairs or other mobility devices can have different areas that create barriers or supports than persons with vision or hearing difficulty.

This approach to measuring environment differs from asking questions about the individual's difficulties functioning since humans are the same across cultures in terms of their types of physical, mental and emotional functioning capacities. Cultural differences may dictate that some people walk more than others or that some carry heavy loads on their heads and others on their backs, but we all have what can be considered the same equipment (arms, legs, eyes, ears, minds) and when there is a problem with any of those functions we experience difficulty and or limitations in the same way, inability to see or hear, walk or carry. However the cultural organization of societies exist within a variety of natural environments and weather conditions which create very different problems that have generated a variety of alternative solutions for architectural construction, transportation and other social problems like the distribution of resources and the development of value systems. So when we measure the environment we are no longer measuring similar areas of functioning, but instead very different approaches to what are similar requirements for life: housing, feeding, transporting, educating, employing, protecting, etc.

In the past we have recognized that disability actually is the outcome of personal limitation caused by health conditions and impairments and the impact of those limitations on full participation as allowed or supported by environmental characteristics (Brandt, 1997). One element that contributes to disability is the functional limitations a person experiences related to their health condition or injury. That is the individually specific element. All humans have the same basic physical, mental, sensory and emotional functioning potential regardless of the culture they inhabit. Some people may have greater or lesser degrees of physical strength, but we can recognize strength or mental ability (or its lack) wherever it exits, whether it occurs in a black man in Africa or an Asian woman in Bangkok. The experience of functional limitation is relatively uniform cross culturally although type of diet or employment in various areas may increase the presence of certain kinds of limitations (Foetal alcohol syndrome in South Africa and among Native Americans). However, the cultural environment, both physical and social can vary widely. Similar levels of physical functioning difficulty can have widely different outcomes based on the physical and cultural environments the persons occupy. In order to measure the effect of culturally different environments it is necessary to develop measures that can vary with the characteristics of the specific culture, but can also capture the cross national experience of persons with varying levels of functional difficulties. So, for example, assume there are two men with similar mobility limitations due to a spinal cord injury at the 5th vertebrae. The ability to toilet independently for person A, who lives in an accessible new apartment construction (with indoor plumbing, raised toilet seats and transfer bars) in California, will be very different than the ability of person B to toilet independently using an outhouse in Bangladesh. Our objective is to somehow make those very different environmental experiences meaningful measures for use in examining the environmental impact cross culturally without comparing the actual detailed environmental elements. Person A when asked about the accessibility of toileting facilities can report independent toileting capacity as successful based on a supportive environment while Person B can report his independent toileting as restricted due to inaccessible facilities.

Measurement

The various taxonomies associated with environmental context for persons with disabilities identify multiple conceptual categories of the environmental components that can provide barriers or supports to persons with disabilities, including such things as building structure, weather conditions, modes of transportation and attitudes of others. Typically the tools that have been developed for assessing the environment will concentrate on only one or two aspects of participation that have been considered

important and measurable. For example, the built environment seems to be an area that can be measured successfully and is frequently used in examination of circumstances of the aging population. However the built environment is one that covers very broad areas of possible participation, the immediate environment of the home, the work environment or the environment of any of the various types of public places, from parks to health provider's offices. Each participation area can have a variety of features including the multiple components of the built environment, the material aspects within the built environment and other people occupying that same context. It is not possible to encompass all types or all elements of environmental contexts. Therefore in development of measures, decisions must be made as to the level of approach (individual or societal), environments associated with a range of participation activities to be included and the elements within that participation area to be addressed. It is not possible to encompass the complete environmental context in any great detail, so decisions about the focus of measurement require careful consideration.

