

ASSISTIVE TECHNOLOGY AND ACTIVITIES OF DAILY LIVING  
FOR WHEELCHAIR USERS

by

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## ABSTRACT

There are over 1.7 million wheelchair users in the United States today. They share a common bond in that they all have physical limitations and daily obstacles to overcome. Activities of daily living (ADLs) are tasks performed day to day for self care, including eating, grooming, dressing, using the toilet, walking and bathing. These and other routine daily activities that are taken for granted by able-bodied people can be particularly troublesome for the disabled. An assistive technology (AT) device is a piece of equipment or product system designed to improve the functional capacity of individuals with disabilities. When used, AT can improve both independence and quality of life.

This study aimed to explore physical functionality and AT device use/nonuse among wheelchair users. Qualitative methods including interviews, observations, surveys, and internet chats were applied to better understand the wants and needs of the end users of AT. An iterative approach to product design was employed in the development, testing and fabrication of the Pneumatic Arm Lift (PAL). The goal of this project was to involve the end user from the beginning of the design process in the creation of an inexpensive, durable, and efficient device. This would lead to increased independence and reduce device abandonment.

The study showed that a successful device could be created through several iterations and user feedback. The qualitative aspect of the research uncovered similarities in troublesome ADLS. It also showed that many users of AT create their own devices and adapt them to their individual needs instead of

paying high prices for products that do not work as well. This is particularly relevant to industrial designers as their occupation is to improve lives through product innovation. Researchers, designers, and engineers need to collaborate to create new AT devices for the diverse disabled community.

## DEDICATION

I would like to dedicate this thesis to my wife, Jessica, whose love, guidance, support, and above all patience enabled me to finally complete my higher education. Your creativity and passion for everything you do is truly inspiring.

My parents, Ken and Patty, thank you for giving the world to me. Your love and faith have kept me afloat all these years.

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## CHAPTER 1

### Introduction

#### *Overview*

It is estimated that there are over 1.7 million wheelchair users in the United States alone (Kaye, Kang, & LaPlante, 2002). These individuals are living with a variety of disabilities. Many factors can lead to the need for a wheelchair, including but not limited to aging, injury, or disease. All wheelchair users share a common thread in that they have some sort of physical limitation or impairment. This presents many obstacles and challenges that they have to face on a daily basis to do things that the non-disabled community takes for granted.

Technological advances and human-centered design have made life easier for most people in the civilized world. Though hardly noticed, we all benefit from products and technology that assist us through our daily lives, including home, work, and play. Our living experience is enhanced through products that aid us in cooking, cleaning, traveling, working, communicating, personal hygiene, leisure, and entertainment, just to name a few (King, 1999).

For individuals living with disabilities, the design of assistive devices is helping them to become increasingly independent. The term *assistive technology* (AT) device was created in the passing of the Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407), better known as the Tech Act of 1988 (Johnston, Beard, & Carpenter, 2007). An AT device is defined as any piece of equipment or product system, whether acquired commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities (U.S.

Congress, 1988). Some examples of such devices are wheelchairs, canes, hearing aids, prosthetics, speech synthesizers, modified utensils, etc.

AT devices have the potential to promote independence and improve the quality of life for anyone living with disabilities. This research focuses on those in the disabled community who require the use of a wheelchair for mobility.

Independence can be viewed as one's ability to perform daily tasks without the help of someone else (i.e. a caregiver, friend or relative). These activities can be divided into three categories: Activities of Daily Living (ADLs), Instrumental Activities of Daily living (IADLs), and leisure activities. ADLs can be categorized into six functional activities: eating, grooming, dressing, using the toilet, walking, and bathing. IADLs are also tasks related to daily life that need to be performed in conjunction with ADLs for a person to function independently. Some examples of these would be managing the house, managing finances, shopping for food or essentials, using the telephone, and managing medications (Mann, 2005).

Every person who is living with a disability has a set of needs, wants and desires relating to their independence and quality of life. Likewise, each has a unique hierarchical set of functional limitations or physical/cognitive problems that need to be addressed through the use of assistive technology. This involves an individual user assessment to determine the need for AT, the cost associated with the device, the balance of functional capabilities and limitations, the level of training required, and the overall usability and aesthetics (Scherer, 2005).

The same factors should be considered in the design and development of new AT devices. Sometimes the end user, regardless of age or disability, is

forgotten about in the design process. The initial product idea seems helpful and proactive on paper, but once it hits the market it is a complete failure. Blind AT advocate George Covington (1998) states:

Too often in the past, individuals without disabilities and groups came up with projects and products that they knew “would be great for handicapped people.” They never bothered to ask such people for input. Their enthusiasm was great, but their idea or product was a disaster. (p. 87)

This situation can easily lead to the misuse or abandonment of a device. Aside from user input and opinion, there are many other factors that can lead to failure. Poor performance, lack of training, discomfort, a change in the user’s needs, and inappropriateness of said device are just a few. The concept *abandonment* is a term that is widely used in the field of assistive technology by designers, healthcare professionals, and users (Verza, Carvalho, Battaglia, & Uccelli, 2006). A device is sometimes not totally abandoned, but misused in order to achieve functionality. People with disabilities often modify an existing mainstream device to better suit their limitations.

The high rate of abandonment reiterates the need for *user-centered design*. The needs and desires of the end user should be considered from the onset of a product’s development. Actively involving the consumer in the design and decision making process will improve the safety, functionality, aesthetics, and overall success of the finished product. Field testing of a device through the prototyping stages help to eliminate flaws in the design or engineering that could have otherwise been easily overlooked (Scherer, 2005).

Human factors and ergonomics also are crucial in the design and development process. The way in which humans interact with the world around them is important in the design of everyday devices and technology. A device should not only be viewed by what it does, but by the context and environment in which it is being used. Human factors are essential in AT development. It helps the designer to find special needs and limitations and match a device to a user. The goal is to ever increase the efficiency and ease of use of a product, while maintaining the safety and comfort of the end user (King, 1999). This concept of human factors and user-centered design has fueled this research in the field of assistive technology.

As I worked for my undergraduate degree in Industrial Design, I found it easy to lose focus on who I was designing for and concentrate more on aesthetics and “cool” emerging technologies. Since I was human, and was after all designing for humans, I could easily see myself as a user of the product. The problem with this is, as the guru of human factors Don Norman (1988) describes: “...designers often become an expert with the *device* they are designing. Users are often experts at the *task* they are trying to perform with the device.” This realization led me to the study of human factors and user centered design in graduate school. In a human factors class, a woman (Tedde) who has advanced Limb Girdle Muscular Dystrophy (LGMD) came to us with a design problem. She has very limited mobility and functionality of limbs, and can only move her facial muscles, fingers and wrists. She was interested in a device that could lift her arm to help her with the task of eating. This sparked the idea explore human factors

through an iterative design process where the user's needs and input would fuel the design of a new assistive device.

This thesis will explore the possibilities of designing an assistive device that is affordable, user-friendly, safe, effective, and efficient. An early and continual focus on the user, along with qualitative and empirical data, will result in an AT product that can benefit many users. This design process will be backed by qualitative design research and analysis of the ADLs and IADLs of multiple wheelchair users in an attempt to create design recommendations for future development of AT products geared toward individuals with limited mobility.

#### *Statement of Problem*

Approximately one in three assistive technology devices are abandoned by their users over time. Some are too expensive to ever be used by a large population, while others were developed without considering the real-world needs of the end user. There is a great number of potential beneficiaries to a device that can improve the quality of daily life and increase functional capabilities. This study will therefore focus on the use of human factors, iterative user-centered design, and qualitative research methods in the design of both a tangible device and actionable insights geared toward the development of future assistive technology.

#### *Topics and Questions*

This research was guided by and attempts to explore the following topics and questions:

*Assessment of functional limitations and assistive technology relating to the arm-lifting device development*

- What are the subject's physical limitations and capabilities? What are the ergonomic measurements of her arm, and the mechanical movement necessary to lift it to her face?
- What AT devices does she currently use or have abandoned in the past?
- What technology and materials can be used that are safe, inexpensive, and efficient? Can this technology be powered by her existing chair battery?
- Aside from eating, what other tasks could this device help her with in her daily life?
- How can the design of a developing device be modified and adjusted with continual input from the subject?
- How can I determine the success of the design, providing the user with a device that will increase independence and quality of life? (Also be safe, inexpensive, efficient, and aesthetically pleasing?)
- Can this approach create a device that could be used by a wider population with conditions similar to Tedde's?

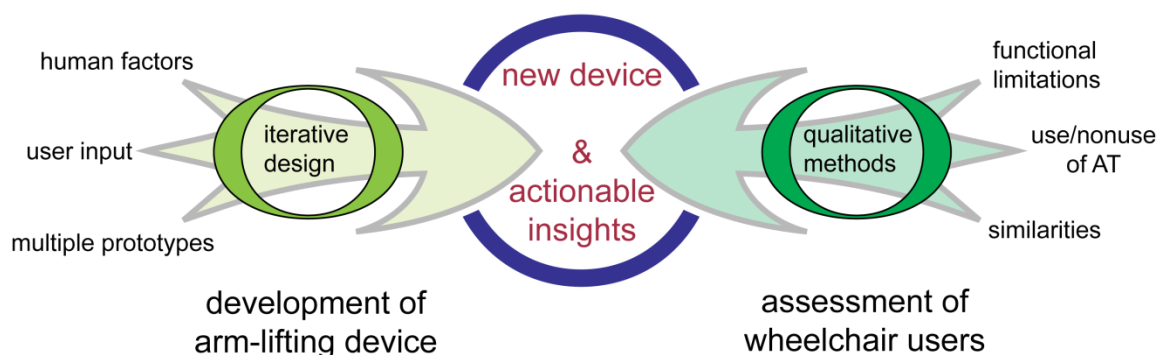
*Assessment of wheelchair users' current condition, assistive technology, ADLs, and IADLs*

- What condition do they live with (what caused their current disability)?  
What body parts can be moved/ not moved?

- What daily activities are the most problematic for the individual? Which specific functions would they require the most help with?
- What assistive devices do they currently own or have owned? Are they used how they were intended to be?
- Have they ever made their own assistive device to tailor to their specific situation or modified an existing device? Is there a specific activity that they would really like to do but cannot?
- Are there similarities in these people's responses that could lead to the development of a new device?

### *Conceptual Framework*

Based on these topics and questions, a conceptual framework was developed. The methodological approach to this study was two-fold. The first aspect of the research was to work with a specific user, Tedde, and with her help iteratively design and develop an assistive device tailored to her special needs and wheelchair. The second aspect of the research was to qualitatively find similarities and differences in ADL's and IADLs of wheelchair users.



*Figure 1. Conceptual Framework*

The two sides of the research are shown in Figure 1. The assessment of wheelchair users includes those with neuromuscular diseases, spinal cord injury, and aging. These users were assessed based on their functionality, limitations, and use of assistive technology, and similarities were looked for. The development of the arm-lifting device through iterative design is based on user input, human factors, and multiple prototype iterations. This will lead to a new device, and both aspects will lead to design recommendations and actionable insights.

### *Definition of Terms*

Some definitions of terms used throughout this study are as follows:

*Disability:* Having any sort of physical, intellectual, sensory or cognitive impairment that limits one's ability to function in a normal way. This study is specifically referring to those with physical limitations that require a wheelchair to be used for mobility.

*Assistive Technology:* also known as *enabling technology*, are the tools that allow people with special needs, challenges and disabilities to better perform daily activities. They enable the user to participate more and be more independent in their lives along with people in their home, workplace, school, or community (King, 1999).

*Human Factors:* this is the study of how human beings interact with products, systems or environments. This means designing for safety, comfort, ease of use, productivity, and aesthetic quality. This is important in assessing a

person's physical functionality, including anthropometry, range of motion, reach, grasp, mobility, strength and stamina (Rice, V. J. B., 1998).

*Iterative Design:* this is a design methodology where throughout the process, there is a cycle of design, testing and prototyping based on user feedback.

*Universal Design, Inclusive Design:* the design of all products and environments to be usable by people of all ages and abilities to the greatest extent possible (Story, 2001). This emphasizes accessibility in both product design and architecture.

*Activities of Daily Living (ADLs):* daily activities that are performed for self care, including eating, grooming, dressing, using the toilet, walking, and bathing. These also can be used as a functional assessment of disabled individuals or the elderly.

*Instrumental Activities of Daily Living:* These are also activities that are performed on a daily basis, but are not fundamentally necessary to functioning. Some of these include managing the house, managing finances, shopping for food or essentials, using the telephone, managing medications, child rearing, care of pets and others, and meal preparation and clean up.

### *Limitations*

Because the AT device is being designed to be tailor-made to only one person's special needs, some of the wheelchair connections were a custom fit. If this device were to be produced on a mass scale, more considerations would have to be made as how to adapt it to a wider range of wheelchair styles. From a

design standpoint, the device went through several prototypes and iterations. The goal first and foremost was making the device fit Tedde and her chair, and work to her specifications. The intent was to design a skin to go around the actuator components of the product. Also, designing a quick connection between the battery and the switch would be ideal for device attachment/removal. However, due to time constraints I was unable to do so. Ongoing research will be done in this area.

### *Potential Contributions*

The initial goal of this research project was to bring more independence and quality of life to our willing participant, Tedde Scharf. She came to us with a problem, and we worked with her to try and solve it with both user-centered design and human factors in mind. Because there are so many wheelchair users in the world, the potential for this device or a similar one to benefit a much larger population is high. This is where the second qualitative phase of the research came about. I wanted to sample a group of wheelchair users, and use their input about physical limitations, ADLs/ IADLs and assistive devices to gain a better understanding of what their wants and needs are.

From a social standpoint, this research is important as many times the needs of the disabled community are overlooked. Since “able-bodied” people are the majority of consumers, companies frequently design for this market as, from a money making perspective, it is the easy route. Although only a small percent of the population, the disabled community is quite large. Ethically and socially,

they deserve a chance at utilizing emerging technologies and the power of design to better their independence and quality of life.

From a design standpoint, I feel it is the responsibility of designers as a whole to step up to the challenge of this special needs genre. Design has been improving the lives of everyone in the civilized world, especially in the technology boom of the last twenty five years. This same enthusiasm and quality research and design should be focused on those who need it most. It not only will make their lives easier, it can break down social, physical and emotional barriers that they face each and every day. A goal of this research is to share challenges faced and come up with recommendations for designers to use to help them better understand the needs of people living with disabilities. In the preliminary phases of this study, it was discovered that many devices are abandoned or not designed around the real world needs of the und-user. No qualitative data could be found showing commonalities in ADL limitations of wheelchair users.

From a business standpoint, this research has the possibility to create a marketable AT device that can benefit a larger population. It is essential to show that qualitative research coupled with iterative design is a good business model no matter who the intended users are and what their functionality is.

## CHAPTER 2

### Literature Review

#### *Introduction*

The literature reviewed throughout the course of this research centers on the main theme of assistive technology for people who require wheelchairs for mobility. It began with defining the role of the industrial designer in the modern world. The review then shifted to living in a wheelchair (reasons for needing a chair for mobility, a brief history of the wheelchair, and types of chairs currently available). The next main topic was a perspective on living with disabilities (social stigmas of being “disabled,” the disability experience, assistive technology device use/non-use and device abandonment). The final topic investigated was the role of human factors and an assessment of current assistive technology devices (human factors of assistive technology; assessment of current devices on the market today).

