# AC 2007-1480: AIDS FOR ASSISTED LIVING PROJECTS BENEFIT BOTH THE ENGINEERING DESIGN CLASSROOM AND THE DISABLED COMMUNITY

**Kara Chomistek, University of Calgary**

**Graham Armitage, University of Calgary**

**Phillip du Plessix, University of Calgary**

**Daryl Caswell, University of Calgary**

**Clifton Johnston, University of Calgary**

**Mohamed Nazir, University of Calgary**

**Marjan Eggermont, University of Calgary**

**Diane Douglas, University of Calgary**

**Brigit Knecht, University of Calgary**

# Aids for Assisted Living: Creating a new curriculum to eliminate socially constructed barriers in disability research


## Abstract

Independent life becomes a challenge for individuals with disabilities when disability research and development fails to produce results that are beneficial for the disabled community. Poor research and development in disability research creates socially constructed barriers that not only offend the disabled community but also make means of attaining the maximum amount of independence more difficult. These barriers include the discriminatory actions and attitudes of non-disabled individuals as well as poor design in infrastructure, communication and transportation. Insufficient engineering and a lack of consideration of the needs and abilities of the disabled community has led to the incorporation of a Aids for Assisted Living project in a first year engineering curriculum. Engineering Communication and Design is a course that has developed two projects in collaboration with the disabled community in hopes of increasing awareness among students and staff as well as providing means for the community to be actively involved in product development and research. The first project focuses on increasing the independence of children with disabilities in play, through the design of toys and multi-functional play centers for a children's hospital. The second project focuses on the increase of independence for adults with disabilities around the home, specifically in the kitchen, bathroom, bedroom and living room. Both of these Aids for Assisted Living projects were developed through extensive consultations with the disabled community with the common goal of starting to diminish some of the socially constructed barriers experienced in disability research. This is hoped to be achieved through student-research subject interaction as well as engineering principles and design. Engineering principles, incorporated through the foundation of the design trinity: familiarization, functionality and testing will be applied to disability design by students who will use these principles to create a fully functional prototype.


## Introduction

It is challenging for individuals with disabilities to get the necessary assistance they need to become fully 'enabled,' without surrendering their independence to those wishing to reverse the effects of their 'disablement'.[1]

Insufficient access to engineering and a lack of consideration for the disabled community leads to the question addressed by this paper: Can the incorporation of engineering design education together with unsolved problems in aids for assisted living help to both overcome socially constructed barriers in disability research and provide engineering students with a meaningful experience in real world design?

Individuals with disabilities face challenges every day to acquire the necessary assistance they need to perform basic activities of daily life. For disabled individuals, independence is the ability "to perform practical tasks alone or without direct help" as well as "being able to make decisions about one's own life, to be in charge in daily life, regardless of how this is being accomplished."[2] Independence is one of the highest priorities of the disabled community but methods of gaining this independence particularly through disability research has often been seen as bothersome and unsuccessful.[1,3]

Disability research is often "researcher –orientated" concentrating on the non-disabled researcher's agenda and methodologies while ignoring the disabled participants wishes and concerns.[3] Kitchin describes how the 'data mining' of these individuals does not fulfill their wish to participate in disability research and only adds to their continual frustration with "academic abuse."[3] By exploiting the knowledge of individual's with disabilities to advance the goals of the research, the research subjects become subjugated by the researcher and are left with no more knowledge of research development than before research had begun. Research conducted in this method leaves little room for expansion of the researcher's methods and ignores the inclusion of ideas from those who would benefit the most. The non-disabled researcher experiences an "automatic blindness" towards the needs of people with disabilities and therefore severely hinders the progress of disability research and development.[1]