The orientation of the approach to measurement has also been very focused on the relationship of the individual to his/her environment primarily coming from a rehabilitation perspective, particularly from the perspective of an individual with a mobility limitation. As proposed by Stark et al (Stark, 2007) the purpose of the environmental questions they developed were to examine the ecological validity or receptivity of physical features from the perspective of individuals with mobility impairments. Their focus was accessing a building and using it. A very different approach is that of Clark and George who focused on what are called the 3 Ds, density, diversity and design, environmental conceptions that are used to represent the built environment in many study areas such as examinations of transportation use, poverty, and crime and violence (Clarke, 2005). The focus of measurement in this approach is housing density, the ratio of number of housing units per square mile in each census tract, land use diversity, measured by the proportion of workers in the tract who commute to work within 5 minutes. Other aging literature is closely related to a medical approach and concerns about rehabilitation. They examine the household itself and ascertain physical characteristics related to presence of stairs, accessibility of bathroom and kitchen facilities and adequacy of lighting. Finally a fourth frequently used measure of environment for the aging population is associated with the use of assistive devices to mitigate some of the limitation (Agree, 1999).

Since we are trying to develop an internationally useable set of measures to identify environmental factors and their impact on participation, this strong overlap of cultural and physical environments makes it difficult to create measures that identify similar

constructs across various cultures which may use different tools or have very different ways to accomplish a specific task. Getting water to make a pot of soup, for example, may have very different physical and intellectual requirements. In one country, where modern plumbing only requires turning on a faucet to get water from a sink that is situated next to a stove, makes the process very simple compared to other countries (or areas of the same country) where acquiring water requires going to a well, filling a container, lifting and carrying the container with the water back to the cooking area. How do we reconcile those two different experiences and how do we measure the environmental contexts so that we are getting at the environmental barriers and facilitators that are conceptually equivalent? **Or, do they need to be equivalent**? Is it possible, given a particular culture, to identify the nature of physical and social barriers and supports that exist without comparing across cultures to ascertain the similarity or differences among the descriptions of those barriers or supports. In other words, **is it more important to identify specific barriers that exist that have a commonality across all or most cultures or can we examine the common activities (maintaining a family life) or common facilities/locations(community churches) or common services (transportation) that exist and develop a country specific profile of the types of barriers or facilitators that are associated with these locations or types of activities**. This is probably easier to do if we concentrate on physical environment than if we examine more culturally related activities such as specifics of work situation or the nature of the value system a culture has developed. Thus, for this **first** attempt at environmental measurement, I propose an emphasis on the physical environment and common services associated with the three primary areas of daily activities, home, transportation and community spaces.

Having examined the question sets that have been developed to try to begin measuring the interaction of individual and environment I identified three approaches to this task. The first approach is a descriptive one. Keysor, Jette and Haley have used this approach in the HACE instrument (Keysor, 2005). This instrument focuses on the self reported description of mobility related characteristics of the home (such as the presence of stairs), community and transportation system (such as whether or not transportation is close to the home), use of assistive devices, and appraisal of attitudes (attitudes of people in the community in general). Another version of the descriptive form of instrument is that developed by Stark et al (Stark, 2007) which focuses on community receptivity which through a rank ordered checklist (CHEC) which can be administered in the community by health professionals or community members and does not require respondents or questions. It does not reflect the personal experience of the individual with mobility limitations but can document the potential accessibility depending on the

nature of limitations. As such it is a valuable tool for rehabilitation professionals in order to understand what skills need to be addressed to improve patient mobility.

The second and third approaches to measuring the environment are also found in rehabilitation literature and focus first on the personal experience with the environment based on level of difficulty and frequency and secondly with the evaluation of that experience. Whiteneck's et al (Whiteneck, 2004) work with the CHIEF combines a measure that identifies the frequency a particular difficulty or problem is experienced in the environment with an evaluation of the level of that problem. As an example, the question about transportation asks "In the past 12 months, how often has the availability of transportation been a problem for you? Daily, weekly, monthly, less than monthly, never." It is followed by a question asking "When this problem occurs has it been a big problem or little problem?" The answers provide a combination of frequency and intensity descriptions of the problems the person experiences when interacting with the transportation environment . In **actuality the resulting score is a measure of the level of disability based on the person/environment interaction as defined in the IOM as the displacement in the environmental mat** (see figure in Appendix depicting that relationship). The amount of displacement in that mat represents the amount of disability that is experienced by the individual and this combination of questions provides an approximation of that construct.