#### *The Role of the Industrial Designer in the Modern World*

Design is everywhere. From the time we wake up to the time we go to bed, we are constantly surrounded by it and immersed in it. From the chairs we sit in, the phones we talk on, the mp3 players we listen to, the gadgets we cook and clean with, the vehicles we drive in, and the computers we work on (just to name a few), an industrial designer played a vital role in that product’s development.

The field of industrial design is not very well known and often misunderstood for a variety of reasons. The underlying goal of the majority of Industrial design is designing for mass manufacture. Most consumers buy

products from companies, not the designers responsible for its rich feature set or sleek looks. There is a disconnect in our material culture where people don't put very much thought into how the products they buy are designed and developed.

Although he or she may not be well known, the designer plays an integral part in the growth of our civilized economy. The infrastructure of the consumer product market allows for a perfectly coherent seamless integration. The product flows through design, mass manufacture, store shelf, and finally into the end user's home. In this respect, the designer is the invisible hand that starts and guides the process. Product design is a meld of art, invention, engineering, research, marketing and innovation.

This innovation must begin with understanding both the individual needs and wants of the target user, as well as cultural trends in the current market. This can be a daunting task, as one is attempting to design for individuality while at the same time creating a product to sell to the masses. In his book *Emotional Design*, Don Norman describes how user interaction with commercially bought products is dynamic and adaptable. He writes:

The best designs are the ones we create for ourselves. And this is the most appropriate kind of design- functional and aesthetic. It is design that's in harmony with our individual lifestyles. Manufactured design, on the other hand, often misses the mark: objects are configured and made according to particular specifications that many users find irrelevant.

Ready-made, purchased items seldom fit our precise needs, although they might be close enough to be satisfactory. Fortunately, each of us is free to

buy different items and then to combine them in whatever way works best for us. Our rooms fit our lifestyles. Our possessions reflect our personalities. (Norman, 2004)

The paradigm of design has shifted from functionality and usability to emotional ties and personal experience. Throughout the 80s, technological innovation was enough to make a product successful. The computers were all the same color, had the same look, and were styled for function in the marketplace. In the 21<sup>st</sup> century, this has changed dramatically. The head designer at Nokia, Frank Nuovo, said, “The technology may enable a product to get out there, but it does not turn it into an object of desire. It is the emotional response from the consumer that makes them choose something. The process involves a heady and complex stew of brand, look, feel and user experience” (PRODUCT DESIGN: Set in Emotion. 2003).

In order to look at user experience, a designer has to look first at user behavior. In order to do this, many companies and design firms have incorporated techniques from the social science disciplines into their research strategies. There are four disciplines that can have a significant influence on product design research and design management. These are cognitive psychology, social psychology, economic sociology, and anthropology. As seen in Table 1, each field specializes in analyzing human behavior and cultural interaction in an interpersonal setting (Seidel & Pinto, 2005).

Table 1: Overview of Selected Social and Behavioral Sciences			
Discipline	Main focus of analysis	Example question addressed	Example analysis method
Cognitive Psychology	Internal mental processes, with implications for social interaction	How do individuals make decisions?	Experimentation
Social Psychology	Patterns of behavior within groups	How does individual behavior change in group settings?	Field observation
Economic Sociology	Patterns of exchange among people or organizations	How is productive output affected by social relationships?	Social network analysis
Anthropology	Social activity within cultures	How do individuals behave within their societies?	Ethnographic observation

*Table 1.* Overview of Selected Social and Behavioral Sciences.

Some large companies and design firms, such as IBM, Philips, Intel, IDEO, and ZIBA employ social scientists as part of the design team. However, smaller businesses or individual designers can still utilize these methodologies and analytical tools. In a general sense, they can improve the user-needs assessment in the design process. It is important to incorporate social science strategies early in a product's development, whether it be assistive technology or a new toaster. In a *Business Week* article on ethnography in design, Spencer Ante reiterates this point:

Using ethnography at the beginning of the product development process is key because it helps identify consumers' unmet needs. It's those findings that can inspire a hit product or service. One danger of waiting too long to

bring in social scientists is that you might end up with “feature creep,” simply adding unnecessary bells and whistles. (Ante & Edwards, 2006)

Product designers can bring a well refined skill set to the development of assistive technology devices. This includes not only aesthetics and functionality but an understanding of social and cultural interactions to identify unarticulated needs. Peter Wolf, a design researcher and lecturer at Arizona State University, suggests that product designers have a unique view of a consumer’s needs. Because of this, there should be a collaboration between designers, AT researchers and rehabilitation engineers in the development of new and innovative AT devices. This synergistic approach will result in better researched and designed products, and the end result will be a product or service that is more desirable to consumers. Although there are thousands of AT devices on the market today, one out of every three gets abandoned by their user. This abandonment can be seriously reduced with a shift from a medical approach to a more social approach in the research and design of AT. The end result is a product that can seamlessly integrate with the user, vastly improving daily activities, social interaction, employment, and their overall quality of life (Wolf, June 2006).

### *Living in a Wheelchair*

#### *By the Numbers*

In the United States, it is estimated that over 1.7 million people use wheelchairs or scooters for mobility. This figure is based on data from a 1994-1997 National Health Interview Survey (NHIS). Not included in this study were

any residents of institutions, such as nursing homes, residential facilities for persons with mental illness or physical disabilities, or prisons. Furthermore, the study reported that the use of walkers and wheelchairs doubled from 1980 to 1990 (Kaye, Kang, & LaPlante, 2000). In Europe, the estimated number of users (only manual chairs included) is roughly 3.3 million (van der Woude, L. H., de Groot, & Janssen, 2006).

These numbers are more than likely low for many reasons. The NHIS study was conducted ten years ago, and based on their previous recorded level of increase it can be inferred that this number went up significantly. The population is exponentially growing, and both of these estimates only include the US and Europe. Both China and India have over one billion people each as of 2007. The amount of people living with mobility disabilities worldwide must be staggering, a number that is extremely hard to estimate. Another factor that would lead to an increase in the number of chair users is the aging population (that over the age of 65) is growing rapidly. By 2050, the US Census Bureau interim population projections indicate that roughly 20%, or 85 million people, will be over the age of 65. This number is more than double the forty million in that age group in 2007 (U.S. Census Bureau, 2007). Age is a contributing factor to a variety of ailments that could result in the need for a mobility device. Technological advancement in medicine and increased survival rates among trauma patients also leads to a wider need for wheelchairs.

### *The Disabilities Involved*

With so many people needing and using wheelchairs in every part of the globe, it becomes obvious that this is a rather untapped market for assistive technology development. This study is not aiming to redesign or reinvent the wheel (chair), but rather look at how or what devices can complement the wheelchair in increasing functionality. In order to look at what types of users we would be designing for, we must first look at why people are in wheelchairs to begin with. There are many disabling conditions that could lead to mobility problems. Some of these are a result of accidents, trauma, or illness, while others are genetic. Some are age-related as the body weakens, while others could be from birth defects. Some conditions are stable and unchanging, while others are degenerative as functionality slowly deteriorates as time progresses. It is important to look at each to show how vastly different a person's mobility and functionality can be. An individual's disabled experience could be much different than another with a similar condition due to extenuating factors, such as attitude, coping, openness, and resources available (Karp, 1999).

### *Trauma*

The spinal cord is a soft bundle of nerves running from the base of the brain down to the lower back. Impulses and sensory messages travel to and from the brain to the rest of the body. These control muscle and motor function as well as the sense of touch. The bony spinal vertebrae protect the nerves from damage. However, if the cord is damaged, the impulses and messages are blocked at the point of injury. The body is affected progressively worse the closer

to the brain the injury takes place. Many factors can cause this, such as a severe blow due to a fall, an automobile accident, or a gunshot. The injury can be either complete or incomplete: complete means that there is no movement or feeling whatsoever below the point of the injury, and incomplete means some movement or feeling still remains (WebMD, 2007a).

There are two general classifications of spinal cord injury: paraplegia and quadriplegia. They are based upon the level of bodily paralysis (and the level of the spinal vertebrae where the damage occurred). A paraplegic suffers an injury at or below the first thoracic vertebrae, or T1. They are able to maintain full control of their upper extremities (arms and hands, as well as shoulders, chest and head). The individual is classified as quadriplegic when the injury occurs at or above the seventh cervical vertebrae, or C7. At this point, feeling and movement are lost in the upper extremities and chest as well. The worst case scenario is a C3 injury, where almost or all function is lost below the neck. There are somewhere in the range of 230,000-280,000 spinal cord injuries in the US, with over 10,000 new cases a year (Karp, 1999). The injury is most common among young adults. This is an important consideration since they will be spending a good portion of their lives relying on a wheelchair for mobility (Spinal Cord Injury Law, 2006).

Amputation or injury to one or both of the legs can also result in the need for a wheelchair. Since the upper body strength is not adversely affected, manual wheelchairs are a common option. This injury is regularly sustained by disabled veterans wounded while serving their country. Land mines, car bombs,

explosions and gunfire are commonplace at times of war, and all can inflict serious injury on the lower extremities. Injury to one leg can usually be assisted by another form of assistive technology, like a prosthesis, cane, walker or crutches. When both legs are injured, especially above the knee, a wheelchair is almost certainly required for mobility.

A traumatic brain injury (TBI) is a general term for trauma relating to the head, specifically the brain tissue. This can be due to a severe impact from a fall, a blow to the head, or whiplash action in which the brain literally bounces off the inside of the skull. The result of these traumas is swelling of the brain. This can have very serious and adverse effects since the skull limits the space for the swelling to occur. The blood vessels have nowhere to leak or drain, which in turn causes more swelling. The swelling after-effects are part of the secondary damage that occurs with a brain injury. For twenty-four hours after the head trauma is sustained, the damage continuously worsens. This secondary damage is responsible for most of the chronic, long lasting effects of the injury. Some continual physical problems could be memory loss, headaches, seizures, speech impairment, loss of motor control, and paralysis. Relearning how to do tasks, such as eating, speaking, or walking are not uncommon. Brain trauma can require the temporary use of a wheelchair, and permanent use in some cases where paralysis has occurred (Karp, 1999).

Traumatic brain injury often happens in conjunction with other serious bodily injuries because of accidents or falls. For instance, a car accident could severely damage the legs at the same time as the head. Another example could

be a several story fall, which could damage the brain as well as the spinal cord. Close to 400,000 people in the United States suffer a brain injury every year, with 100,000 sustaining life-long after effects (Karp, 1999).

Cerebral Palsy (CP) is another type of brain injury which happens in the early development of a child, usually resulting in lifelong mobility problems. This can happen while the child is still in the womb, during the child-birth process, or in the first few years of a child's life. Some causes of this brain damage include premature delivery, lack of oxygen to the baby's brain, or illness during labor or pregnancy. After birth, accidental head trauma, illness or lead poisoning have also been known to cause CP (Scherer, 2005).

CP is similar to injuries of the spinal cord because it can severely limit motor functionality. Muscle spasticity and paralysis result in jerky and uncoordinated movements. However, it can be as mild as a limp or as drastic as loss of motor control and sensory function (speech, hearing, and sight). The ways in which it can affect a person vary greatly. Mental competency can also be reduced to the point of retardation in some, and in others they remain completely competent. It is the motor disability that has the highest occurrence in children, at a rate of 2 to 2.5 per 1000 live births (Ostensjo, Carlberg, & Vollestad, 2005). There are 500,000 to 700,000 people living with CP in the U.S., with 6,500 new cases reported each year (Scherer, 2005). Because the onset is at such a young age, CP is classified as a developmental disability. This is a large growing population that will require assistive technology to help them with daily activities.

Many people with CP will require a wheelchair for mobility throughout the majority of their lives.

### *Neuromuscular Diseases*

Neuromuscular disease is an umbrella term that covers many diseases and disorders relating to the nervous and muscular systems. This can occur directly (through intrinsic muscle pathology) or indirectly (through nerve pathology). Both kinds of ailments impair the functionality of the muscles and limit movement (Wikipedia, 2007). The diseases that will be discussed in the following section are the ones that have a significant impact on mobility and motor functionality.

Muscular Dystrophy (MD) is a group of “several hereditary, progressive muscular diseases with an often slow deterioration of muscular function” (Boström, Nätterlund, & Ahlström, 2005). There are nine types of MD, all of which involve a deterioration, a mutation, or a lack of specific muscle proteins. In some forms, the proteins are affected by missing pieces of DNA or repeating pieces of DNA (genetic mutation at the chromosome level). Which type of MD a person has is partly determined by the age of the individual at the onset of the disease. The rate of progression of muscle deterioration can be very slow with some forms and rapid with others. Overall, more than 50,000 Americans are living with various forms of MD (WebMD, 2007b).

One type of MD that is specifically pertinent to this research is Limb-Girdle Muscular Dystrophy (LGMD). Tedde Scharf (the woman who is our ongoing research participant and the inspiration for this study) has been living with LGMD

since her teens. This disease can begin from childhood through adulthood. There are at least nineteen forms of the disease, which are classified by the fifteen flawed genes that produce muscle proteins. The limb girdles are the areas surrounding the pelvis and shoulder region. These proximal muscles (those closest to the trunk of the body) are affected first and begin to deteriorate. The disease is both progressive and degenerative (Muscular Dystrophy Association, 2006). Limb movement and functionality is slowly lost throughout the course of a person's lifetime. It begins in the limb-girdle area but can move outward through the limbs to the hands and the feet. In Tedde's case, she has had the disease for almost fifty years, so the progression is at an advanced stage. She has some movement left in her wrists and fingers, and she can move her facial muscles. She explained the progression to be so slow that she never noticed it day to day. It is very common for people with this disease to need a wheelchair for mobility because it affects the hips and leg muscles. Manual wheelchairs can be used, but the shoulder muscles are also deteriorating which makes propelling the chair a difficult task. People living with advanced forms of LGMD often require a scooter or powerchair. Because of the impact on arm and leg use, assistive technology development for ADLs and IADLs can be particularly beneficial to people living with LGMD.

Amyotrophic Lateral Sclerosis (ALS) is better known by the name Lou Gehrig's disease. This disease is usually manifested during late middle-age, but can come in early adulthood. An individual with ALS will gradually become paralyzed due to a loss of nerve cells. These motor neurons, located in the brain

and spinal cord, are responsible for voluntary muscle control throughout the entire body. The progression of the disease is considered rapid, with symptoms worsening over a period of months to a few years. ALS is considered fatal, with a life expectancy of an average of three to five years after diagnosis. People have been known to live for decades though with the disease. A very famous example of this is physicist Steven Hawking who was diagnosed in the 1960s. He requires assistive technology for mobility, breathing, and communication. This is also proof that the intellect remains intact. Since ALS generally starts in the legs and arms and ends in total paralysis, a powerchair will be required after a certain amount of time with the disease (Muscular Dystrophy Association: ALS Division, 2008).

