People with Disabilities Designing for the Mainstream User: Empathic Design Research
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Introduction
Worldwide population demographics are shifting. People are living longer and expecting a higher quality of life. Over a typical lifespan people can develop a range of physical disabilities which are no longer perceived as a barrier to having a good quality of life. Users expect more than functionality alone from their products. They expect their cultural, social and aspirational needs to be satisfied by the products with which they surround themselves.

Industrial Design (ID) practitioners are innovative problem solvers, serving as the voice of the user in the product development process. They ensure more appropriate design outcomes by engaging and studying people in their naturalistic environments to gain a deeper understanding of user behaviors and perceptions towards products. Designers are traditionally and ostensibly able-bodied men and women.

The user experience of people with disabilities is often significantly different from able-bodied people. They face challenges that an able-abled person may not even be aware of. More often than not, people with disabilities are not in a position to take for granted what others accept without question – e.g., able-bodied people have an expectation that they will be able to enter, exit and move around a new venue easily, where a person in a wheelchair may not have the same assumption. The conditions that provide the starting point for people with disabilities re-imagining the material landscape (i.e., the products that people surround themselves with and that fill their personal and public environments) may or may not be radically different from their able-bodied counterparts. What they must contend with, however, are the limiting factors of the environment, the nature of their disability and interpretation of it by others, as well as the seemingly universal phenomenon of devaluation (Vash & Crewe, 2004). In particular, people with disabilities face barriers in accessing the materials, skills, and facilities where industrial designers are educated and work.

To the extent that barriers are excluding people with disabilities from the designing process, we are faced with an under-utilized resource and therefore missing significant opportunities for novel and more creative solutions – not just in the realm of everyday objects for people with disabilities, but in the realm of everyday objects for the entire population. An ongoing course and research project (Disability + Relevant Design) at the University of Illinois Urbana-Champaign are concentrating on breaking down barriers which prevent people with disabilities from becoming active participants in the designing process.

Empathic Design Research
Empathy “… is simply about achieving greater awareness, an extended imagination and sensitivity to another person’s world in a powerfully memorable way” (Fulton-Suri, 2003, p. 52). Empathic design research deepens the designer’s understanding of the user throughout the designing process. Intangibles such as feelings, emotions, dreams, aspirations and fears can provide the designer with critical visual cues, triggers and inspiration that provide the essence to more balanced functional and supra-functional (Weightman and McDonagh, 2003) product outcomes (e.g., iPod, Mac Air laptop). “Developing empathy enables the designer to become closer to the user through respectful curiosity, genuine understanding, and suspension of judgment. Through this intimate, trusting relationship they create knowledge together” (McDonagh et al, 2009, p. 310). Using empathic methods such as ethnography, empathic modeling, and shadowing, designers gather a range of textual, verbal, and visual data within the natural environments of the users. The incubation period that follows provides designers with an opportunity to reflect, imagining a design solution/outcome that refines, develops and/or matures
what already exists. It requires designers to develop new ways of seeing, thinking, and experiencing as they generate more visionary ideas and concepts. Empathic design research builds on the synergy of individuals developing relationships (Khuri 2004) and is the essence of qualitative design research (Fulton Suri 2003). Industrial designers combine this qualitative research with more traditional objective research data (e.g., market research, socio-economic and anthropometric data) to fuel their creativity, develop inspired products, and ensure more relevant and innovative design outcomes.

It is beneficial for industrial designers to look beyond their own personal life experiences and capital and embrace life-expert-users as co-creators to inform the designing process (refer to Figure 1). Designers need to connect deeply with other people, developing empathy by engaging, listening and understanding their outlooks. However, simply including the life-expert-user as a member of the design team does not ensure effective synergy or fluid communication, there must be a basis for understanding between these people with very different capitals (e.g., background, physical abilities, and education) to enable connections and interchanges. This dialogue allows the life-expert-user who engages with the world from an alternative perspective (i.e., a person with disabilities) to become an integral part of the designing process (Strickfaden et al, 2009). Rather than designing for the users, we need to be designing intimately with them to ensure that more intuitive design outcomes are generated. Empathy is the critical component that deepens the designer’s understanding of users who may be very different from the designer. Empathic design research relies on the user being an active and participatory partner within the information creation and designing process.