The lack of emphasis on the experience of what it means to be disabled has led to the creation of socially constructed barriers that have had a notable affect on decreasing the independence of disabled individuals.[4] Socially constructed barriers are the challenges disabled individuals face on a daily basis that are a result of non-disabled individuals' limited perspectives and ignorance towards the disabled community's needs. These barriers are created by the lack of organization in disability research and society to include the needs of the disabled community. Unintentional discriminatory actions and attitudes of non-disabled individuals as well as poor design in infrastructure, communication and transportation all contribute to the construction of these barriers and must be reversed before innovation towards disability independence is investigated. To improve the level of satisfaction experienced by the disabled community when involved in aids for assisted living research, specific self design projects were developed for the first year engineering curriculum (2006/2007) at the [Removed for blind review] School of Engineering, University of [Removed for blind review]. The central goal of these projects was to remove socially constructed barriers at several levels: student, faculty, practical and social. Aids for assisted living devices help to eliminate some of the socially constructed barriers experienced by individuals with disabilities by centering the design process around the disabled individual's particular needs and concerns. The design oriented projects focus on decreasing the amount of dependence that disabled individuals have on others and increasing their independence through assistive technology. The development of this technology encourages the creation of a strong relationship between the disabled community and the student researcher allowing them to work together and produce successful results.

In formulating the projects, data mining and medical methodologies were supplemented through extensive consultation and collaboration with the disabled community on every aspect of project planning. During these consultations members of the disabled community were able to express how this project could best suit their needs and together as a team their requests were transformed into a viable curriculum for the students. Disabled individuals and non-profit organizations were given the opportunity to have full participation in the creation and direction of the projects as well as organizing student run research and development. Student run research for the project is based on the recommendations of the community and presents one mutual agenda for providing a means to achieve a higher standard for independent life.

## Background

*Models of Disability Research*

Two models exist in the field of disability research: medical or individual and social. Traditionally the medical or individual model has been the on the forefront of disability research. In the past few years the medical model has been challenged by disability advocates for excluding the fundamentals of the social model. The right of a disabled individual to have equal opportunity to express their opinions, make decisions and live their life as they wish is the corner stone of this new social movement. The push to view individuals with disabilities as any other member of the non-disabled community has been ignored by the traditional model which continues to characterize the disabled individual by their physical handicap and limitations.

The medical or individual model of disability limits a disabled individual to live their life based on diagnosis, clinical practice and 'medical facts.' The medical model does not take into account the feeling of social oppression experienced by disabled individuals and subjects them to false expectations, led by medical statements of categorization and biological stereotypes. These stereotypes can be carried into disability research in such a way that social issues are often overlooked and research is focused only on the medical agenda. By concentrating on the medical model the researcher ignores the needs of disabled individuals and alienates them from the researching process. The estrangement of disabled individuals from disability research can and in our experience most often does result in a biased research process that does not satisfy the needs of the disabled community. The medical model of disability inhibits and oppresses the needs of disabled individuals by focusing on partial diagnosis which ignores their experiences and opinions.

While the medical model of disability focuses on 'medical facts' that categorize individuals with disabilities as being "flawed in some aspect of their humanity,"[1] the social model of disability concentrates on the experience of living with a disability, as an individual with different abilities and needs. The lack of emphasis towards the social model has led to the creation of these 'socially constructed barriers'.[4] The Union of the Physically Impaired Against Segregation (UPIAS) in 1976 defined socially constructed barriers as "disabilities which are imposed on top of our physical impairments by the way this society is organized to exclude us."[5] This statement clearly defines the lack of disability conscious design such as building design, transportation, and communication as well as the lack of respect for individuals with disabilities by those that had these designs executed. Therefore, the deficiency in disability conscious design has led to the exclusion of individuals with disabilities from fully participating in activities of daily life and an increased movement towards the social model and the elimination of socially constructed barriers.

In Kitchin's paper on *The Researched Opinions on Research: disabled individuals and disability research* he interviews thirty-five disabled individuals about their experiences and opinions concerning research. The general feeling of these people is one of annoyance, frustration and betrayal believing that most researchers have a 'set of baggage' and a 'predetermined agenda' that they bring to a project that does not benefit the disabled subject. These individuals don't want a 'theoretical exercise' but are asking for 'something that is going to have an impact on our [the disabled community's] lives'.[3]

A continual theme that can be seen throughout Kitchin's paper is the irritation towards the lack of action in disability research.[3] Interviewees express the researcher's "need to advertise their 'research when it is finished", and make sure it 'reaches an audience who can act upon it".[3] Kitchin advocates for a need to change the movement away from the medical model of disability and focus on positive, mutually satisfying relationship between disabled individuals and disability researchers.[3] This symbiotic relationship is something we are going to make happen will providing an enhanced learning environment for engineering students.