Multiple Sclerosis (MS) is a chronic disease that attacks the central nervous system. Nerve fibers throughout this system are protected by a fatty substance called myelin. When a person has MS, their own body's defense mechanism is triggered and attacks healthy myelin. This attack can also result in damaged nerve fibers. When the myelin is damaged, it forms scar tissue (sclerosis), hence the name of the disease. Impulses sent from the brain to the rest of the body are blocked or distorted when myelin or nerve fiber is damaged. There are different kinds of MS, both remitting and progressive. Symptoms range from limb numbness to paralysis. Approximately 400,000 people in the U.S. have MS (200 new cases a week), and an estimated 2.5 million have the disease worldwide (National Multiple Sclerosis Society, 2008).

There are several other neuromuscular disorders that can lead to wheelchair use. Spinal muscular atrophy (SMA) is a disease that affects the anterior horn cells of the spinal cord. It primarily affects the voluntary muscles closest to the center of the body. Since the legs are affected more than the arms, wheelchairs are frequently used by those who are living with SMA. Friedreich's ataxia (FA) is another disease that damages the nerves of the spinal cord. Within ten years of the onset of the disease, the individual loses the ability to walk (Karp, 1999). As with many other neuromuscular diseases, a wheelchair becomes the best method of personal transportation.

#### *Age Related Disabilities*

As people age, their bodies grow weaker. Muscle tissue deteriorates, as does joint and bone health. This can easily affect a person's ability to walk. Later in life, a not-so-serious fall can result in a broken leg or hip. Some diseases, such as arthritis, are much more prevalent in the aging population. This is a degenerative joint condition that can affect the joints throughout the body, including those required for mobility (hips, knees, ankles, and feet). It can result in the need for a wheelchair or other forms of assistive devices (canes, walkers). A stroke is another condition that typically occurs later in life. Of the 700,000 reported strokes in the U.S. annually, two-thirds are suffered by people over the age of 65. A stroke is a cerebral-vascular trauma in which a blood vessel in the brain is either blocked or hemorrhages. This results in oxygen not getting to parts of the brain, which can cause those parts to begin dying (Karp, 1999). Hemiplegia, which is the paralysis of one side of the body, is a common side

effect of suffering this trauma. Depending on the severity, motor ability and function can be severely limited.

There are many other reasons that a person would require the temporary assistance of a wheelchair to get around. Sometimes, an illness can weaken a person to the point of needing help with mobility. After surgery, there is usually a period of time where doctors recommend wheelchair use. Sports-related injuries, such as broken legs and torn anterior cruciate ligaments (ACLs) can require a wheelchair for a short period of time.

It becomes obvious through reviewing these disabling conditions and disorders that the market for assistive devices for wheelchair users is large. Other forms of AT can complement the use of a wheelchair to help an individual be more independent and active in their daily lives.

### *A Brief History of Wheelchairs*

The two main components of a wheelchair, the wheel and the chair, are some of the earliest known inventions of man. These date back to 4000 BC. The first known combination of the two is the spoke wheeled chariot, found in China (1300 BC). The Chinese were also the first to create a wheelbarrow, which was sometimes used to transport the sick and disabled. They were also the first to create a wheelchair, an image of which was carved onto a sarcophagus in 525 AD (Cooper et al., 2007).

The first known wheeled assistive device similar to what we know of today dates back to the 16<sup>th</sup> century. King Philip II of Spain (1527-1598) had a rolling chair, with movable arms, backrest, and footrests (see Figure 2a). Also known as

an invalid's chair, it had very small wheels and required someone else to push the device. In 1655, a paraplegic watchmaker from Germany named Steven Farfler created the first self-propelled chair. He created a metal gear box with a hand crank to power his invention. This device remained popular through the beginning of the 18<sup>th</sup> century (see Figure 2b) (Tudor-Craig, 1998).



a.

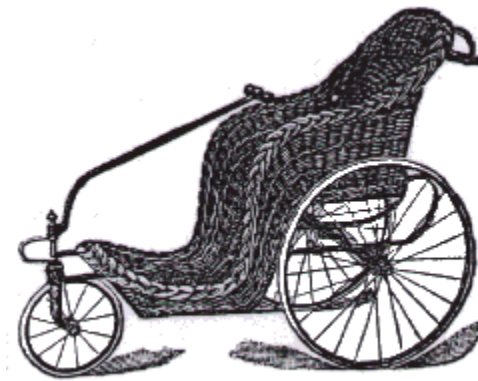


b.

Figure 2. King Philip's chair, Farfler's hand-crank device

In 1783, an Englishman named John Dawson developed the Bath chair. Named after his hometown, this model had a stronghold on the market until the 19<sup>th</sup> century. It was common then for chairs to be made of wood or wicker (see Figure 3). In the 19<sup>th</sup> century, human factors considerations were finally being added, such as reclining backs and footrests. Wooden wheels were scrapped for more durable iron, and then replaced by hollow rubber tubes. Pushrims were added to make the device more self-sufficient and versatile than a hand crank model. It took an accident and some ingenuity to make the wheelchair resemble what it is today. A mining engineer named Herbert Everest broke his back in a

cave in 1919. He and friend Harry Jennings designed the first bent metal tube collapsible chair so Mr. Everest could fit the chair into his automobile. Everest & Jennings revolutionized the industry with this design (Faust, 1993). The first motorized wheelchair was made around the same time, but didn't see significant development until the later part of the century.



*Figure 3. Wicker Bath chair*

### *Types of Wheelchairs*

There are five basic categories of wheeled mobility devices available to the disabled community today. These are the manual wheelchair, the power-assisted wheelchair, the power scooter, the electric powered wheelchair (EPW, powerchair), and the sports wheelchair.

#### *Manual Wheelchair*

The most common type of wheelchair on the market today is the manual powered variety. This device is made of tubular steel or aluminum framing with large rubber wheels in the back and small castors in front. It has handles to be

pushed as well as pushrims to be self-propelled, and is usually collapsible. Metal footrests are hinged to allow for easy access. The seat pan and back are cushioned for support and comfort (see Figure 4). This type of chair is typically used by individuals with the upper body strength, function and stamina to propel it. They are also frequently seen in hospitals and nursing facilities (Cooper et al., 2007).



*Figure 4. A manual powered wheelchair*

#### *Power-Assist Wheelchair*

Power-assist wheelchairs are based on or have add-on devices to the manual chair. There are three types: an external device the user holds onto, a device that attaches to the chair with a steering mechanism, or a pushrim activated system which has motors in the wheels. Some of these devices can be pricy, but offer a good alternative between the versatility of a manual wheelchair

and the ease of use of an EPW. The pushrim-activated system works in the same fashion as the manual device but requires much less energy. A battery powered electric motor is located in the wheel hubs. When power-assist is enabled, the user's push force is combined with a force of the motor (see Figure 5). These wheelchairs are suitable for people with low endurance or weak upper arm strength (Cooper et al., 2007).



*Figure 5. E-Motion Pushrim-Activated System.*

#### *Scooter*

A scooter is a powered mobility device made up of a long platform with a chair on the top of it. There are two medium sized wheels in the back, and either one or two wheels in the front with a steering mechanism attached. The device is common with the aging population who have mobility problems. Because of its larger size and platform to step up on, it is better suited for individuals who can

walk around the house but not long distances. It is also used by people who have trouble walking due to obesity problems. Since it is large and has a greater turning radius, getting around tight areas can be difficult (see Figure 6a). Some models, like the Hoveround®, eliminated the long wheelbase and steering column to increase maneuverability. This brand can be thought of as a hybrid between a scooter and an EPW (see Figure 6b).



Figure 6. Three wheeled Celebrity scooter; Hoveround® personal mobility vehicle

### *Electric Power Wheelchair*

Electric Power Wheelchairs allow people with disabilities a great amount of independence. For individuals with severe motor and/or sensory function, an EPW is the only functional means of mobility. The wheelchair consists of a four-wheeled electric base, with large batteries and an electrical system. A padded

office-like chair sits on top of this, connected to a movable frame structure. Since the chairs are battery operated, they need to be charged daily. Most units are joystick controlled, which enables the user to control its many functions with only finger and wrist movement (see Figure 7). For those incapable using their hands, technological advancement has lead to the development of new kinds of input devices. Some can be controlled with head movements, while others use sip-and-puff technology where air pressure from the mouth is read by a wand device. Most EPWs have power-controlled seat movement, allowing the user to fully recline, lift up and down vertically, or sometimes even stand up to eye level. This type of movement has health benefits as well as it improves circulation and reduces static seating pressure.



*Figure 7. A common Electric Powered Wheelchair.*

There are several brands of EPWs, and many have unique features that incorporate advanced robotics. One such chair on the market today is the Independence iBOT® 4000. Its revolutionary design lets the user “stand up” on two wheels to reach things or to be at eye level with others (see figure 8a). Its advanced balancing system utilizes gyroscopes to adjust the user’s center of gravity. The wheels have the capacity to rotate up and over each other for stair climbing (see Figure 8b) (Independence®, 2008).

It also has a detachable remote, so the chair can be driven unoccupied up a ramp or into a transport vehicle. Four wheel drive mode and treaded tires make driving over grass, sand and gravel a breeze (Independence®, 2008).



a.



b.

*Figure 8. iBOT® 4000 in balance mode; iBOT® 4000 in stair climb mode.*

### *Sports Wheelchair*

The sports wheelchair is specially designed to allow persons with disabilities to participate in recreational or competitive sports. Some of these sports include wheelchair racing, basketball, tennis, rugby, hockey, cycling, dancing, golf, volleyball, and powerchair soccer. These kinds of leisure activities provide excitement, challenges enjoyment, and satisfaction that increase an individual's quality of life. The chairs mostly used in sports are modified versions of the rigid frame manual chair. The frames are often made of ultra-light weight materials, like aluminum or titanium to reduce weight but still be durable. The camber of the wheels (the outward wheel angle) is aligned so the top of the wheels are closer together. This increases the width of the chair, but makes it much less susceptible to tipping over while performing spinning and turning maneuvers (see Figure 9a) (Bryant & Bryant, 2003).

Some sports require customization in order to adapt the chair. Wheelchair rugby players, for instance, frequently collide with one another (often very hard) during game play (see Figure 9b). To minimize damage to the chair or its occupant, rugged metal guards act as bumpers. Some racing chairs are customized with a single wheel out in front for speed. Tennis players increase the forward lean of the seat to give them more power with the tennis stroke (Emmer & Soldatenko, 2008). EPW users who participate in powerchair soccer customize their chairs with add-on metal cages near the footrest to "kick" the large soccer ball.



a.



b.

Figure 9. A custom basketball wheelchair; a collision during wheelchair rugby.

### *Living with Disabilities*

Assistive technology does have the potential to improve a disabled person's independence and quality of life. The designers and rehabilitation engineers responsible for creating this AT sometimes overlook how a person comes to terms with living with a physical disability. They often look at the potential benefits of technology without considering their *disability experience* and *quality of life*. Marcia J. Scherer has done qualitative research on this topic, conducting in-depth case studies into the personal lives of several people living in wheelchairs for various reasons. She shows how different people cope and adjust to their individual lives with their disability and the AT that can potentially help them. Some are success stories with challenges overcome, while others have a great deal of difficulty coping with the problems associated with being disabled. The study was done over a period of almost two decades. Social and

environmental factors, growing personal experiences, and an ongoing self evaluation can alter a person's individual perspective on life. Scherer says,

*Quality of life* considerations require focused attention on a person's desired achievement psychologically, socially, intellectually, and vocationally in spite of limitations in physical functioning. (Scherer, 2005)

In looking at the real lives of these human beings, it can be seen that creating a positive identity and a greater self esteem is essential. The functionality limitations need to be addressed, but to have a successful AT device the user's personality and disability experience must be considered.

### *Social Stigmas of Being Disabled*

A 1991 poll by Harris & Associates was conducted to a group of non-disabled people in order to survey their perceptions about being disabled and the disabled community. Fifty eight percent of the people interviewed said they felt anxious, uncomfortable, or embarrassed when around a disabled person. Forty seven percent of those interviewed said they felt *fear* (Covington, 1998). This fear factor exemplifies the social stigma associated with having disabilities.

Since the beginning of man, people who were born disabled or deformed were often disregarded or left to die as they could not be of any benefit to the tribe. This was the "survival of the fittest" shown in early man. Many cultures also believed that the disability was their fault because they had displeased the gods in some way. Over the next millennia, the attitude toward the disabled slowly shifted. In the 19<sup>th</sup> century, many Catholic and Protestant theological writings show that people with disabilities were thought of as being cursed by God or

children of the devil. Toward the end of the 19<sup>th</sup> century and into the 20<sup>th</sup> century, science was making many experimental breakthroughs. The paradigm shifted from thinking these people were monsters or devils to believing they could be cured by modern medicine. This overzealous attitude leads to a form of social Darwinism. Over a thirty-year period starting in the 1920s, more than 60,000 individuals who were diagnosed then as having mental retardation were sterilized. Modern day scientists believe that many of these people may have been misdiagnosed (Covington, 1998).

This backwards way of thinking since the dawn of humanity has only started to really change in the last 30 to 40 years. The terminology that has been used to describe people with disabilities reflects the stigma and adds to the fear factor. In 1982, polio survivor and psychologist Irving Zola wrote a chronicle about life with a disability. He writes, "We are de-formed, dis-eased, dis-abled, dis-ordered, abnormal, and, most telling of all, called an in-valid" (Zola, 1982). The term *cripple* is another that reiterates the way society sees the disabled. Since the 1990s, terms like *crippled*, *invalid*, and *handicapped* have been deemed politically incorrect.

Other negative terms have been associated with being disabled. Some of these have been media driven. George Covington, a blind man who lectures on the stigmas and social views of disabilities, describes the media as having two views of the disabled. They are usually portrayed in print, on television and in movies as one of two stereotypes. People with disabilities are either "the poor,

pitiable, pathetic creature of charity” or the “heroic, undefeated, *Supercrip*” (Covington, 1998).

The first stereotype of the disabled as objects of charity is centuries old. The slowly increasing social tolerance didn't really manifest until the 1980's and 1990s. Media outlets often referred to individuals with disabilities as *victims of...*, *afflicted with...*, and *confined or bound to a wheelchair*. All of these terms connote a pitiful and negative view of disabilities as a whole. Another reason behind this media-driven view is charities for the disabled. Although their cause is noble and they have raised millions of dollars for their organizations, they have negatively impacted the social view of disabilities. The thought of a Jerry Lewis telethon for instance conjures the image of defenseless, helpless sick children who are in dire need of our help. This was a fantastic marketing approach to raise money and awareness but made that social stigma and fear grow (Covington, 1998).

The second stereotype Mr. Covington explains is that of the *Supercrip*. This one is a classic television and movie tale of a person “usually struck down in the prime of life, who fights to overcome insurmountable odds to succeed as a meaningful member of society.” One main problem with this representation is it implies that achievement is rare among those with disabilities. They are only thought of as succeeding if they somehow achieve a “normal” life. These distorted views of the disabled culture as a whole only fuel negative attitudes toward disabilities by the public (Covington, 1998).