Conventionally, user feedback was sought after the concept refinement stage had occurred near the end of the designing process (refer to A). Then with the more user-centered approaches of Universal design (refer to B), users became a more integrated part of the process. We advocate that design is too important to leave to designers alone and integrating the user at the beginning of the process offers more benefits to all, including the mainstream user (refer to C).

For many professions, empathy may not be critical, but for designers to be effective they need to be able to identify and acknowledge their own boundaries of understanding and knowledge. Using empathic design research methods is a key factor in “expanding the designer’s empathic horizon” (Denton and McDonagh 1999, McDonagh 2008, Laurel 2003) and provides designers with more relevant data and creative product outcomes.
Case Study: Disability + Relevant Design

Empathic research methods are being employed in an ongoing, design course-based project at the University of Illinois Urbana-Champaign. The case study highlighted here describes the participants, course context, and empathic design research methods. It also examines project outcomes, including product opportunities, and explores their potential to be responsive to a shift in demographics in which people are living longer and are expecting a higher quality of life than previous generations. We will illustrate the engagement of life-expert-users and product design students in preparation for their professional practice.

Figure 2. Designers and students with disabilities participants in the Disability + Relevant Design pilot project, fall 2007.

The Disability + Relevant Design course began as a pilot project within the industrial design studio course curriculum in the fall of 2007. This ten week research project brought together University of Illinois Urbana-Champaign students with physical and sensorial disabilities and industrial design students from the School of Art + Design. Its goal was to raise awareness of how industrial design can positively impact the daily experiences of people with disabilities through interactions with products within their personal material landscape. The project was a result of the inspiration and collaboration of the academic and professional team of Professor Deana McDonagh (School of Art + Design), Dr. Lydia Khuri (University Housing) and Susann Heft Sears (Division of Disability Resources and Educational Services).

D+RD Pilot Project:
Graduate and sophomore level industrial design students were partnered with students with disabilities who came from diverse social and educational backgrounds and were studying subjects outside the design field (refer to Figure 2). The students with disabilities were volunteer participants and not enrolled in the design course.

This was a non-traditional research relationship - rather than researcher/subject, these partners worked to form a shared understanding and empathy for each other, developing designer/life-expert-user roles. While the students with disabilities became co-creators of knowledge, the designers primarily developed products for their student with disabilities partners. Research fieldwork was conducted in the students with disabilities naturalistic environments on the University of Illinois Urbana-Champaign campus (e.g., students’ kitchens, dining halls, and
classrooms). Using ethnographic type observations (refer to Figure 3), the designers gained insight about their partners’ interaction with their material landscapes. "Ethnography provides rich insights into how people make sense of their world. … By examining the artifacts that reflect people’s lives, we learn what they value and hold dear. As a result, we can design products and services that evoke meaningful experiences for them" (AIGA, 2007). Design ethnography "is 'people-centered' in that critical inquiry is informed by and responds to experiences and needs of people, especially those belonging to traditionally disenfranchised groups" and "it supports empowerment through the development of common knowledge and critical awareness" (Barab et al, 2004). 