*Link to Engineering Course Work*

Engineering Communication and Design at the University of [Removed for blind review] is a course that introduces students to the practical concepts of design. It teaches students how use drawing, writing, communication and team management skills to develop a design idea and bring it into a prototype stage. The course encourages the use of a unique design methodology or "design trinity of familiarization, functionality and testing" to fully explore all aspects of what the students are to design.[6] Familiarization fully immerses the students into the background and influencing factors of their design. Functionality focuses on the ability of the design to satisfy the final goal of the project. Testing allows the students to test their designs and encourages them to redesign areas that may demonstrate weakness. Within this design concept students learn to use mathematics, communication, art and science as tools to improve their skills as designers and recognize how they will be able to use these abilities in the future. Since its inception, a key feature of the course has been to create greater social and cultural awareness within the engineering student cohort.

*Recognition*

The success in both the focus and methodology of the course has been recognized by a number of awards. In 2003 this program won the Alan Blizzard Award for Collaborative Education. This award is presented to one program in Canada each year by the Society for Teaching and Learning in Higher Education and includes the publication of a monograph describing the philosophy of the course by McGraw-Hill Publishers. At the American Society for Engineering Education Conference in Salt Lake City in 2004, a paper describing the familiarization, functionality and testing components of the course won the PIC V best paper award, the best paper in its category out of 2500 papers. In addition the course won the Curriculum Innovation Award from the American Society of Mechanical Engineers resulting in a presentation at the 2006 ASME Beijing conference. Finally this course is the subject of a "Green Guide" on Creative Problem Solving published by the Society for Teaching and Learning in Higher Education. The Guide was released at the 2006 STLHE conference in Toronto in June, 2006.

*Previous Projects*

Engineering Communication and Design 251/ 253 is a course that moves away from the traditional engineering curriculum by annually introducing new, innovative projects and teaching techniques. The course begins with a series of smaller projects each focusing on a separate portion of the design trinity, and finishes with a series of larger projects focusing on trinity collaboration. In past years curriculum focus has included: designing speeding skater crash pads, skating robots, building sand diggers for children with disabilities and medical equipment. The

most recent project involved designing multi-functional platforms for small rural communities in Ghana. These implements were run from exercise bikes to simulate a ten horse power diesel engine found in Ghanaian villages. This project was moderately successful but the distance of Ghana and the lack of resources for the student researchers making the multi-functional platform a difficult design project. Students felt that their designs would make little difference in a country so foreign and far away from them and no plans went past the prototype stages. The lack of feedback from the Ghanaian community made measuring the success of student designs difficult, therefore course coordinators began to focus more on local concerns.

## Method

### *Approach to Project*

Fifty-two contacts ranging from non-profit organizations to professionals at the University of [Removed for blind review] and the [Removed for blind review] Children's Hospital were approached about helping to develop a curriculum based on developing assistive living devices and participating in the project. With these contacts a mutual agenda was created surrounding their opinions regarding their own disabilities and or expertise. Participants made suggestions on how aids for assisted living devices could impact their own lives, which kinds of implements would be best for student design, which disabilities were in most need of assistance and how much future involvement they would like to have in the project. Participants also emphasized the expense of such implements and suggested the introduction of a budget to the student designs. Attempting to address the concerns brought to life by Kitchin,[3] project organizers wanted to make the curriculum a rewarding experience for both the students and the disabled community by making a point of assuring that disabled participants would not "see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life."[7] To ensure that none of the participants felt violated in their experience, every part of the curriculum plans were discussed and approved with community members. In his paper Kitchin expresses how "interviewees felt they had been exploited- their knowledge and experiences 'mined' by the researcher(s), who were never heard of again."[3] This "rape model of research"[7] was avoided by continual updates and a final project proposal that was discussed and critiqued by all participants at the end of the planning stages.

### *Collaboration*

For this project to be successful, collaboration with the community to over come socially constructed barriers was one of the biggest concerns. To address these concerns individuals with disabilities were included in every stage of the planning process. It was the wishes of the organizers of the curriculum to not discriminate against the disabled communities ideas and give them the opportunity to help over-come design barriers that have caused them a large amount of grief. By helping to plan the curriculum and assisting the students through their designs, participants in the project are able to start a movement towards eliminating socially constructed barriers. These individuals in collaboration with course organizers are able raise social awareness about the needs of the disabled community and how their needs can be further met in the future.