The wheelchair itself became the universal symbol for disabilities in 1968. Also known as the International Symbol of Access or the (International) Wheelchair symbol, the symbol has positive connotations for where access has been improved in a particular environment. It is seen on parking spots, ramps, bathroom stalls, automatic doors, etc. (see Figure 10). This image is burned into our brains as a symbol for having a disability. For acquired disabilities like a spinal cord injury that occur later in life, this can have a negative impact on the acceptance of this assistive device. It is normal to have fear of becoming disabled because of the societal stigmas involved. People have a tendency to place feelings and beliefs that had for others with disabilities onto themselves immediately after becoming disabled. Many times these feelings are pity, fear, dread and hopelessness, which in turn make it difficult to accept.



*Figure 10.* International Symbol of Access

### *The Disability Experience*

Although there are hundreds of thousands of people who share the same type of disability or impairment, each situation is unique. Disabled persons are as diverse a group as the non-disabled. There are several other factors aside from the disability itself that shape a person's *disability experience* and their outlook on living. Some of these include upbringing, personality, cultural and social background, and the onset of the disability. This personal and social experience has a major influence on an individual's quality of life considerations. The disability experience and quality of life considerations are determinants of assistive technology use (or non-use).

Life with a disability can be a difficult one. There are many challenges faced and obstacles to overcome. A person's attitude may be different if they have had the disability a long time or possibly born with it compared to a recent injury from a fall or a stroke. Regardless of the situation, the individual goes through an ongoing adjustment and acceptance process. Coming to terms with life with a physical disability is less about functionality and more of a social and emotional response. Speaking to the individuality of this adjustment process, Marcia J. Scherer writes:

Often individuals respond in ways that are derived from learned patterns for need satisfaction, their personality characteristics, and the expectations other have of them. These responses produce hope in some individuals and despair in others. The inclination toward either hope or despair influences a person's view of opportunities, growth, and the use of

technological or other assistance, and ultimately determines his or her *disability experience* and quality of life. (Scherer, 2005)

There are three primary elements that make up a person's disability experience. The first and most obvious is the physiological component. This physical condition of the self determines the body's functionality, energy level, and comfort level (pain tolerance, temperature, etc.). The state of health and complications associated with the condition, especially in progressive illnesses, shapes the course of treatment and rehabilitation process (Vash, 1981).

The second element in the disability experience is a psychosocial one. Attitudes and responses of others during any form of social interaction have an impact on the experience of being disabled. These environmental and social determinants can influence a person's self image, motivation, and goals in a positive or negative way. Social support networks can have a very positive and influential impact on people with disabilities in this psychosocial sense. Having supportive people and others who share in the same experiences can change a person's outlook on life and the options they have (Vash, 1981).

The third element that defines a person's disability experience is their attitude of themselves. This is a psychological factor that can greatly vary among people who even share the same disability. They view their limitations and capabilities in their own personal way. This also involves the individual's adjusting and coping mechanisms to lean toward hope or despair. Each person's experiences, upbringing, temperament, and social surroundings impact their attitude towards self (Vash, 1981).

A good example of how past events can alter the disability experience can be seen by looking at the differences in perception between disabilities acquired abruptly and disabilities since birth. A person with an acquired disability has a different outlook on assistive technology and the disability experience. Since they were at one time non-disabled, they will compare their functionality and quality of life to how they were pre-injury. They in essence have a new identity to cope with: that of a disabled person and a wheelchair user. Their old sense of self never really goes away, and often contradicts the new disabled identity. This makes it difficult to accept and adjust to using assistive technology. They see the chair or other devices as making them look disabled, and place their own pre-injury views of being disabled onto themselves. They let the attitudes of others and how they are being perceived by society outweigh the benefits of the technology. In his book *Life on Wheels: For the Active Wheelchair User*, Gary Karp (a SCI paraplegic) explains this resistance.

You are now a member of a minority foreign to most non-disabled people you will meet. You will remember your previous identity and always retain a sense of it. In the case of traumatic disability, a part of you will resist accepting membership in the society of chair riders (Karp, 1999).

For someone with cerebral palsy or another disability they have had since birth or a very young age, assistive technology and rehabilitation have opened doors for them. They are more accepting and open to AT, and comfortable with their disabled identity. They have a more complacent attitude toward AT because it has shaped their disability experience in a positive way (Scherer, 2005).

### *Assistive Technology Use/Non-use and Device Abandonment*

People with disabilities use assistive technology devices with the goal of gaining back a reasonable level of functionality. These devices are generally prescribed or recommended by an occupational therapist or rehabilitation specialist. Doctors, nurses, family members, friends, others in the disabled community, or one's self also can play a role in a person trying out an AT device. Regardless of the effort to try and get a person to use AT, it may still end up being rarely used, misused, or abandoned.

"The term 'abandonment' refers to the disuse of a previously obtained device, for any reason" (Verza et al., 2006). This abandonment can occur due to numerous circumstances. These include but are not limited to:

- poor user input in device selection
- change in a user's needs or worsening physical functioning
- poor device performance
- sub-par durability or reliability
- lack of training (or lack of ongoing support)
- not an appropriate match of user to technology
- complexity of the device (confusing to users and caregivers)
- fatigue or discomfort while using the device
- other options to fall back on to accomplish same task (Verza et al., 2006)

Developing or restoring functionality in a user's ADLs and IADLs has been a primary goal of many AT devices. The effectiveness of the device and

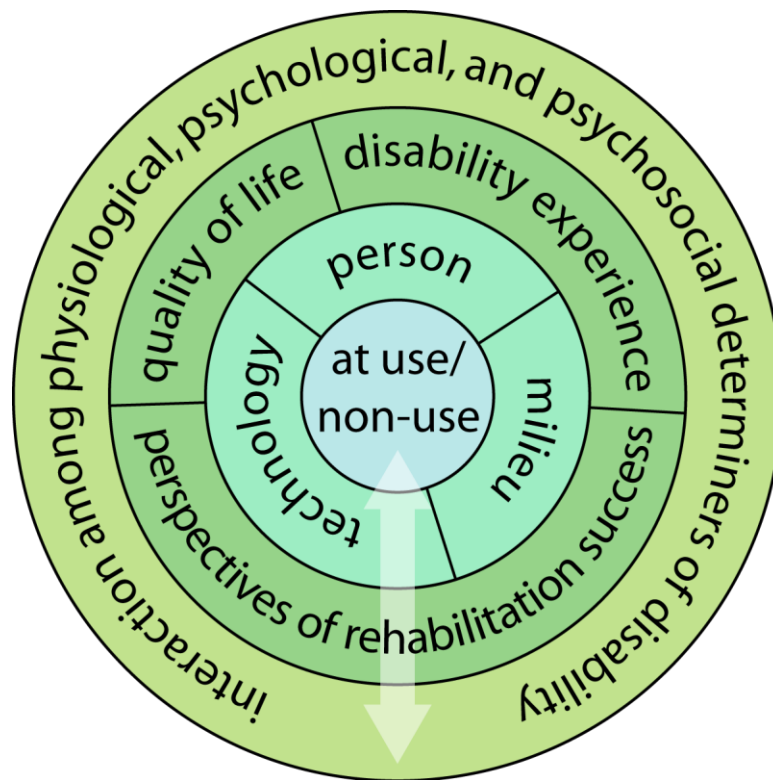
continued device interaction however does not solely rely on improved functioning capacity. Even with proper training on how to use a particular AT and subsequent follow-up procedures by rehabilitation therapists, there is still non-use. This relates to the train of thought that if a technology is designed to improve functionality, and is then abandoned, it must be because of user error, confidence, or skill level.

There are other factors in the abandonment of assistive devices that must be considered in the design of AT. Marcia J. Scherer's book *Living in the State of Stuck* takes a more personal approach to understanding the use and non-use of assistive technology. Her interviews with many disabled individuals and their experiences sheds light on the need to look beyond functionality to a more person-centered approach. This means that instead of looking only at the individual's disability and how to restore lost capacity, it is ultimately more important to enhance a person's quality of life. Being person-centered in the development of AT means looking at a particular person's social and emotional needs. The device should contribute to a positive identity, improve self esteem, and enhance their quality of life (Scherer, 2005).

Reducing device abandonment is an important consideration in AT development. Abandonment affects the individuals who use devices physically (less functional capacity), financially (devices can be expensive and out of pocket), and emotionally (reduced freedom and quality of life). It also impacts occupational therapists and rehabilitation specialists on a service delivery level. They are wasting valuable time and funding when devices are discarded. The

limited supply of government funding on local, state and federal levels gets squeezed tighter when AT is abandoned.

In her article “The Impact of Assistive Technology on the Lives of People with Disabilities,” Marcia Scherer created a flowchart for device use/nonuse (see Figure 11). It shows the impact the disability has on the individual along with their behavioral adaptation. The outside circle in this diagram represents the interactions with the consequences of the disability itself. These include but are not limited to functional capability, level of pain, financial resources, access to quality care, and social and cultural interactions. These definable influences of the disability create the next ring of the circle, which is a more subjective one. The three terms in this ring are largely self-defined. Previously in this chapter, two of these terms were discussed: the disability experience and quality of life. The third term, rehabilitation success, is a personal definition of individual goals. These three factors in ring two will then define and determine the third ring inward. This circle is composed of the milieu (the environment in which the AT device will be used), the person (characteristics of the user), and technology (characteristics of the device itself). This is the definitive level where it is determined if a device will be abandoned or not. Personal adjustment and coping strategies are an important consideration in device use/non-use. From a rehabilitation standpoint, it is important to match a particular user to an appropriate level of technology. A person must need and want a device for it to be successful and in turn improve that person’s quality of life (Scherer, 1998).



*Figure 11. Factors determining AT use/nonuse (Scherer, 1998)*

The concept of looking beyond functionality and more at the person who will use an assistive device is discussed further by Dr. Clare Hocking of the Auckland School of Occupational Therapy. In her article “Function or Feelings: Factors in abandonment of Assistive Devices,” Dr. Hocking talks about an occupational therapist’s clinical reasoning when trying to best match AT devices to their users. She draws on how concepts from psychology, anthropology, sociology, and consumer research can help therapists to better understand why some devices are used and others are abandoned. A person’s readiness to use an assistive device is linked to their values and emotional responses to AT. Occupational therapists need to balance a person’s willingness to use AT and

their individual preferences with evaluating their functional capabilities (Hocking, 1999).

Another factor discussed by Dr. Hocking (also by Scherer and Karp) is the user's sense of identity. This can impact an individual's readiness to use AT. This concept of one's self image draws on psychosocial and cultural influences. The notion of having a disabled and non-disabled identity and coming to terms with being disabled is a psychological process. Dependent on environment, identity, cultural upbringing, and views of others, this is an individual mental negotiation which is often ongoing throughout the person's life. This internal struggle between identities can affect a user's willingness to adapt to assistive devices. This is especially true in adolescents and people who have acquired disabilities later in life. Disabled teenagers have it especially hard, since these are the years where one's identity begins to take shape. They face pressures of conformity from their able-bodied peers, which in turn makes the battle between independence and AT a difficult one. There are also other identity issues during the teenage years that could impact device use or abandonment. Trying to fit in, establishing friendships, one's sexual identity, and gaining social confidence all can counteract dependence on assistive devices.

From a psychological standpoint, the visual appearance of assistive devices in one's environment could have a negative impact on that individual's identity. People who are disabled do not want to be portrayed as "sick" or "different." It is important for therapists to also consider how complicated a particular device is. If a person can complete the task the device was designed

for with ease, they will have a positive experience with it and be more likely to use it regularly. However, if the person has trouble using it and then feels anxious, frustrated, or uncomfortable with the new technology, the rate of abandonment increases.

Personal style is an important consideration in the use/non-use of AT. Personal possessions are a means to creating our own identity in this consumer society. Acquiring and discarding objects that hold personal meaning in turn can shape one's identity. This phenomenon has been noted by consumer researchers in the development of new product lines. People buy new clothes, jewelry, cars, etc. to increase their confidence and make their outward appearance more enticing. Objects like wheelchairs and some assistive devices can negatively impact a person in the same manner. Material possessions convey a person's social status and social roles. Hocking says,

Considered from this perspective, wheelchairs and other visible assistive devices signal membership of a minority group- 'the disabled' with its attendant images of passivity and helplessness, rather than individual identity or uniqueness. (Hocking, 1999)

Dr. Hocking looked at how psychological, psychosocial, anthropological, and sociocultural factors can influence an assistive device's use or abandonment. She argues that occupational therapists need to take a person-centered approach and look beyond functionality, task, and environment. In her own words, therapists need to focus on "interactional and conditional reasoning about

the person and their attitudes and emotional responses to using assistive devices” (Hocking, 1999).

This paradigm shift to a more person-centered approach can be directly integrated into the design field. Designers who are responsible for the development of assistive technology also need to look beyond simply improving functionality. In his article “Better Designs, Better Outcomes: The Role of Product Designers in Assistive Technology Research,” Peter Wolf argues the need for the integration of product design research into AT development. Wolf also cites the importance of “personal factors” involved in device abandonment, including identity and the social stigmas of being (or looking) disabled (Wolf, June 2006).

He suggests that we should take a different approach to AT research. This approach involves using an ethnographic strategy of consumer research. It is sometimes difficult for a consumer to tell you what it is they exactly want in a product, whether it be AT or otherwise. By probing into the daily lives of consumers (in this case, AT users), unarticulated needs and wants can arise. Instead of designing based on technology or functionality of a disability, the design is centered around true human behavior. In the field of industrial design, this type of ethnographic research has lead to actionable insights that spawn innovation. In his article, Wolf discusses a shift from a medical approach to a consumer approach. People with disabilities who use assistive devices should have choices like any other consumer. The look and feel of a device is important just like any other consumer product. AT is usually based solely on functional capacity without consideration for product appearance or individual style. The

look of a device can bias a user's opinion of the product, regardless of how well it works. This is a core philosophy of industrial design: a meld of aesthetics, innovation, and functionality.

AT development should become multidisciplinary, with a collaborative effort between occupational therapists, engineers, business strategists, and product designers. This type of teamwork while using an ethnographic design research approach could spark innovation in device development. It is also will almost certainly lead to more device acceptance and less abandonment. Collaborative design and research will lead to more selection of AT products, better sales for the companies producing them, and most importantly a better quality of life of people with disabilities (Wolf, June 2006).

### *The Role of Human Factors and a current AT assessment*

#### *Human Factors of Assistive Technology*

Human factors can play a critical role in the design, development, and implementation of AT. Designers should research how people with disabilities (and those around them, e.g., family, friends, caregivers) interact with devices and technology. "Human factors in AT is concerned with finding out the special needs, capabilities, and limitations of users, and then matching devices and controls to each individual user" (King, 1999). It is also focused on increasing comfort, maximizing convenience and effectiveness, reducing cost while increasing efficiency, reducing exertion, reducing stress and fear of use, reducing danger to the user, and limiting possible failure of the device. All of these human

factors considerations will lead to a better designed, higher quality, less abandoned AT device.

In his book *Assistive Technology: Essential Human Factors*, Thomas W. King explains ten specific human factors that relate to the development of AT. Many of the concepts outlined are derived and adapted from Norman (1988). These are concepts that designers and AT professionals can look to as a guide on how human factors can influence assistive technology development.