![Figure 3. Ethnographic observation in a naturalistic environment](image1)

![Figure 4. A design student simulating limited mobility while preparing meal.](image2)

Design students employed empathic modeling to temporarily experience disabilities by using wheelchairs or limiting their own flexibility with mechanical devices (refer to Figure 4). While it is impossible for a designer using a disability simulating device for a brief moment in time to authentically understand the life experience of a person with physical disabilities, it is an extremely powerful means by which the designer can begin to generate products with more intuitive outcomes, not only for the individual with disabilities, but for the entire population. The project provided a unique opportunity for the able-bodied design student researchers to go outside their personal comfort zones, transcending boundaries (cultural, social, medical and/or educational) as they worked with a population group that may be overlooked by the design community. The pilot program included students with a variety of disabilities: Amputation, Cerebral Palsy, Dysreflexia, Muscular Atrophy, Muscular Dystrophy, Retinitis Pigmentosa, Sclerosis, Scoliosis and Transverse Myelitis. The industrial design students eagerly seized the opportunity to develop design concepts that responded directly to everyday ‘real’ and ‘authentic’ needs of their life-expert-user partners.

The projects undertaken emphasized the development of small, simple, insightful products which had an incremental impact on the user, focusing mainly on improving the quality of life for the student with disability. Particular emphasis was focused on activities of daily living (e.g., cooking, eating, working, exercising, and bathing). The goal was to create products that did not carry a stigma and would visually integrate into the individual's lifestyle and personal environment.
Figure 5. Designers created small, simple, insightful products focused on activities of daily living for their student with disabilities partner.

Products that were conceptualized included: accessible shelving for a wheelchair user, a headset for a student with Cerebral Palsy which uses puffs of breath to dial a cell phone (refer to ethnographic research in Figure 6), and a pointing device to enable a law student with paraplegia to use his computer. The designer of this pointing device, a sophomore industrial design student, was one of three finalists for the Lemelson-Illinois Student Prize for outstanding innovation and invention with this product.

Figure 6. Jade uses a cell phone with assistance. She would like to be able to make a call in privacy. This pilot project resulted in a public exhibition at the Illini Union Gallery (refer to Figure 7), which coincided with Disability Awareness Week in April 2008, that celebrated the student collaboration and illustrated the designing process and concepts. The exhibition enabled the school to share this project with the wider university community of students and faculty, as well as with the general public. It was featured in local press and drew a television film crew from Public Broadcasting System (PBS) where this project is highlighted in a story about the founder of the Division of Disability Resources and Educational Services (DRES) at the University of Illinois – Dr. Timothy Nugent. The exhibition provided the opportunity for critical conversations with colleagues outside design that further supported the efforts to develop the project into a more substantial and sustainable course that integrates the contribution of faculty and students from across the university.

Figure 7. A public exhibition at the University of Illinois Illini Union Gallery celebrated the student collaboration and illustrated the designing process and concepts. The opening was hosted by the Vice Chancellor of Academic Affairs.
D+RD Ongoing Course:
The vision of Dr. McDonagh, Dr. Khuri, and Ms. Heft Sears for this industrial design studio project in 2007-2008 has led to transformative education. An ongoing ID seminar, Disability + Relevant Design, began in fall 2008 as a design and general studies course. This seminar has been host to students from disciplines as diverse as product design, architecture, engineering, and sport/recreation/tourism. It brings students with disabilities and able-bodied students into the same learning/studio space.

In these ensuing semesters, the program has become more formalized than the initial pilot project, immersing the students in video media, literature and guest lectures by stakeholders in the field of disability, both from within and outside of the university, some of whom are people with disabilities themselves. It has also included a design component similar to the pilot project where the designer partners with a student with disabilities (a fellow class member or a volunteer participant) to identify and develop a product for specialized needs.

Some of the techniques taught in this course for eliciting authentic needs for both people with disabilities and able-bodied people (Weightman & McDonagh, 2003) include personal diaries - audio, video, and text based (Lifchez & Winslow, 1979), one-to-one interviews (Bruseberg & McDonagh-Philp, 2001), observation (Kuniavsky, 2003), cultural probes (Aldersley-Williams et al, 2000), ethnographic shadowing (Hammersley & Atkinson 2003), and empathic modeling (McDonagh, 2008).