## Curriculum

*Justification for Concentrating on Aids for Assisted Living Devices*

Aids for assisted living devices and assistive technology can assure that disabled individuals are able to "maintain their health, their functional ability, and independence"[8] through personal choices, on their own terms.

Although this solution seems simple in solving the challenge of a disabled individual's independence, there are many barriers that prevent candidates for assistive devices from obtaining the right assistive technology for their needs. Such barriers include financial and health plan support as well as social, physical and communication difficulties in areas of disability research and development.

One of the most significant factors that prevent individuals with disabilities from obtaining assistive technology is the cost of these implements and availability of outside funding. According to O'Day and Corcoran, "financial barriers are the most common reason for [disabled individuals] not having needed assistive equipment."[9] Health plan coverage is often restrictive and does not replace or implement needed equipment in a timely matter. Individuals that are disabled "are nearly three times as likely to live in households with a combined annual income below $15,000 [American],"[8] making it difficult when health plan coverage does not produce immediate funding. In California, a study of "medical necessity decisions by managed care organizations found that requests for durable medical equipment are the most likely to be denied on the basis of medical necessity."[8] Due to the lack of funding by health care organizations approximately half of disabled individuals with assistive devices and over three-quarters of those that have had home renovations purchased them without any "third-party payer" assistance.[8]

Aids for assisted living devices must be first developed and researched before they are put out onto the market. Physical, social and communication barriers often lead to difficulties in full research participation amongst disabled individuals. People with disabilities are limited to partake in research methods using "standard research instruments"[10] such as surveys, census' etc. Meyers and Andreson make a point that disabled individuals do not always have access to "standard sampling methods" and can not always "comprehensively" complete these instruments as well as non-disabled individuals.[10] The instrument content, if these individuals are able to participate, is so demeaning and so insulting "that persons with disabilities cannot or will not take part."[10] It is barriers such as these that subject disabled individuals to "the handicap of inappropriate research methods and research instruments"[10] and prevent them from accessing the equipment they need to gain a full range of independence.

*Development*

The development of aids for assisted living devices should be conducted as a "partnership approach" where the disabled community has "a degree of control over the research process."[3] The organizers of the Aids for Assisted Living project for first year engineers approached this project in conjunction with the community, while paying close attention to their needs and concerns. It is clear that individuals with disabilities want "no participation [in disability research] without representation."[11] This was a main consideration throughout the project development and has had the greatest impact on shaping what the students will experience. The

project was designed to reduce many concerns of disability research and development seen in the past and aims to begin a new relationship between the researcher and the community.

Modifications to the curriculum were made based on community suggestions and concerns. After the curriculum was created, each participant was contacted and project content was reviewed. The curriculum was adapted according to each focus groups suggestions and a new curriculum was formulated from their concerns. Such concerns that were addressed included student awareness about each disability, their knowledge about anatomy, how detailed the case studies given to the students should be and to what degree sensory disabilities (seeing, hearing etc.) were considered. Case studies and the process of student research were tailored so that both the students and the community would be fully satisfied about the project and enjoy the results.

The irritation towards the lack of response and advertisement of completed research seen in Kitchin's paper,[3] was avoided by hosting an open house. The open house will take place at the end of each project and display all student designs, making them public for both the community and the media. In addition to the open house, an assistive technology magazine was contacted and it was arranged that the top ten student designs would be considered to go to market.

*Curriculum Outline*

Engineering Communication and Design is a year long course that will see approximately 750 engineering students in the 2006/2007 school year. These students are separated into six lab sections consisting of four labs each (24 labs in total) and will produce approximately 200 projects per semester. Students work in groups of approximately three or four and have a budget of 40 dollars to construct their prototypes.