In the work of Gray, Hollingsworth, Stark and Morgan (Gray, 2008) there is a similar combination of identifying an environmental element as an influence on participation and the evaluation of that experience with the environment element. In this instance, however, the respondent can identify the environmental element as an influence that is either helpful or limiting and can also provide an indication of the frequency so that a score can include both positive experiences as well as negative ones. Questions from Gray et al (2008) include home and community environmental components and also information about community destination access. A representative question from the Gray et al instrument asks: "In your home, do the following influence your participation activities? Stairs? Yes, No, NA. If the answer is Yes the following questions are asked: "How much? (Help a lot, help some, limit some, limit a lot – level of difficulty or helping) and How often? (Daily, Weekly, Monthly, Less than monthly – again a frequency measure). Once again there is a combination of frequency and intensity of the experience only this approach provides a scale that ranges from positive to negative rather than just a negative descriptor. The result of the combined measures of how much and how often in this instrument is another version of displacement in the environmental mat. Both are good measures of the severity of disability that the individual with a limitation in a basic action experiences in their immediate environment.

The resulting data provide important information for the rehabilitation process by identifying where in the environment the individual patient experiences problems (or in Gray's study also support), the disabling effect the person experiences as a result of the problem and the intensity of that effect. In a very simple way it reflects the results of the person – environment interaction. However rather than creating a measure of the environment, the resulting measurement is a descriptor of the person /environment interaction. A simple indication of the barriers/facilitators in the home or the transportation availability without how much of a personal problem it is and how often it occurs would be a more focused environmental descriptor from the person's perspective.

Table 1 provides examples of the questions used to depict various environment areas that have been used by researchers. It gives examples from both descriptive applications and respondent interviews about experiences.

Table 1: Examples of Instrumentation to Examine Environmental Aspects

Source	Description		Personal Experience	
	Immediate Surroundings	Extended Surroundings	Describe Experience	Evaluate Experience
Natural Environment				
Gray, Hollingsworth, Stark, Morgan (2008)				In your community does summer weather (heat and humidity) influence your participation in activities? help a lot, help some, limit some, limit a lot
Whiteneck, Harrison-Felix et al (2004)			In the past 12 months how often has the natural environment – temperature, terrain, climate – made it difficult	When this problem occurs has it been a big problem or a little problem?

			to do what you want or need to do? (Daily – Never)	
Intersection of Natural and Cultural Environment				
Built environment				
Keysor, Jette, Haley (2005)	How many steps are at the main entrance of your home?	To what extent does your local community have public transportation that is close to your home?		
Gray, Hollingsworth, Stark, Morgan (2008)			How frequently you encounter the home feature (stairs): Daily, Weekly, Monthly, less than monthly	How much home feature (stairs) influence participation in activities: help a lot, help some, limit some, limit a lot
Whiteneck, Harrison-Felix et al (2004)			In the past 12 months, how often has the design and layout of your home made it difficult to do what you want or need to do? (Daily to never)	When this problem occurs has it been a big problem or a little one? (Little, Big)
Assistive Devices				

International Measurement

Purpose

How do these data differ from what is needed in *an international* survey context? To begin with, data in the Census and survey situation can focus on either the impact of the environment on the individual (difficulty and intensity as defined above) or on a description of the environment in which the individual is doing their functioning or both. However to include both would be subject to more respondent burden and greater cost. The issue becomes, what is the purpose of the data collection about environment? Do we want to document the person/environment interaction in various countries across the world which will provide information about how the environment disables individuals with functional limitations or do we want to document/measure/describe the environment as it is experienced by the population with disabilities in various cultures to identify areas where improvements are necessary. When we document characteristics of the individual experience of the environment based on difficulty and frequency we describe the person/environment interaction without necessarily ascertaining exactly what aspects of the environment create the problem or provide the support. If we have persons with disabilities identify the environmental locations that give them trouble and indicate what characteristics of that environment cause the problem or facilitate access we get less information about the level or intensity of the environmental problems for the person, but more information about the location and characteristics of the environment that create problems for persons with disability in various cultures. However, the mapping of environmental barriers/facilitators even with an extended set of questions is very difficult since space limitations, costs and respondent burden will limit the range of questions that can be asked. Instruments used in clinical situations, which only focus on the personal impact of environment are just too long for general survey purposes. Asking environment questions in a survey context requires a serious examination of the purpose of the questions and will of necessity force a narrowed focus.