1. *Transparency-translucency-opacity of devices and tools*. This concept addresses the user-friendliness and visibility of a device during actual device operation. It is directly related to device use/nonuse. A transparent device is one whose operation is self evident and easy to operate. A translucent device may be familiar, but need instructions to use properly (e.g., alarm clock, VCR). An opaque device is completely foreign, complex, and difficult to use.
2. *Cosmesis of AT devices, tools, and systems*. The appearance of a device and how it fits with its particular user's desires can influence device use or abandonment. Cosmesis is concerned with how a device looks and how it is accepted by others who see the user with the device.
3. *Mappings of AT learning, use, and operation*. This concept involves how a devices controls are designed to utilize natural human mappings of movement sequences. Direction, organization, and groupings can help to map movement in a way that is natural to the user and to the environment they are in.

4. *Affordances*. This relates to the perceived and actual properties of the device. Affordances provide visual cues to the operation of the AT. When properly designed, a simple thing should not need a picture or instructions to explain how to use the item.
5. *Learned or Taught Helplessness*. When a device or system fails, it is human nature for the users to blame themselves. This is common with all of the consumer technology we have today. After a few failures, the user begins to question their competency. This learning barrier can be avoided in the design of the device and veer the user away from almost certain abandonment.
6. *Feedback from switches, controls, screens, and devices*. Feedback from a device or system lets the user know that input has been received. This can be any kind of sensory reaction, such as tactile, auditory, or visual that can indicate device response. A quick and accurate response is particularly important in people with special needs.
7. *Knowledge of AT use: "in the head" vs. "in the world."* Knowledge in the head refers to the operational information that the user already knows. It is based on learned experiences, as well as exposure to other devices or similar technologies. Knowledge in the world in relation to AT refers to operational information that is either built into or displayed on a device. It is important to consider which type of knowledge is determining the transparency of the technology.

8. *Constraints of AT use.* This human factor is centered on what we can or cannot do with various devices or technologies. These constraints can be physical, semantic, cultural or logical and deal with device perception and use.
9. *Incorporation of failsafe functions.* This concept involves forcing a device or system to behave in a certain way to increase device efficiency. It is also used to limit user error, as well as to prevent misuse of a device and subsequent injury to the user or others.
10. *Prevention of errors, mistakes, and mis-activations in AT use.* Error prevention can be reduced or eliminated through efficient design and human factors considerations. As AT is for people with special needs, limiting errors in device interaction is essential (King, 1999), (Norman, 1988).

These human factors considerations are especially important to use as guidelines in the design and development of new AT products. Because the users of AT generally have motor, sensory, cognitive, or other impairments, their unarticulated needs are often greater than the general public. The market for AT products and their development is considerably narrower than for other consumer products. The high rate of device abandonment proves that more attention to human factors is needed in the design of AT products.

### *The Assistive Technology Continuum*

There are different levels of technology associated with AT devices. A product does not have to be very expensive with a high degree of technological advancement to be useful. Depending on the individual who is using the device, a low-tech device might be more suitable, less expensive, durable, and more effective. Giving advanced technology to individuals who may not be ready for it can lead to misuse or abandonment. In their book *Assistive Technology: Access for All Students*, Johnson, Beard and Carpenter describe an effective method to visualize the different types of AT. It is called the Assistive Technology Continuum, and it describes the technological range of various AT products. The continuum consists of three levels of AT products: no-tech, low-tech, and high-tech. These terms were first used in a journal article in the early 1980s (Vanderheiden, 1984). Even though our concept of technology has drastically changed since then, the continuum is still as effective now as it was then at visualizing the range of AT devices.

The first level of the continuum is referred to as “no-tech.” A no-tech solution is one that can be accomplished without the use of any technology. In the AT community, this generally means using one’s body to perform a given task (in a way that it is not typically used). No external device or tool of any sort is employed to accomplish an objective. These body parts are moved in rule-governed patterns to accomplish a task. An example of this could be a person using eye movements or blinking to signal “yes” or “no”, or paraplegic using upper body strength to transfer from chair to bed or navigate up a small staircase

by crawling. Sign language could also be considered a no-tech system of communication. *Endosomatic*, which means within or part of the body, is a good term to describe no-tech AT systems. Because of the nature of this thesis project, the goal was to design an *exosomatic* AT device (external to the body). No-tech systems are not really relevant to the current AT assessment of this project (King, 1999).

The second level of the AT continuum is made of “low-tech” devices and systems. This stage of the hierarchy can also be referred to as “light-tech.” The devices that fall into this category are simple to use, non-electronic, and non-motorized. “Low-tech systems involve a reliance by the user on rules and patterns of use and movement coupled with an (AT) device to accomplish a purpose. They are simple but effective; their mappings are natural, their affordances are evident, and their constraints are logical and obvious” (King, 1999). Some examples of light tech devices would be reading glasses, specially shaped silverware with built up handles that is easier to hold, grabbers that allow people in wheelchairs to reach high objects, or a scrub brush with a long handle to allow people with movement limitations to clean themselves. Low-tech devices are the most reliable, durable and cost effective solutions on the continuum.

The third level of the AT continuum consists of “high-tech” devices. These devices have electronic components. They have a power source (outlet or battery) used to run them. Some examples of high-tech devices would be a power wheelchair, computer hardware and software for synthesized speech, talking clocks or devices that allow for speech output, or adapted automobiles for

hands-only driving. In general, a high price tag comes with high-tech devices. This can be a problem depending on the funding for such a device. These products can also have a steeper learning curve for use, especially if they deal with learning computer software. Although more opaque for some, to others high-tech devices can be life changing. Professor Steven Hawking for instance, who is living with ALS, is able to communicate verbally with a voice synthesizer when he otherwise would not be able to talk. Wheelchairs like the iBOT® are allowing the severely disabled to climb stairs on their own. Prosthetics are available that can translate brain activity in order to move the false limb. High tech devices have the power to literally change a person's life forever. It is important though as designers not to fall into the "technology trap." This means going overboard with the latest and greatest technology when a lower-tech option would be cheaper and more effective.

### *Current Assistive Technology Assessment*

This basis of this thesis project was to help Tedde, a woman with LGMD, perform a specific task. She came to us wanting a better solution for helping her eat than the AT devices she currently was using. In the early stages of device development, the researcher realized that other hand-to-face related activities would also be possible to accomplish. Since the subject could not move her arms but still had some finger dexterity, the goal was to devise a mechanism that would lift her arm up to her face. There are many different kinds of AT on the

market today. The following section will focus on devices relative to arm movement and what is currently available for purchase.

There are several low-tech devices on the market associated with the task of eating and arm lifting. The devices that the subject is currently using for this task are an important consideration in this research. Tedde eats at her powerchair. The chair has a tray built onto the front of it, but it is too low for her to eat off of. She had a specialist custom make a sliding acrylic secondary tray which brings her food about 8 inches closer to her mouth (see Figure 12). By increasing the lean angle of her powerchair, she is able to get her head even closer to the tray (this would be considered an alternate use of a high-tech device). Tedde also uses an extension fork, which enables her to lift food from the tray to her mouth by only using wrist and finger movement. To drink, an elongated straw enables her to sip without lifting the cup to her face.



*Figure 12.* Tedde's low tech devices to help her eat.

There are other low-tech eating devices that are on the market today. There is a variety of utensils with many different features to choose from. Some have built up handles (for low grip strength or arthritis), adjustable angle bends or extensions, combination rocker knife/forks or spoon/forks (for one hand use or limited dexterity), loop handles (to allow claw gripping), or a swiveling weighted head to keep food from spilling (see Figure 13) (AbleData, 2008).



*Figure 13. Swiveling utensils with built-up handles (easy to grip, prevent spills)*

There are mechanical and electric varieties of feeding arm supports and self feeders. One such product is the Action Arm. This device mounts to a table or wheelchair tray, and has a utensil holder. It can dampen spastic motor movements, and has multiple joints that simulate the motion of the human arm (see Figure 14) (Flaghouse, 2007). Another device that can assist in lifting the arm to the face without a power source is the Jaeco WREX. This exoskeleton device totally eliminates the effects that gravity has on the limb by counteracting it with elastic band elevation assists. This allows people who have low shoulder/limb strength to be able to move their arm around with minimal effort. It can be mounted on most wheelchairs, and dramatically increases the user's upper limb range of motion. Jaeco Orthopedic has a product line of four mobile arm supports, with the WREX fitting most closely to this research (JAECO Orthopedic, 2008).



*Figure 14. Action Arm utensil holder and arm support.*



*Figure 15. Jaeco WREX arm lifting and motion device.*

The Armon is a non-powered orthosis used to support the arm for various ADLs (see Figure 16a). It is spring loaded, yet the springs to the device are cleverly hidden through elegant design. The device connects to the upper arm and forearm. It supports the weight of the arm using springs, allowing a user with neuromuscular disease or low muscle function a much greater range of motion. The varying load of the device is electronically controlled, allowing for adjustments to pick up objects or for heavy clothes. This also enables users with a wide range of muscle ability to benefit from the Armon (see Figure 16b). It compensates the total weight of the arm and has smooth, natural movements. From a design standpoint, the Armon is a great mix of aesthetics and functionality. It has sleek looks that hide the mechanical components, and works well for people with limited muscle function in either arm (MicroGravity, 2007).



a.



b.

*Figure 16. Armon spring-loaded arm support.*

High-tech eating and arm lifting devices are also available for use by the disabled community. There are many powered self-feeders on the market today. These devices are electronic, and use a small lever arm with a utensil attached. One such unit named the Winsford Feeder uses a chin switch to activate (see Figure 17). With a slight head motion, the spoon is lowered to the plate or bowl, filled with food, the automatically raised to the mouth at a set pace. The plate rotates as well to allow food to be taken from different parts of the plate. This device is battery operated so it can be used without the need for an outlet nearby. Like many high-tech AT devices, this one is expensive. It carries a price tag of \$3,799.99 (Sammons Preston, 2007).



*Figure 17.* The Winsford Feeder

The most high-tech assistive arm lifting device available for purchase right now is the ARM: Assistive Robotic Manipulator (formerly known as the Manus). This assistive robot has six degrees of freedom and is meant to help people with severe upper limb and hand disabilities. It is wheelchair mountable, and has various control modules available to suit different users' needs (a joystick, a 4x4 keypad, a head controlled module, or a custom made input controlled by a usable body part). There is an LED display matrix, along with a buzzer that beeps to warn the user of dangerous situations or errors. The ARM has a shoulder, elbow, and wrist joint, along with a gripper that can apply up to four pounds of variable grip pressure (see Figure 18). These components can independently move around six axes. It also has utensil attachments for eating. The ARM was designed with the goal of assisting users with upper limb disabilities perform an infinite number of ADLs that they otherwise would not have been able to do on their own. Some of these include preparing and eating meals, personal hygiene, picking up objects, turning on light switches, taking medication, or anything else and able-bodied individual could perform with their own arm. This device costs in the range of \$15,000, which the manufacturer suggests will pay for itself without the need for a caregiver in one to two years. This price tag is still rather high considering that many people with disabilities have to pay for assistive devices out of pocket. There is also a learning curve associated with the device, and a desire to use a high level of technology to increase one's independence and quality of life (Exact Dynamics, 2007).



*Figure 18.* Two users of the ARM pour a beer with the device.

## CHAPTER 3

### Research Design

#### *Introduction*

The approach to this research is a qualitative, mixed-methods design. This type of strategy fits well with the study's exploration of the ADL's and design needs of people living in wheelchairs. Its flexibility allows for multiple research methods to be used. The purpose of this study is two-fold. First, a tangible device will be created using a user-centered, iterative design process. Secondly, different qualitative methods will be employed to study the ADL's and device use/non-use of a larger group of wheelchair users. This ideally will lead to actionable insights and recommendations for future assistive technology design and research.

This thesis started as a class project in DSC 544: Human Factors Systems and Documentation. Five Industrial Design Masters students were involved in the initial project: Christopher Grasso, Dean Bacalzo, Jiyi Liu, Amol Surve, and Gema Munoz Alarcon. Over a two semester period, the researcher was in charge of prototype design and development. During these two semesters, the main design objective was to lift Tedde's arm up to her face for eating-related ADLs. There were many project constraints discovered and analyzed by the research team. In order to meet the main design objective, several smaller objectives were set throughout the development process. These will be looked at further later in this chapter. The first qualitative method utilized in the design process (front-end task analysis) was conducted during the timeframe of the DSC 544 project. The design of the device from prototype I

through IV was also in this timeframe. Prototype V (as well as the final video analysis and in home trials of the device) was developed solely by the researcher.

The type of action research employed in the device creation would use human factors and qualitative research methods (videotaped participant observation, semi-structured interviews) to help better understand the capabilities and needs of the subject (Tedde). Using human factors and human-centered design principles, the goal is to work with Tedde throughout the entire design process, and have her test the different prototypes along the way. This would let the researcher analyze and refine the design of the product several times. Since this phase of the research could be limiting in that it was being designed based on one woman's needs, input, and even powerchair, more thorough qualitative research will be done to gain insights into a larger population of wheelchair users. Email surveys, internet chat room sessions, and an instant messenger interview are the methods to be implemented in this phase of the research.

A literature review was conducted in order to define and address the following topics (main sections in Chapter 2): living in a wheelchair, life with a disability, and human factors considerations and current assessment of assistive technology. The purpose of the review was to ground the study in established theory and to validate the research questions and methodology. The objective was to arrange the literature and information that had conceptual relevance to the initial research question into a coherent system. Using this information as a guide, the research topics could become more focused. The volume of literature

was continually referenced throughout both the device design process and the development of the survey and interview materials. (Groat & Wang, 2002)

### *Methodology and Methods*

This thesis includes using a design project as a type of design methodology. Research methods employed in this flexible, qualitative strategy include:

#### Part one (class project goals)

##### DSC 544 Human Factors Design class project

- Analysis of given elements
- Project constraint development
- Project design objective development

#### Part one (iterative design of device)

- Front end task analysis to determine the user's physical limitations and goals (using observation and interview)
- Video and photo documentation to ascertain the subject's current device use and ability in her work environment
- Iterative design process molded around constant user feedback, human factors considerations, and the design and testing of many prototypes
- Final video/photo observation and in-home trials of the device

#### Part Two (qualitative research on ADLs and the use/nonuse of AT)

- Survey questionnaire of current wheelchair users on AT and ADLS



### *Part One: Sample*

This research began as a project for a 500 level class in the College of Design at Arizona State University. This class, taught by Professor Donald Herring (committee chair), was titled “DSC 544: Human Factors Systems and Documentation.” While studying applied research in the field of human factors, it became evident that the main project could be used to help someone improve their quality of life.

The research team was introduced to Tedde, a woman living with LGMD and at that time working in the Disability Resource Center at ASU. Her advanced condition requires the permanent use of a powerchair, along with a caregiver and several other devices to help carry out her daily activities. Tedde had come to Professor Herring to find a solution to aid in her eating-related activities. Her current adapted method using low-tech AT was slow, uncomfortable, and inefficient (see Chapter 2, p. 59-60). She was outgoing, eager to try new things, and ready to be a willing participant in a research study. She also has had the disease since her teens (she is now in her sixties). This meant that her disability experience has led to a general acceptance of AT to help improve her quality of life. According to several pieces of literature (Scherer, King, Bryant, Johnson), Tedde’s optimistic and cooperative attitude, motivation, patience, and view of new technology made her an ideal candidate for this research project.