***Fall Semester***

The fall curriculum for Engineering Communication and Design 251/253 2006 begins with a series of smaller projects. These projects include a small introduction to tool safety as well as a three week project on designing for developing countries. The focus of the fall semester however was a seven week long project dealing with designing aids for assisted living devices. This semester focused on children with disabilities and concentrated on recreation and play. Two sub-projects within this genre were split between the 750 students enrolled in the course. These projects included designing toys and games for children with disabilities as well as multi-functional play centers. These implements were not necessarily designed for therapy but more so that children with disabilities could partake in play without much difficulty.

Suggestions from therapists, parents and community members led the way for the development of the fall curriculum. A special request from these groups, especially from the [Removed for blind review] Children's Hospital was to create a multi-functional play center.

To cover a wide range of child disabilities, each lab section was assigned a particular disability. The organizers of the 251/253 curriculum contacted members of the community about which focus groups would be the best to design for. Each group was assessed based on need and community participation and finally narrowed down to six. The six disabilities that the fall project focused on were Arthrogryposis, Cerebral Palsy, Paraplegia, Quadriplegia, Guillain-Barre Syndrome as well as children going through rehabilitation due to accidents or infections.

For each focus group, community members were asked to create two anonymous descriptions of individuals that coincide with their respective disability. These descriptions or case studies include the individual's background, cultural information, disease description as well as particular needs and abilities. From these descriptions student designers developed their projects over the course of six weeks and physically developed and built a final prototype of their design. Throughout the six weeks students orally presented the conclusions of their research and developed two reports and a series of drawings on the progress and final stages of their design.

On the seventh week students presented their projects to the public, media and kids in week long open house. Children and their parents were be able to walk through the labs, talk with the students, look at the development of student designs through drawings and posters as well as play with the toys, games and play centers. At the end of this week long event seven projects were chosen based on the reaction from the community as well as the discretion of the project organizers. The prototype of these projects will then be sent to the assistive technology magazine, Abilitations Creations, where they will be further assessed and possibly be put on the market.

***Winter Semester***

The winter curriculum for Engineering Communication and Design 2007 will be run similarly to the fall curriculum but will concentrate on a different aspect of aids for assisted living technology. The winter semester focus is on adults with disabilities living in an apartment or a housing situation where renovations are not a possibility.
Through contact with the community it was discovered that not all individuals with disabilities can afford to renovate their homes. Other cases showed that some individuals experienced a temporary disability where permanent renovations were deemed impractical or undesired. Another scenario was the case of living in an environment with non-disabled individuals. What was a good environment for individuals with disabilities wasn't necessary the best situation for other non-disabled individuals in the home. From the collaboration of all these community concerns the concept of designing non-permanent, removable assistive devices was implemented for the winter semester.

To add to the success of student design another suggestion made by the community was to build test beds in each of the labs, mimicking domestic environments found in the home. After many conferences with the disabled community and non-profit organizations it was determined that the best environments to concentrate on would be the kitchen, bathroom, bedroom and living room. Each of these environments was then assigned a particular lab and built to the satisfaction of the community. An open house took place at the end of the curriculum planning stages (before both semesters begun) and the community was able to further critique building designs finalizing the basis for the curriculum.

In addition to building the domestic environments, the winter curriculum differs from the fall by choosing disabilities focusing more on the older population. Disabilities for the winter semester were chosen based on recommendations from non-profit organizations and various disabled individuals working within these organizations. The focus groups for the winter session include Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Cerebral Palsy, Quadriplegia, and Paraplegia as well as stroke victims. Again, each society produced descriptions of two 'mock' clients and one disability was distributed per lab section. For the winter semester students will have another

six weeks to design for their clients and must produce a functional prototype by the end of week six. Again students will deliver two reports, several drawings as well as produce an oral presentation.

On the end of the seventh week there will be a second open house show casing the student's design process and their prototypes within each of the domestic environments. The community and media will again have the opportunity to walk through the labs, talk to the students and see the final results of their development and research. Similar to the fall semester community members and participants will be handed out surveys asking their opinions about their participation and student design. From the community reaction and organizer feedback five more prototypes will be sent to an assistive technology magazine with the opportunity to go to market.