Hierarchy of Environments

If we consider how we live our lives, we recognize a hierarchy of contexts that can influence participation and the range of venues in which participation takes place. The contexts of concern radiate out from the person's living space to the areas where their most distant travel will take them. In some instances the range is very small and limited; in others it can eventually include the space station. For most it takes place primarily in their native community and possibly nearby communities (see Figure 1). The most basic level of that hierarchy is the home context, the place where the individual does most of their living, eating their meals, sleeping and participating in family relationships. One can think of these contexts in several ways, first focusing on the physical situation, meaning the size and shape of rooms, the lighting, the

availability of water or heat, or the presence or absence of stairs and so forth; or a second way of thinking about it is in terms of the social actions that take place in those physical environs including the way one goes about using the space, the kinds of things that can or cannot be accomplished in the space or the possible interactions with others in the space. We can also think of the physical space as it relates to life activities, cooking, eating, bathing, sleeping, interacting with family and friends. In some instances it will not be easy to separate the physical environs from the social way of doing things which will make measurement more difficult. In terms of measurement of these experiences across architectural styles, room and building sizes and comfort, one wants to think not so much about room size, existence of multi levels or number of rooms, but of the ability to accomplish activities within the space that is available and as it is constructed. It may be that a person cannot access all the rooms in a home, but can they accomplish all the activities within the rooms they can access?

The next level of engagement is the immediate community surrounding the home. The various activity spaces – work, school, recreation, service provision, all require the same examination of the physical structural environment that was established in the home. However the environment outside the home may or may not include paved areas, streets with traffic or close neighbors. Distances between the home and places of work or school, community centers and churches, or shopping and service provision may vary in some instances requiring some form of transportation. For that reason the need for transportation and the types of transportation available become an important additional piece for understanding the environment.

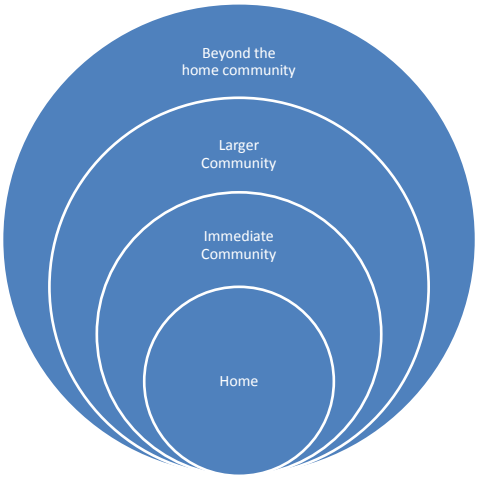

Figure 1: Hierarchy of Participation Contexts

The final element of concern in this first approach to understanding and measuring environment on an international basis is the presence or absence of discrimination or negative attitudes that exist in the social environment in which the person with disabilities engages. Though it would be difficult to identify all social interactions and interpret the negative attitudes that may exist in each one it probably is important to at least get some perspective on how widespread discrimination is in a particular culture.

Possible Approaches to Data Collection

There are two possible approaches to environmental measurement – the personal difficulty with the environment which is reflective of the respondent's situation acting in that environment - or a profile of the built environment/transportation system of the culture that provides a map of the typical locations/resources available in the country. The first allows us to capture the lived experience of a wide variety of persons with limitations or difficulties. The second would provide some key focus areas of the environment in which important participation takes place and provide a general description of the facilitators or barriers that those environments provide. This can be a general documenting of how the individual experiences the commonly used areas of environment and how well those environments fulfill the needs of the general population with disabilities. It would appear that focusing on the activities which are common across cultures (important life activities) and aiming for a general level of data