This phase of the research project (part one) had a small sample size of one participant. Functionality greatly differs in people with disabilities (even in those with the same ailment). Wheelchair specifications, as well as comfort level

and taste in design are also highly individualized. In rehabilitation engineering, it is common knowledge that a user has to be properly matched to a device. “In a broad sense, the ‘person-technology match’ is an effort to identify the perfect ‘fitting’ of a device to an individual” (Bryant & Bryant, 2003). This sometimes includes designing a device from scratch to meet a user’s wants, needs, and desires for AT and their interaction with it. It was appropriate in this case to use only one subject as the initial research goal was to solve that subject’s problem. This would also allow for a comfortable lab setting and a trust to be built between researchers and subject.

### *Part One: Strategy*

#### *Front End Task Analysis*

The first method employed in the device development phase of this research was a front-end task analysis. This could be considered the starting point in the design process. The central component to an AT device assessment is the individual user. The purpose of this analysis was to determine the subject’s physical capacities and limitations. Before a device is designed, it is essential to evaluate activity specific tasks. In this case, the goal of the device was to act as an arm lifting mechanism. This required knowledge of her strength, flexibility, coordination, and movement. User functionality was determined through observation of simulated ADL activities and informal interviews. This method of data collection also was used to determine her individual problem, and her goals associated with solving it through AT device development (Axelson, 1998).

As part of this task analysis, a semi-structured face-to-face video interview was given. “Face-to-face interviews offer the possibility of modifying one’s line of enquiry, following up interesting responses and investigating underlying motives in a way that other self-administered questionnaires cannot” (Robson, 2002). Video was chosen instead of just audio recording because the interview took place during lunch at Tedde’s place of work. The opportunity was there to observe the subject in her natural environment, manipulating objects and artifacts. She was taped eating and then performing other work related tasks. Videography can capture ordinary events that could be viewed and replayed to aid in the design process. The recording could be scrutinized and used to analyze movement and behavior. It is important to frame the design problem in the real world and be able to visualize possible solutions. The accompanying audio was transcribed for reference. The interview and video recording was completed solely by the researcher.

An in-home photo observation was also completed in Tedde’s home. This task, completed by the DSC544 team, aimed to observe and document home-related ADLs including eating and drinking. It was also important to see other tasks performed in the chair that an attached device may or may not impede. These included hair washing (reclining of chair), driving from room to room (environmental constraints), and driving into and out of her modified van. Measurements were taken of door widths on both her home and on the van.

### *Iterative Design Process*

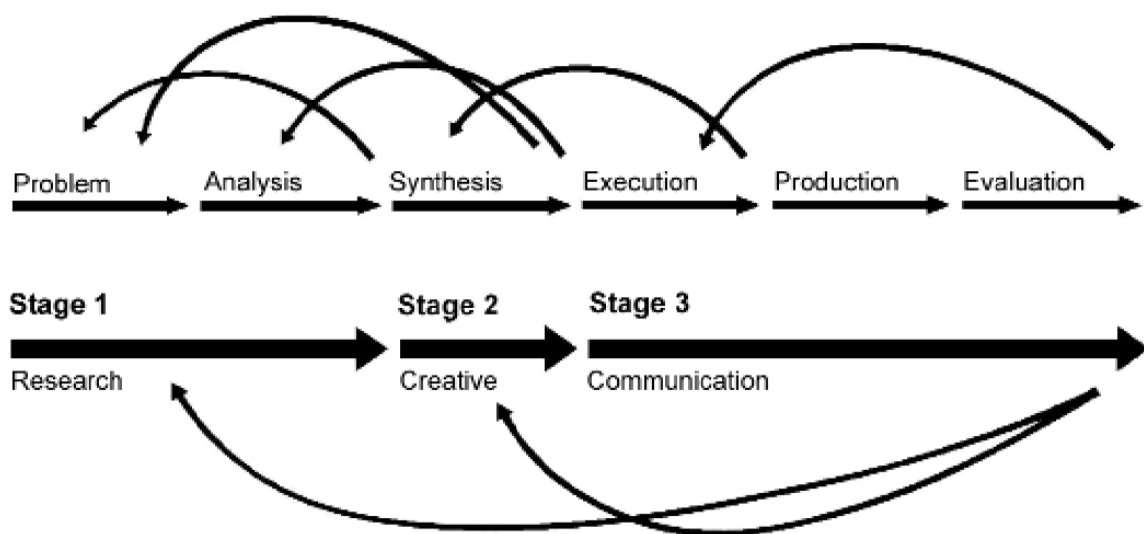
Iterative design is:

A design methodology based on a cyclic process of prototyping, testing, analyzing, and refining a work in progress. In iterative design, interaction with the designed system is used as a form of research for informing and evolving a project, as successive versions, or iterations of a design are implemented. (Wikipedia, 2008)

This method has been used extensively in both engineering and software development. It is also used frequently in the field of product design. As a product is being developed, there is background research done into the consumer market and the end users. The next phase generally involves sketching and ideation. Several ideas are brought to the table including but not limited to the product's feature set, aesthetics, manufacturability, cost, etc. Through multidisciplinary collaboration, several ideas are whittled down to a few plausible ones. Rough prototypes are made which can give a better feel to a three-dimensional product than a sketch can. Before deciding on a final design, there are sometimes hundreds of sketches and prototypes made. It is important to note that this is not a linear process. "The design process is iterative. It can only be effective if it is a constant process of revisiting the problem, reanalyzing it and synthesizing revised solutions" (Swann, 2002). This action research design approach is similar to testing research hypotheses in the field of science. Although a bit more chaotic and rough, action research can represent months or

years of development. This process becomes a researched method that evolves into a final tangible product.

Cal Swann, in an article about “action research,” describes the design process as having six basic elements: problem/research, analysis, synthesis, execution, production, and evaluation. A model of this non-linear process shows the importance and need for reevaluating each step (see Figure 20). Reaching a solution in design is not an instant result. Several cycles of designing, reviewing, testing, amending, and adapting are a necessary part of the process (Swann, 2002).



*Figure 20.* The iterative design process model.

Since this thesis included a design project, the iterative process of designing the AT device is a valuable research method. The iterative design process is driven by the main research goal: lifting Tedde’s arm to her face to aid in the task of eating. The aim was to create several working prototype variations of the product throughout the process. The subject volunteered her time on

numerous lab visits to test each iteration. She was able to converse with the research team and give her opinion on design and function. It is critical to have the subject present early on in the ideation phase and then continually through the development of the product. The goal of using several cheap prototypes is to break the cycle of the user purchasing a product and discarding it after a short trial period. The needs of the subject (consumer) can be met more thoroughly and abandonment can be significantly reduced with this user-centered approach (Cooper, 1998).

#### *DSC 544 Design Objectives and Constraints*

The DSC 544 project focused on one main design objective of raising Tedde's arm to her face for eating-related ADLs. With this in mind, the team looked at the given factors that would shape the design process (see Table 2).

<b>Given Components to Design Project</b>	<b>Description</b>	<b>Unique Additional Systems</b>
One subject	Tedde	design the device around Tedde's ADLs, needs, and feedback
One electric wheelchair	Permobil C2K	respirator system (control unit, tubing, independent battery), secondary double-stacking and hinged tray, additional on/off large push button for electronic components
Electric battery	24V power supply for chair	2 12V batteries in series, located under plastic housing beneath seat pan. 24 hours of battery life; recharged when subject is sleeping at night
Air Muscle technology	donated by Kinetic Muscles, Inc (KMI)	inner bladder, external braided mesh sleeve, end plugs, air valve, tubing

*Table 2.* Given components to the design project.

The design of the assistive device was based on the ADL-related needs and wants of one subject. Tedde wanted AT that could help her eat easier, quicker, and more efficiently. The proposed device would need to attach to her specific electric wheelchair. Tedde's chair is a Permobil C2K, and has unique additional aftermarket systems. These include a respirator system on the rear of the seat back (with tubing and independent battery), a secondary hinging tray for eating (see Figure 12), and a large on/off button near the joystick for the electronic components. Since the device was to be powered by the electrical supply of the wheelchair, the battery system was also a given component. There are two 12V batteries in series located under the seat pan. This 24V system can last 24 hours without the need to be recharged. It was decided before the design process began that air muscle technology would be used to generate the required lift. This technology fit very well with the researched human factors guidelines. KMI of Tempe, Arizona donated the air muscle components to the project.

After careful review and analysis of the given components to the project, a list of design constraints was made (see Table 3). This would help to break the main design objective into smaller tasks.

<b>Project Constraints</b>	<b>Description</b>
Chair dimensions and range of motion	take measurements and document length, width, and height of her specific chair; and angles of reclining chair back
Tedde's ADLs	find what ADLs the device could be used for or get in the way of
Tedde's physical functionality	observe and document existing range of motion for her shoulder, arm, wrist, hands, and fingers
Environmental dimensions	keep device within dimensional constraints of doorways (van, home, and office)
Ideal location of device	locate the ideal placement for the mounting brackets, the arm-lifting mechanism, control switch, and air pump
Battery systems	research location, type of connection, and safety considerations for connecting electronic components of device to powerchair

*Table 3.* Project constraints developed for device design.

The first constraint identified was to determine specific ADLs or IADLs that a mounted device could get in the way of. This would require observation of Tedde at home, work, and means of transportation.

The second constraint was the size and range of motion of her specific chair. The angle of recline and height of power lift needed to be considered to maintain full chair functionality when the device is attached.

The third constraint was Tedde's physical strength and functional ability. The range of motion of her shoulder, arm, wrists, hands, and fingers needed to be observed and documented. This would give the team a baseline for designing the components of the device. The mobility of her left wrist, hand and finger (arm not being lifted) were also examined as this hand would activate the device via control switch.

The fourth constraint was the environmental dimensions Tedde faces while driving her chair. Ideally the device would stay within the chair's footprint so it would not impede her normal traveling routine (getting into van, driving through doorways).

The fifth constraint identified was possible locations for the device and all necessary components to mount to the chair. Her specific powerchair and additional systems posed a unique design problem to solve.

The sixth constraint to the main design objective was the battery system. It needed to power the device safely without impeding current chair functionality.

Once the project's given elements were analyzed and constraints were identified, it was possible to break down the device design into several smaller tasks. The main design objective of lifting the arm to the face to help Tedde eat was the driving force behind all tasks and iterations. With this in mind, a table of nine objectives (including the main) was created with descriptions and possible materials (see Table 4).

Table 4 represents an overview of the goals of the DSC544 class. The iterative prototyping process was implemented to conquer these challenges. The constraints addressed in Table 3 were referenced throughout the design project. Some objectives are interconnected, so making a change to one meant another needed to change as well. For example, the design of the device (objective seven) would change based on the mechanics to lift the arm up (objective three) or how it was mounted to the wheelchair (objective four). Table 4 will be

expanded on in Chapter 4 of this document, and the solution to each design objective will be explained.

<b>Design Objective</b>	<b>Description</b>	<b>Possible Materials</b>
1. lift Tedde's arm to her face for eating tasks	This is the main design objective of the project	(see below)
2. design of testing rig and testing electronics	important to test prototypes while using outlet power when subject was not present	plywood, abs plastic, electronic components
3. mechanics to lift arm up	find out the best solution to achieve optimal lift	pulleys, hinges, pivots, cable, fasteners
4. mounting device to chair	find the strongest and best placed location on powerchair to attach device	bolts or screws, metal mounting bracket
5. mounting air muscle to device/chair	find the most efficient method and place to attach the air muscle	steel bands, zip ties, eye hooks
6. design of arm cuff	create strong, lightweight, and comfortable supporting brace for arm	sheet styrene or polypropylene, foam, fabric
7. design of arm-lifting device	taking mechanics and mounting into consideration, develop prototypes that explore functionality and aesthetics.	tubular steel, steel conduit, aluminum, ABS, PVC tubing, custom components
8. user controls	type, location and configuration of user input control device	switch type (toggle, three-way, slide, DPDT, self-neutral), mounting options (fasteners, bracket, Velcro)
9. mounting of air pump and release valve	find the ideal location for electronic components, and best way to manage wires and air tubes	gauge of wire, fuse, length of wire and air tubing, fastening options
10. connecting electronics to power source	find the safest means to connect pump and valve to wheelchair battery system	wire, fuse holder, fuse, eye terminal connector

*Table 4.* Design objectives for the development of an arm-lifting device.

### *Part Two: Sample*

Part two of the research strategy incorporates three qualitative methods in the sampling of a larger population of wheelchair users. The purpose of Part Two is to gain a better understanding of ADLs and AT device use of the participants. The first sampling was taken through an email survey. The researcher's initial intent was to go through Arizona State University's channels to reach out to potential respondents. After contacting the school's disability resource center, an unexpected response was returned. It was made known that they could not send out surveys using their email listserv, even though this had been done in the past, because it may be construed as spam. The researcher accessed another local channel in Mesa Disabled Sports. This is a facility in Mesa, Arizona which hosts many wheelchair sports and leagues, including basketball, powerchair soccer, and rugby. The administrators here saw value in the research that was being conducted and thought their patrons would agree. The survey and cover letter were emailed to Mesa Disabled Sports, and were sent out as an attachment from their email address. This yielded twelve respondents. Because the researcher was unable to email the survey directly due to confidentiality agreements, it is unknown how many people received it.

Part two also incorporated two Internet chat sessions on the Muscular Dystrophy Association (MDA) website. The sample size was solely at the digression of how many people joined the chat session each time. Each session has a two hour time slot, and users are allowed to enter or exit at will during the duration of those two hours. During the first session, Wheelchair Gang, sixteen

people (including the researcher) logged in to chat. During the second session, LGMD Chat Group, there were eleven people (including the researcher) involved in the chat session. Some of the MDA Chat users from the first session were also logged into the second session.

The first chat session yielded an unexpected additional research method as it came to a close. One of the members logged on when the session was about to expire, and suggested using an instant messenger client to conduct an informal interview. Since we could no longer chat in the MDA Chat window, this was a great way to continue the conversation with a subject eager to weigh in on AT and assistive device use. This interview had one subject.

*Part Two: Strategy*

Qualitative Method	Sample Size	Advantages	Disadvantages
Email survey	12	straightforward approach to gain insights to ADLs and device use. Questions can be worded to invoke relevant information to the study.	low response rate, difficult to get surveys out due to confidentiality of email addresses.
Internet chat	27 (16 and 11)	ability to connect with multiple disabled people simultaneously. Focus group style dynamic environment	hard to control the exact topic of conversation with many people chatting at once
Yahoo® Messenger interview	1	spur of the moment method. Able to download and install software fast. Brought an international subject to the research.	Difficult for subject to type for an extended period of time due to muscle fatigue (because of MD)

*Table 5.* Qualitative Research Methods used.

Table 5 illustrates the three qualitative research methods employed in this study. The sample size of each and their advantages/disadvantages can be compared. It is important to note that all communications were done through the use of the Internet. Emailing surveys is common practice, but using online chat rooms and instant messaging as methods is new. The Internet has unlimited potential to connect people to each other in this dynamic virtual environment. There are many devices available to help the disabled community use computers. The freedom and anonymity the Internet can provide lets disabled people feel enabled. It helps them to connect to each other and make friends and get support in a social setting.