## Application

### *Community Involvement*

Community involvement is one of the most important aspects contributing to the success of the curriculum planning. Through the time and commitment of community members, organizers of the design course curriculum have been able to form a respectful relationship that will hopefully contribute to the success to this project. In addition to the community's generous involvement in the co-planning of the curriculum, many participants have agreed to come in during the semester to help advise students with their designs. The community is willing to prepare presentations, answer questions and provide students with information about their particular disability. Participants and non-profit organizations will be spending time with each lab, working with the students to produce a high quality design. For all the time spent helping the students the community will witness some innovative ideas and start a new movement towards community serving disability research.

### *Familiarization, Functionality and Testing*

As the basis for the Engineering Communication and Design course, the design trinity is essentially the basis for student design work. Applicable to areas of assistive technology, the design trinity was uniquely incorporated into the student design experience. For the first two weeks of the project students will focus on familiarizing themselves with the disability they are designing for as well as assistive technology. This familiarization will include internet research as well as a visit from community participants to each of the labs. These visits will give the students the opportunity to fully experience what designing for a real client is like and how to address their needs and concerns. The following two weeks will focus on the functionality of their devices. They will have to look at the specific functions of their implement and determine the best ways to gather materials and construct it. Once the construction of their implement is complete, students will then look at the last design component, testing. Here they will eliminate problems not foreseen in the early design stages and will work on the process of redesign. After the completion of all areas of the design trinity students should have familiarized themselves with the most essential tools of the design process and produced a relatively successful prototype.

## Measuring the Success of the Project

By the end of the first open house 40 out of 200 projects were chosen in collaboration with the disabled community to be further evaluated. The top 40 prototypes were taken to the Alberta Children's Hospital where children, therapists, aides, teachers and parents were consulted on which toys and play centers they felt best suited their needs. The Cerebral Palsy Association in Alberta was also interested in some of the designs and is currently working with course coordinators and students to install an interactive wheel chair game at the Rotary Challenger Park in Northern Calgary. In total seven projects have been selected to send to Abilitations Creations or to be custom built for the disabled community.

In addition to the designs that were successful, course coordinators wanted to evaluate the success of the project further by evaluating the collaboration of the disabled community with the student body as well as the amount of social awareness created by this project. At the end of the fall project, 212 randomly selected students were asked to fill out a questionnaire about their experiences.

The data produced the following results:

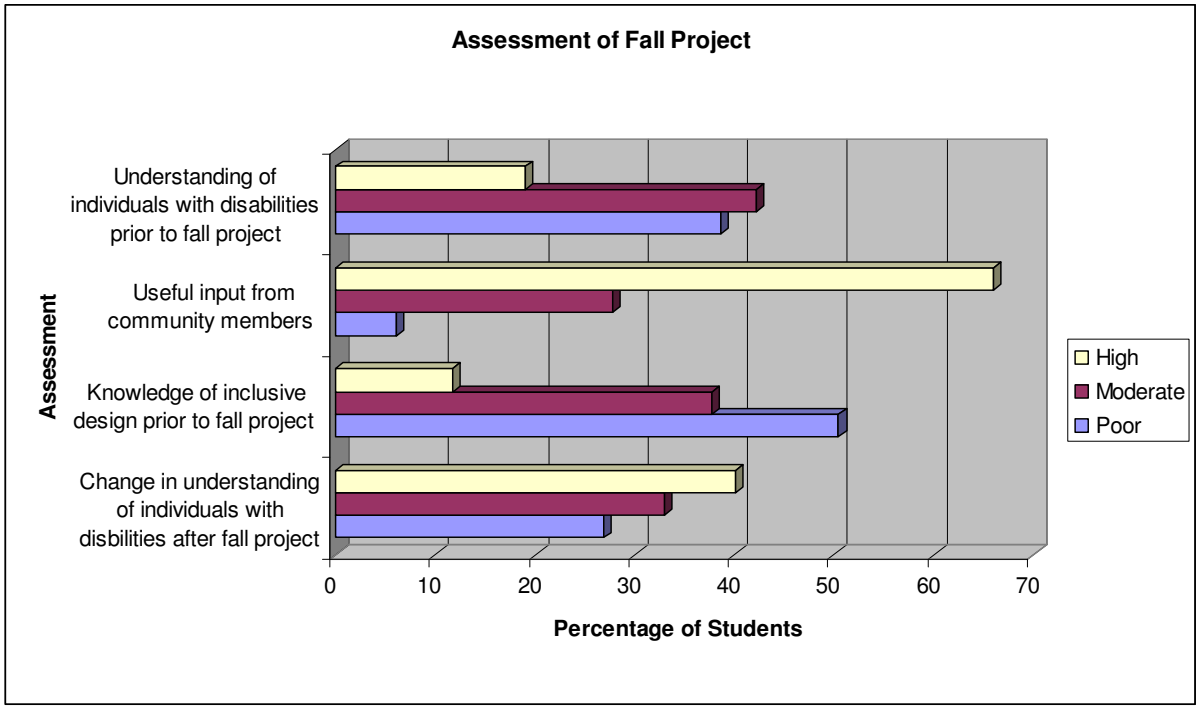


*Figure 1: Assessment of Fall Project*

In figure one it is clear that students had, overall, limited understanding and knowledge of individuals with disabilities or inclusive design. Approximately 38 students had a moderate understanding of inclusive design and 50 students had little or no knowledge of the concept. From the questionnaire it was found that 88 % of students questioned had a moderate understanding or *less* of inclusive design, supporting the concerns of Brisenden[1] and Barnes and Mercer.[4] If these students were not exposed to inclusive design in this project it is possible that

they would have entered the workforce with little awareness of the concept. It is lack of awareness that leads to the socially constructed barriers that Barnes and Mercer[4] discuss.

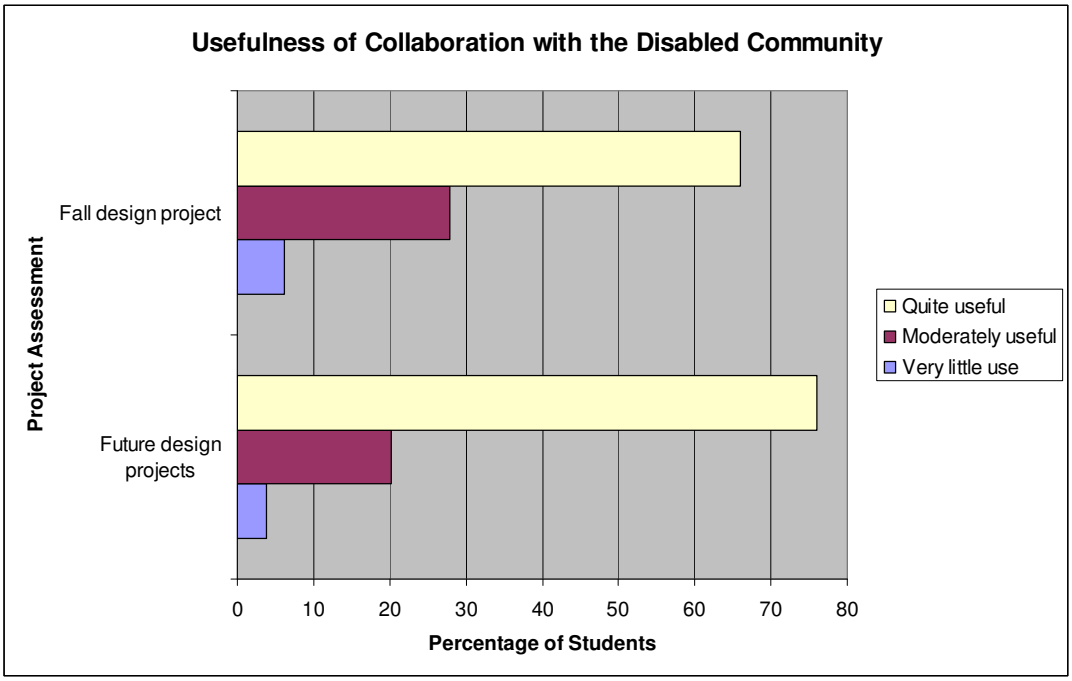


*Figure 2: Usefulness of Collaboration with the Disabled Community*

The collaboration with the disabled community proved to be very important to the students. Figure 2 clearly demonstrates that the disabled community was quite useful in the design process of their implements. Over 75 % of the students questioned, also stated that collaboration with the disabled community would be quite useful for a similar future design project, indicating an increased appreciation of community input compared to their first experience.