would avoid the biggest cultural differences among countries and allow us to talk about home architecture, architecture in public spaces, transportation systems and possibly a broad view of discrimination. If we take this more general view of the environmental system it will allow us to use some of the intra-country details of the transportation system or the home architecture to help respondents to understand what we are asking in the questions but without making those detailed comparisons across countries. For example if we ask about steps in homes in a culture where there are generally steps used, that particular detail can be replaced in cultures that rarely use steps with another more commonly encountered problem area that requires similar functioning capacity such climbing up an incline. The same kind of substitution is possible when asking about transportation. If a country does not have subways or bus systems and instead use horse or human drawn carts, that detail can be included. However the international comparison will focus on the more general aspects of the transportation system such as the cost or frequency when it is available, whether the vehicles are accessible or even whether transportation is available to the places that respondents want to go. The country could use the data relevant for their cultural way of doing things for within country analysis while we would have to develop a format for the between country comparisons. The comparison result would take the form of a statement indicating the general area of the problem as opposed to the specifics. So while in one country lighting in the home may be based on a fire or oil lamps while in another country it is based on intermittent electricity and in a third country it is based on regulated electricity (some form of rationing), the countries would be compared on whether or not lighting in the home was or was not considered as something that limited or prevented the disabled individual's participation in family life. The nature of the type of lighting in that approach is not a comparison element.

Recommendations to the Committee

The following process was followed to produce the questionnaire draft:

a. Identify the home environment; important community environments; transportation and discrimination as the primary areas to address in the question set.
b. Identify the general description approach be taken to develop the data based on the individual's experience with their home, community and transportation systems.
c. Conceptualize the issues of environmental accessibility related to home, work, or community activities in terms of multiple forms of limitations, so that questions need to be general enough that they are applicable to people with any type of functioning difficulty.

It is important to note that the environmental factors influence everyone in a population, not just persons with disabilities. It would be preferable that the total population surveyed be asked the environmental questions so that the environmental elements can be identified accurately as limiting the entire population or limiting the population with disability to a greater extent.

Based on the organization of this paper and my first test draft of questions, I also recommend that we discuss this proposal in three stages at the meeting:

1. First an explanation of the various approaches to disability measurement and (depending on the conclusions of the committee) a suggestion for our preferred approach to the purpose of the measures we are creating, followed by a discussion.
2. A second presentation of possible focus areas of environmental questions – (page 7 of the paper) – common activities (work, family, civic, etc); common facilities or locations (homes, workplaces, community settings, etc.) or common services (transportation, protection, health care, etc.) or a combination of some kind. The draft questions are focused on a combination. This also to be followed by a discussion.
3. Finally the last presentation/discussion on if or how or can we work in the element of choice, what are the ideal number of questions (should there be a short set and a more lengthy set, multiple short sets??). The last thing we also need to discuss is the possibility for testing, where and is there any possible funding.

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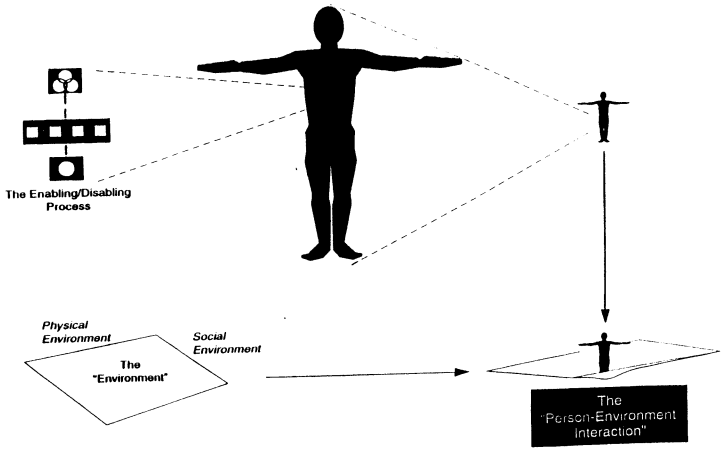
APPENDIX

Current IOM Model



Source: Brandt & Pope, 1997

FIGURE 2: Source: (Brandt, 1997)