All members of one Disability + Relevant Design class made and wore “disability goggles” to briefly simulate the experience of Retinitis Pigmentosa. The goggles impaired the students’ peripheral vision by restricting their focal area in each eye through a narrow cylinder to a cone of about 2 degrees (refer to Figure 8). The students carefully walked down two flights of stairs (the student in the wheelchair took the elevator) and across a gallery to a coffee shop where they purchased beverages. Frustrated with difficulty in seeing the sugar, cream and coffee lids, a number of students abandoned the efforts to sweeten their coffee. Though this may seem to be a small detail, it highlights how quality of life can be eroded significantly over the course of an average day living with disabilities.

Figure 8. This design student’s field of vision is reduced to a cone of about 2 degrees due to Retinitis Pigmentosa (her vision field is illustrated by the image on the left). The class built “disability goggles” to perform empathic modeling of this condition.

The Disability + Relevant Design course enables students to develop more empathic approaches when designing for, and with people with disabilities/life-expert-users. This is a paradigm shift from User-Centered Design (i.e. the designer consults with the user to support effective new product development) to a more intimate working relationship involving the user as a co-participant and co-creator, actively imagining and developing new concepts together with the designer.
The students involved in this course have become critical, active participants in developing the design course curriculum along with the faculty. As faculty and students both gain insight into issues of disabilities, more appropriate research approaches and design pedagogy develop. Looking forward, the course goal is to reduce (if not demolish) barriers that are excluding people with disabilities from the creative process, and create methods and opportunities for design by people with disabilities. Students will continue to be engaged in new ways of thinking and developing more universally designed products and environments usable to the greatest extent possible by all people without the need for adaptation or specialized design (Mace, 1997).

Conclusion
This design course aims to involve the students and faculty in activities outside their personal and professional comfort zones. Prior to participating in this course the design students generally are not familiar with people with physical disabilities, and the students with disabilities in turn are not familiar with participating in the designing process. Though research projects are often rated and valued by the outcomes, the projects in this course create moments with student interaction that demonstrate a shift in thinking, practice, and designing. Though the data are not generalizable, they certainly are transferable. The students will be able to develop their own protocols and approaches to design research based on this project experience. Their interaction demonstrates a shift in thinking, practice, and designing.

The design course and the research associated with it require cooperation, partnership and teamwork among the participants - able-bodied students and students with disabilities. Collaboration tends to rely on natural respect, patience, tolerance and a shared goal. Within the process of collaboration, a shared working language develops that helps to define and sometimes redefine terms, language and processes. This takes time and effort to develop and nurture. The lessons learned are less traditionally studio-oriented (drawing, modelmaking) and more about developing and maturing the designers’ empathic horizons, becoming active partners as they learn to design with the users, and satisfying increased user expectation of products.

References


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i Students with disabilities involved in the Disability + Relevant Design pilot project and the ongoing course are registered with the Division of Disability Resources and Educational Services (DRES). All have a physical and/or sensory disability, are over 18 years of age and are studying and living on the University of Illinois Urbana-Champaign campus.

ii Deana McDonagh, PhD, is an Associate Professor in Industrial Design within the School of Art + Design and a faculty member at the Beckman Institute for Advanced Science and Technology (University of Illinois (Urbana-Champaign). Her research concentrates on the emotional domain of product development and nurturing empathy between the designer and user.

iii Lydia Khuri, PhD, Program Coordinator for Global Crossroads and Intersections Living Learning Communities in University Housing which focus respectively on international issues and on all dimensions of diversity within the United States. It was in this collaborative capacity that she initiated the project that became the Disability + Relevant Design Pilot Project and is co-director of the program.

iv Susann Heft Sears, M.Ed., is a Disability Specialist with University of Illinois Urbana-Champaign Division of Disability Resources and Educational Services (DRES). Her primary job responsibilities include determining reasonable accommodations for students with physical and systemic disabilities along with providing advising and support on career transition issues for all students registered with DRES.