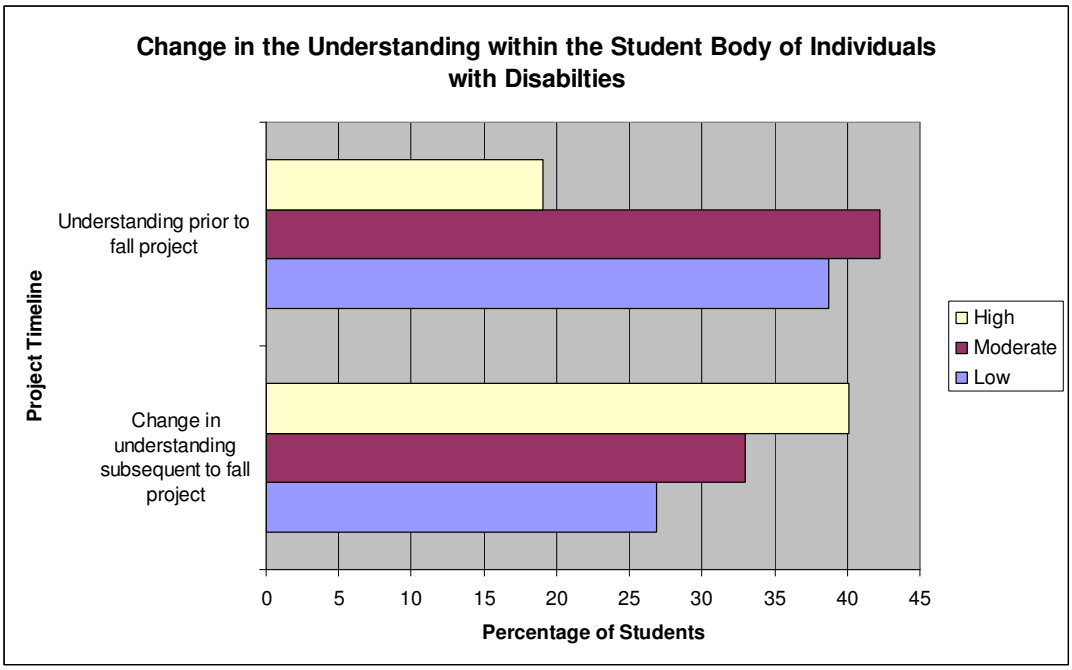


*Figure 3: Change in the Understanding within the Student Body of Individuals with Disabilities*

Figure 3 demonstrates the change in student understanding of individuals with disabilities. For 84 out of 230 students who had a low amount of understanding prior to the fall project 75 % said their understanding changed at least moderately (40% said a large amount, 33% said moderately). Therefore we can fairly conclusively state that for students who had little understanding of individuals with disabilities their understanding was changed by the project.

The results from the fall project are not yet fully assessed but provide course coordinators with useful preliminary information as indicated. Further results collected after the completion of the winter project will allow for more conclusive results as well as a larger sample group. Members of the disabled community will also be consulted about their experience throughout the two projects and whether or not aids for assisted living helped in over coming some socially constructed barriers often found in a research environment. An inquiry will also be made into the relationship between community members and the student designers, as well as their opinions on the overall success of the project.

## Conclusion

The symbiosis of community and educational needs led to the development of a set of design course projects specifically addressing the dissatisfaction of the disabled community, the need for real world projects that are relevant to students, an enhanced learning environment for students, caregivers and individuals with disabilities as well as the start of data gathering and future research on the benefits of such projects for students and community members. The design of aids for assisted living devices, by students in collaboration with the disabled community is helping to raise social awareness amongst the non-disabled community helping to start a path towards changing disability research. As might be expected, a large percentage of students had little understanding about individuals with disabilities and inclusive design. However, after the completion of the fall project 75% of the students felt that they had had a moderate to high

increase in their understanding of this topic. Working in a relationship with the disabled community to produce disability conscious design eliminates some of the discrimination experienced by disabled individuals by beginning to break barriers constructed by members of society. Disability conscious engineering design, in the form of a new curriculum is an attempt to conquer socially constructed barriers in disability research and start a new way of thinking about how "research should be about changing the world, not simply describing it."[4]

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