### *Survey*

The survey was the first qualitative method employed. The focus of this survey was the current physical condition of wheelchair users, their problematic ADLs and IADLs, and their past and current usage of assistive devices. The survey intended to broaden the scope and the sample size of the iterative research conducted in Part One of the study. The subject of Part One is living with LGMD, but it was important to also look at people who were using chairs for other reasons and conditions.

The purpose of the research was to learn personal issues and insights from several actual wheelchair users about their day to day lives and the AT that helps them. The survey was written as more of a consumer survey than a medical one, although there were a few questions about physical limitations and current condition. The researcher wanted the participants to feel comfortable

answering questions about their personal activities and assistive product usage so they would answer both willingly and truthfully. This kind of real world data was not readily available in the review of the literature on assistive technology. Therefore, conducting this research has the potential to add to the body of knowledge in this area.

The survey style was self-completion, where the surveys were emailed out as a Microsoft Word document or a Portable Document Format (PDF) at the request of subjects that didn't have the capability of opening a Word file. The questionnaire was accompanied by a cover letter that explained the purpose of the research project, the option to participate, contact information for both the researcher and the principle investigator, and other pertinent information required by the Institutional Review Board (IRB) at ASU. The respondents filled in the answers on their own, and then returned it (Robson, 2002).

The content of the questionnaire was directly derived from the research topics and questions presented in the introduction (p. 7). There were four main points of interest included. The first series of questions was written to determine the reason or condition for the subject's wheelchair use. The second group of questions focused on how their specific functionality influenced their daily activities and made them more troublesome. The third series of questions dealt with assistive devices they have used to help offset their physical limitations. This included any devices they were using presently or have used in the past but abandoned. This point of interest also looked at devices that may have been modified by the user or homemade. The last group of questions was designed to

get demographic information from the subject. They were asked their age, the style of wheelchair they used, and their current occupation (or field of study).

### *Internet Chat*

The second qualitative method used in Part Two of this research was the internet chat. The MDA site has a built in chat window which requires a log in ([www.mda.org/chat](http://www.mda.org/chat)). Users have to request a log in and password to be able to use this feature. The research project was explained through an email conversation with the MDA chat administrator, and a log in and password was granted. The site hosts a variety of weekly chat sessions every day. Based on the posted schedule, the LGMD Chat Group and the Wheelchair Gang were chosen because they were the best fit for this research. LGMD was significant because this is the disease that the subject in part one is living with. Wheelchair Gang would incorporate people in wheelchairs with a variety of neuromuscular diseases. (Muscular Dystrophy Association, 2008)

The internet chat was chosen because it gave the researcher the opportunity to speak to people living in wheelchairs in a setting that they were comfortable with. All of the participants freely come to this site from the privacy of their homes to talk to others who may be experiencing similar life situations. The chats were set up to bring people with various forms of MD together for support and sharing of stories and ideas. Because it was initially difficult to find respondents to the survey, trying to informally interview ten or more people in wheelchairs seemed like a daunting task. An internet chat would be the ideal situation as numerous people would be able to respond and contribute

simultaneously. Another benefit of this technological method is that it gets transcribed automatically, which saves valuable time. Internet research was conducted as to the best chat room to use, and MDA was chosen because of its popularity and good reputation.

The researcher created the log in name of Chris-ASU to identify himself as a student. The project and its goals were explained at the beginning of both sessions. The informal interview with numerous people in an online chat window has advantages over individual interviews. First off, it is easier to contact people over the internet since it allows people from all over the world to be in the same virtual space at the same time. Secondly, the MDA chat rooms are an established meeting place for people with disabilities. Because many people are there at once, it becomes more of a virtual focus group. Since it is an online chat room, there is informal dialogue and shorthand typing abbreviations frequently used. This allows people to act the way they normally would while chatting from their home computers as opposed to being in a clinical style setting.

#### *Instant Messenger Interview*

The third qualitative method used in Part two of this study was a virtual interview conducted over the internet. This was a direct off-shoot of the MDA chat method. While the session was coming to a close, a man signed into the MDA chat from India. After the researcher explained the project to him, he was interested in sharing his experiences and ideas relating to AT and his own disabilities. Because there was only five minutes left in the slotted two-hour time window for the MDA chat, he suggested we use an instant messaging client to

continue our conversation. Since the man used the Yahoo!® Messenger client, the researcher downloaded the free software from the company's website and installed it on his desktop computer (Yahoo!, 2008).

This informal interview was structured around the points of interest in the survey and research questions. It was conducted much like the chat with the use of Internet shorthand and slang. Informal dialogue is the norm of people who frequently use instant messengers as a communication tool. This style of conversation was used in order for the participant to feel comfortable with the researcher. This is important because the participant is sharing personal information about their health, physical limitations and their daily activities. Using the Yahoo!® Messenger client allowed the researcher to conduct a spur of the moment interview with a disabled man half way around the world. It brought an unforeseen cultural aspect into the research because every other participant was located in the United States.

### *Ethical Considerations*

Ethical considerations were taken to ensure the privacy and well being of all subjects in this study. All participation in every aspect of this research was voluntary. No deceptive or otherwise unethical tactics were used in the recruitment process or throughout the research.

Tedde initially signed an agreement to participate fully in the study at its onset. She was informed that she could stop or leave any time without penalty or prejudice. Great care was taken during the design and testing of the device to not harm or put her in any sort of discomfort. A bioscience IRB application was filed

on her behalf, but since there was only one participant in this section of the study the team was informed that IRB approval was not necessary (letter from IRB in appendix).

The qualitative research that was conducted in part two required a Social-Behavioral IRB application to be filed. This was approved before any research or recruitment was conducted (approval in appendix). The survey contained an IRB certified cover letter explaining the research. It also stated that participation is voluntary, questions can be skipped if the participant feels they are too personal or cause any discomfort, and they can withdraw from the study at any time with no penalty. The cover letter informed the subjects that the return of the survey was their willingness to participate in the study. During the MDA online chat and the Yahoo!® messenger interview, the participants were informed of the same rights. It was also important to disclose the fact that I was neither living with MD nor in a wheelchair as to not be deceptive about data collection. The researcher clearly established that he was doing a research project as a Masters Student at ASU and defined what the intentions were.

Furthermore, all electronic data was stored on a password encrypted hard drive for the duration of the project. The paper data was stored in a lock box. All of the identities of the participants were kept confidential. They were assigned aliases during the analysis of the data and presentation of the materials to ensure privacy. The one exception to this was the participant in Part One of the research. Tedde gave permission for her name or image to be used in print, video or photos for any aspect of this project.

## CHAPTER 4

### Findings

#### *Part One: Iterative Design Process*

##### *Problem*

As with any design inquiry, the first step in the process is to identify the problem. The subject of this part of the study, Tedde Scharf, came to the researchers with an issue she had. She had previously met the Principal Investigator and committee chair Professor Donald Herring, and expressed her openness and willingness to participate in this study. Because of the debilitating effects of her LGMD, it is hard for her to eat. At that time, she currently used several low-tech devices, including a tall tray to make the plate of food closer to her face, a long straw, and an extension fork (see figure 12 on page 60). In conjunction with these devices, Tedde also adjusts the angle of her powerchair seatback to bring her head closer to her tray. Her arm remains on the tray, and she uses her limited wrist and finger movement to manipulate food onto her fork. With her wrist/forearm pressed against the edge of the tray, she can pivot the fork upwards towards her mouth. The fork body (between the tines and handle) is longer than usual, and can bridge the gap between her hand (still against the elevated tray) and her mouth (closer to the tray because of her forward leaning seat position). Tedde has adapted her eating habits to her specific functionality. She uses a series of modified tools to eat her meals independently. However, this method is slow, and she feels uncomfortable eating in a social setting. When she first inquired about assistive technology in 2005, Tedde's goal was to be able to eat more independently. She wanted to be able

to eat in a normal seated position in her powerchair (not leaning forward) without the use of the extending tray or forks. This goal became the initial research question and main design objective: can an assistive device be designed to help Tedde eat more efficiently?

### *Front End Task Analysis*

This introductory stage of the research was to interview the subject, Tedde Scharf. This was performed in January of 2005 at Tedde's office in the Disability Resource Center at ASU. The goal of this semi-structured interview was to meet Tedde as well as find out more information about her disease, her current physical condition, and her functionality. A semi-structured format was chosen because it let the researcher loosely follow a guide of predetermined questions (Robson, 2002). The reason for this was twofold. First, it allowed the interview to flow more like a conversation, and not a scientific question and answer session. Secondly, this style of interview provided a higher level of comfortableness for both the subject and researcher. Since some of the questions were personal (about her ailment, daily activities, physical condition), it was important that both parties were relaxed and open in the conversation.

This first interview was recorded and transcribed for easy reference and analysis. The questions were guiding the conversation to find answers to three areas of interest: 1) what condition she has and the extent of her physical functionality; 2) what tasks give her the most trouble on a daily basis; and 3) what assistive devices does she currently use and what activities would she like a device for.

Tedde Scharf is living with limb girdle muscular dystrophy. She first went to the doctors when she was six years old. This was in the 1950s, and the original diagnosis was that she had post-polio. It wasn't until she was ten years old that doctors performed a muscle biopsy and found out it was MD. There was very little knowledge about the various types of MD at this time, so it was assumed that everyone diagnosed with it had Duchenne. Duchenne muscular dystrophy (DMD) is also a degenerative neuromuscular disease. It is usually onset in early childhood, and has a high rate of fatality. Because of this misdiagnosis, doctors assumed that Tedde would only live for a few years past age ten. The doctors told her parents to "take her home and make her happy," as they assumed she'd only be alive for a short period of time. At the time of this interview in 2005, that was 52 years ago. Tedde laughed that the doctors were slightly wrong on that number. It wasn't until she was 29 years old and already in a wheelchair fulltime that she learned her condition was LGMD.

LGMD is a debilitating, degenerative condition. Tedde said that the degeneration is an extremely slow process. It is not something that is noticed short term because adjustments are made to compensate for loss of function. She notices that her assistive devices change more than her physical abilities over the years. Her wheelchairs have gotten more and more complicated. Her trays have been raised higher and higher so she can eat. A question was asked regarding the extent of her functionality, especially in the limbs, as in what she could move or not move. Tedde responded,

“My ankles still have a little strength in them, and my toes. I can move my legs up and down a little with the ankle. How limb-girdle works is from the central trunk body out. For instance I used to be able to move my fingers and bend them. Now you can see I can only move them a little bit. These ones are getting worse, but the first one is straight I can’t bend it at all.” (T. Scharf, personal communication, January 2005)

She pointed out that even though she has very little movement in her appendages, she has adapted to still be able to perform certain tasks. For instance, she learned to type on her modified keyboard even though her fingers can’t bend or extend normally. Since the keyboard is concave, it allows her to reach the top row of keys more easily. She can answer her cell or office phone, and get papers from the desk or the printer. She only uses the speakerphone function because it is not possible for her to put a headset to her own ear. Tedde uses her powerchair to assist in positioning her body and hands in the right place to do specific tasks.

Further into the interview, Tedde was asked what tasks she had trouble performing on a daily basis. She responded,

“About everything. Let’s see. I have help getting me up out of bed. I have a Hoyer lift, not because I’m heavy but what tissues left will tear very easily if I’m lifted manually. I’m moved from the bed to the chair to the toilet, and all that. And I have attendants that come in and get me up, and help me with bathing and bathrooming and dressing and hair. I can brush my teeth with an electric toothbrush though! (Smiles) they have to put the

tray on, not without the tray I can't. They do my hair, my makeup. I get lipsticks that are real long so I can put it on myself. My caregiver hands it to me... that's not one thing I'm willing to give up! I finally did give up doing my eye makeup. First preparation of food has to be done for me I can't do that. It has to be cut up. I got a whole crew of girls that work for me. I got about 4 or 5 girls at a time, not all the same time. They take morning shifts or evening shifts or they'll come in during the day for bathrooming and to set my lunch up and that sort of thing. They help me fix dinner when mom's not there so I can feed myself and my Dad." (T. Scharf, personal communication, January 2005).

When asked about tasks that take a while for her to perform, she replied that eating was the main one. This is the task that she would most like an assistive device to help her with and would help her to be more independent.

The third goal of the interview was to find out what other assistive devices Tedde used on a regular basis. This question was already partially answered in some of the other responses given. It was evident by meeting Tedde that she used a fairly sophisticated power wheelchair. Attached to the back of the chair is a device that helps her breathe. It uses air to compress her chest to aid in the bodily movement required to breathe. She mentioned using a Hoyer lift with the assistance of a caregiver. A Hoyer lift uses a hydraulic lifting mechanism to transfer a person from wheelchair to bed, or wheelchair to toilet. The caregiver controlling the device is easily able to lift and move a person without the help of others. Tedde also uses various low-tech devices for eating, such as her bent

and extension utensils and elevated tray. She uses electric toothbrushes and long lipsticks to be able to perform personal grooming and hygiene tasks. She uses adaptive technological equipment in her office to help her with work related IADLS. These include a concave keyboard, a large trackball instead of a mouse, and a speakerphone.

In the final few questions of the interview, Tedde was asked if there was any specific activity that she would like or need a device for. She said that shaking hands is something she can't do and it makes others uncomfortable when they meet her. She would like to be able to use at least one arm to do a lot of things like reaching and eating.

The interview yielded quality information on Tedde's condition and on her troublesome ADLs. It became apparent that her functional capacity would be considered a severe disability. Because of the advancement of her condition and very limited functionality, Tedde needs a caregiver to help her with many of her ADLs. Tedde's attitude during the interview and answers to AT-related questions showed she is very open and willing to try new things. She has the personality traits that Marcia J. Scherer describes in *Living in the State of Stuck* (2005). Tedde has goals, and believes that obstacles to her independence can be offset by assistive devices or even overcome. Most importantly, she believes that she can control her quality of life and will take positive steps to make that happen even though she has a debilitating disease.

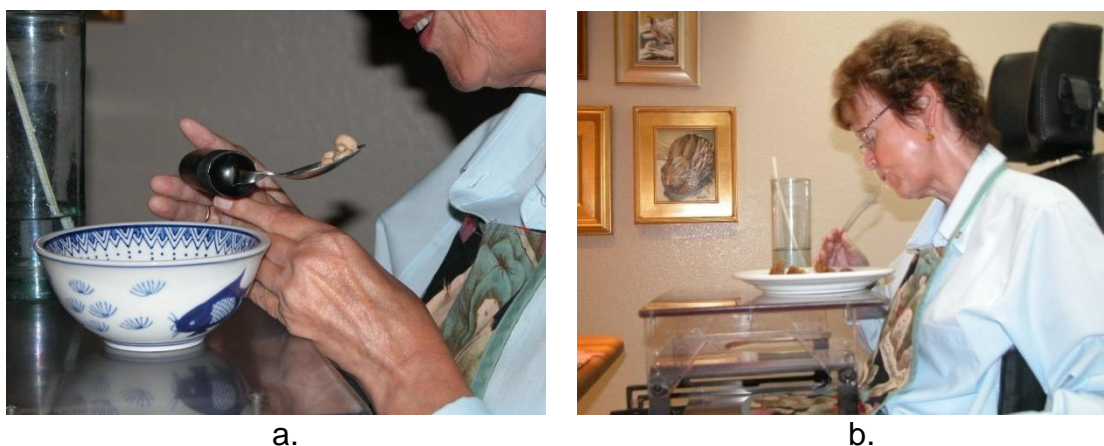
### *Photo and Video Observation*

The second step of the front end task analysis was to observe the subject and to try to better understand how her condition affected her activities of daily living. Project constraints were considered during this time. The constraint of Tedde's physical functionality and her specific environmental constraints were documented. The location constraint of the device and the control switch was thought about during the observations.

The first observation took place at Tedde's home in Tempe, AZ. This was conducted by the DSC544 project team. Photographs were taken of various home related ADLs. The second observation took place in February of 2005 in Tedde Scharf's office at the Disability Resource Center at ASU. This observation was conducted by the researcher. These locations were chosen because Tedde could be observed in a real-world environment. She frequently eats lunch in her office, so lunch time was selected so both work related and eating related tasks could be observed. A video camera was set up on a tripod during this session for data collection. It was important to capture the movement and functionality of the limbs, particularly the arms. The footage was then reviewed at a later date. This allowed for the scrutinization of activities and limb movement in a much more detailed manner. The session was reviewed multiple times to see similarities and track specific gestures. The participant as observer role was the chosen method for this video interview. The subject was aware of being filmed and being observed, and understood why the observation was being done. This enabled the researcher to evoke specific tasks and behaviors that were important to the

project and capture them on film (Robson, 2002). The researcher was also a participant in that he ate lunch with Tedde in her office, while the camera was rolling. This was to establish a closer relationship with the subject and make her feel more comfortable about being filmed.

The first observation yielded quality photos of various home related ADLS. These included eating with both a fork and a spoon. It is evident by the photos that eating can be a difficult task for Tedde, but she has adapted to this frequent activity. She uses a large handled spoon with both hands (see Figure 21a). Figure 21b offers a good view Tedde's right arm angle while eating. This is her dominant arm. Her elbow is leaning on the original wheelchair tray, while her hand and wrist (wielding the fork) are about 8 inches higher on the elevated tray. This position is not very comfortable for her.



*Figure 21. Eating with a spoon, eating with a fork.*

Other ADLs observed were drinking through a straw, getting her hair washed with the help of her mother (see Figure 22b), using the Hoyer lift for transfer out of the chair (see figure 23a), and driving the chair into her modified

van for transport. Getting her hair washed and using the Hoyer lift are ADLs that require the assistance of a caregiver. Her breathing tube is moved to her mouth for these activities to prevent accidental disconnection. It was important to see how the addition of a possible device to the back of her chair could impede these essential ADLs. A device could not be higher than the bottom of the head rest as this was removed for hair washing (see Figure 22a). If it was higher, it would have to be disconnected to perform this activity successfully. Using the Hoyer lift also requires the breathing tube to be positioned in Tedde's mouth (see Figure 23b). A device that attached to the chair would have to be pivoted out of the way or removed when the Hoyer lift was in use. This ADL specific constraint would have to be taken into account in the design of the proposed device. It would be appropriate to make a device that could pivot or be temporarily moved during transfers to and from the chair.



a.



b.

*Figure 22. Caregiver assistance to remove headrest and to wash hair.*



*Figure 23. Tedde's mother assists using the Hoyer lift for transfer.*

The environment in Tedde's house was scrutinized to see if a device could be larger than the footprint of the chair. The exterior doorway to the house was 36 inches. All of the interior doorways were standard 32 inches. Since the footprint of the wheelchair was 25.5 inches wide by 48 inches long, she only had a few inches to spare on each side as she passed through. It became clear that the device should not exceed the current width of the chair footprint. At the time of the observation, Tedde was in the development process of building a new custom home she would move into in the next two years. There would be 36 inch doorways throughout the entire home. Limiting the device dimensions to not be larger than the wheelchair footprint was still important as the standard size for most doorways is 30 or 32 inches.

Tedde uses a modified minivan with an automatic ramp that extends out of the sliding rear passenger door (see Figure 24a). It has the passenger seat and the first bench back seat removed. This allows her to drive up the ramp and into the van (see Figure 24b). She then turns the powerchair and drives into a locking steel harness where the passenger seat would normally be. The width of the sliding door on the van is 31.5 inches wide by 53 inches high. The height of an attached device was restricted by this environmental constraint. The height of Tedde sitting upright in her chair was about 51.5 inches to the top of her head. Her head rises about an inch higher than the topmost part of the headrest. Since there was little room to spare already, the attached device could be no higher than this to fit into her van (her only means of transportation).



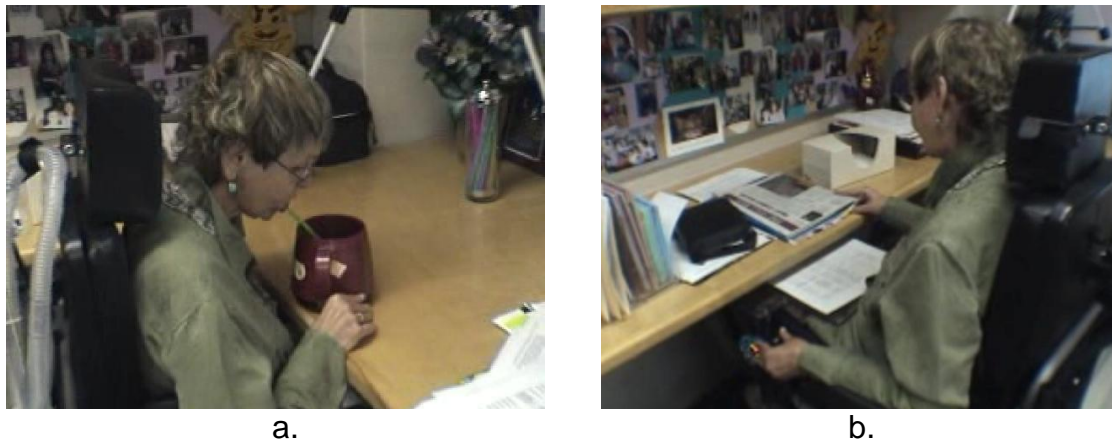
a.



b.

*Figure 24. Automatic ramp on minivan; Tedde driving into van (notice clearance)*

The video observation was the second part of the front-end task analysis. This was conducted at her place of work. Her physical, environmental, and device constraints were observed. Still shots were extracted from the video of Tedde performing various tasks. She is unable to drink from a cup by picking it up, so a long straw is used (see Figure 25a). Tedde can use the electric and hydraulic movements of her powerchair to lift up and move forward, enabling her to put her hand(s) on the desk or dial her phone. She can then “walk” her hands with her fingers to her keyboard, or to reach other objects such as a newspaper (see Figure 25b). She then backs up with the powerchair, pulling the object onto her tray. Figure 12 in Chapter 2 shows Tedde eating lunch in her work environment. This was the same adaption of low-tech devices and limited wrist and finger movement seen at the first observation session. A review of the video of Tedde eating clearly shows her reclining in the powerchair to swallow. The video was also useful in watching the way Tedde manipulates utensils in her fingers when eating. Once the food is on the fork (or spoon), the utensil must be moved in her fingers to angle it toward her mouth.



*Figure 25.* Drinking from a straw, using powerchair to pull newspaper off desk.

Both observation sessions were insightful into how someone of limited functional capacity performs daily activities. Tedde had a system in place through the use of AT, a caregiver's help, and her own physical adaptation to complete daily tasks. It became clear through observation at work and home that an arm-lifting device could benefit more than just the task of eating. Many simple but often overlooked tasks involve lifting an arm to the face. These include but are not limited to wiping the nose, wiping the face, scratching an itch, adjusting the glasses, fixing hair, applying makeup, brushing teeth, taking pills, etc. Tedde requires a caregiver (see Figure 26) or relies on another form of low-tech AT to do this (she uses a stick to adjust her glasses, and has to buy extra long lipsticks and needs her high tray to apply them). These insights seen through direct observation gave more validity to the design of an arm lifting device. They also provided a good starting point to ideate device designs.



*Figure 26. Tedde's mom helping her to wipe her nose.*

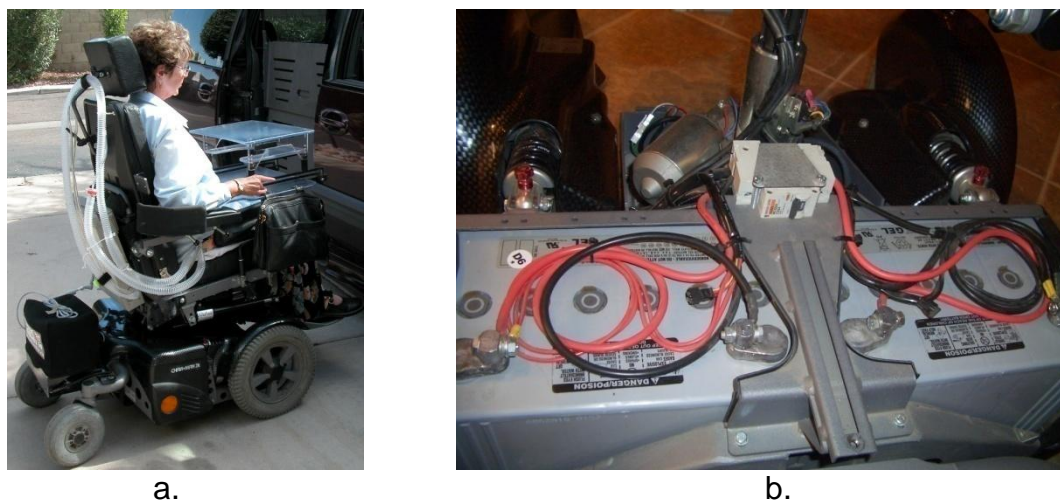
### *Designing the Device*

From the onset of the arm-lifting device design, it was an important consideration to have Tedde present to test out prototypes and give feedback. Early on, it was arranged that Tedde would come to the Human Factors Lab at ASU once every two weeks, or whenever a design was to be tested or a part be fitted to her chair. This allowed the DSC 544 project team to interact with her frequently.

In her first few visits to the lab, Tedde's arm was weighed using a hang scale. The weight of just under eight pounds (including shirt sleeve, watch, and utensil) was used in deciding what would power the device. It also aided prototype making further down the road as weights were used as a substitute when the subject wasn't present. The dimensions of her chair were taken again

to validate the initial measurements. The goal was to fit the device inside the footprint of the wheelchair, which was 48 inches by 25.5 inches by 51.5 inches (length, width and height). It was also noted that she has no range of motion in her shoulders or any muscle down to the wrist. This prevents her from moving or lifting her arms in any way. Tedde's wrists still have some movement, but it is limited. Her index finger on her right hand can no longer bend, but her other fingers can bend somewhat and squeeze to grip utensils or objects.

Her powerchair was also thoroughly inspected to see what its electrical system comprised of and possible places to attach a device (see Figure 27a).



*Figure 27. Tedde's powerchair; the 24V battery system exposed.*

Through physical inspection and looking at the electrical schematics of the chair obtained from the company (PerMobil), it was determined that it was a 24V battery operated system (see figure 27b). Under the seat of the chair in a plastic compartment were 2 12 volt batteries in series. This effectively doubles the voltage to 24 while maintaining the same capacity. There was also a separate

independent battery on the back of the chair whose sole purpose was to power her breathing apparatus. Utilizing the chair's rechargeable battery system while avoiding the third battery was the best means to power any designed device. Although harder to get to, it was also much safer if the chair itself failed than the powered breathing system.

### *Air Muscle Technology*

In order to lift Tedde's arm up to her face, a device would have to be attached to her chair. It would also have to be powered by her chair's rechargeable 24V batteries. Lifting her arm up would require a pulling action that could support the eight pound weight of Tedde's right arm. The means to generate this linear action would need to follow basic human factors guidelines. It had to be cheap, efficient, safe, and fixable in case of failure. At first, a small motor that could wind and unwind a cable seemed feasible. However, a winding cable motor was expensive, bulky, and not failsafe. If the device accidentally stuck in the pulling position and couldn't be shut off right away, the cable would continue to wind. This could result in Tedde's fragile arm being pulled in an awkward position, or worse the device breaking apart and injuring her. After researching possible alternatives, another project that Professor Herring was involved in used an air muscle. Kinetic Muscles, Inc., a Tempe based company founded through ASU research and an NIH grant, uses this technology in rehabilitating devices for stroke survivors. A tour of their facility showed the potential of using the air muscle, and donated to this project the necessary supplies to build them.

The air muscle is a linear actuator which shortens as it fills with compressed air. It is cheap, lightweight, and flexible which makes it usable in many applications. It has the ability to fluidly pull a significant force, resulting in smooth and natural movement. The air muscle consists of a flexible inner bladder (silicone) surrounded by a mesh weave. It is clamped off over a plug on each end, which one having an air valve and hose attachment (see figure 28).



*Figure 28.* Complete air muscle (top), air muscle components (bottom).

As the bladder is filled with air, it naturally expands. The woven mesh prevents it from filling like a balloon. Instead, the mesh expands in girth but pulls inward in length (see figure 30). A small electric air pump is attached to a power source (see Figure 29a), a three way switch, and a release valve (see Figure 29b). When the switch is pressed forward, the pump fills the muscle with air, pulling whatever is attached to it. If the switch is let go and rests in the neutral position, the bladder remains full of air and keeps the line taut. When the switch is pressed to the reverse position, the air release valve opens and quickly returns the muscle to its original unfilled state.



*Figure 29. 24V air pump and electronic air release valve.*



*Figure 30. Air muscle deflated (top); air muscle inflated (bottom).*

From a human factors standpoint, the air muscle looked very good. The air muscle fit with the following human factors guidelines:

- inexpensive
- efficient
- built-in failsafe
- easy to operate

- easy to build and fix (or replace)
- soft, and can be twisted axially
- can be mounted unaligned

The parts that make up the air muscle cost about ten dollars. The part most likely to fail after continuous use is the air bladder itself, which is extremely cheap and very easy to replace. The pump and release valve are small, and can be hidden in Tedde's chair. They also can run on a 24V system. Safety precautions were a necessity, so having a failsafe incase of the device not being able to be shut off was important. The air muscle can only pull a given amount, based on the length of the un-inflated bladder and mesh. If the device was stuck in the "on" position, the worst case scenario would be the bladder would rip open and need to be replaced. It wouldn't damage the rest of the device or it user. The air muscle is soft, and can be twisted or mounted misaligned with no adverse effects.

The amount of actuation was determined by the difference between a given inflated versus deflated muscle length. A longer deflated muscle meant more linear actuation, resulting in greater lift generated. The muscle contracts by about 30 percent of its length. The length of a given muscle would vary depending on the mechanics used to lift the arm. The next logical step after determining how to power a device and what technology to use to build it was sketching, ideation, and creating working prototypes.

### *Testing Rig*

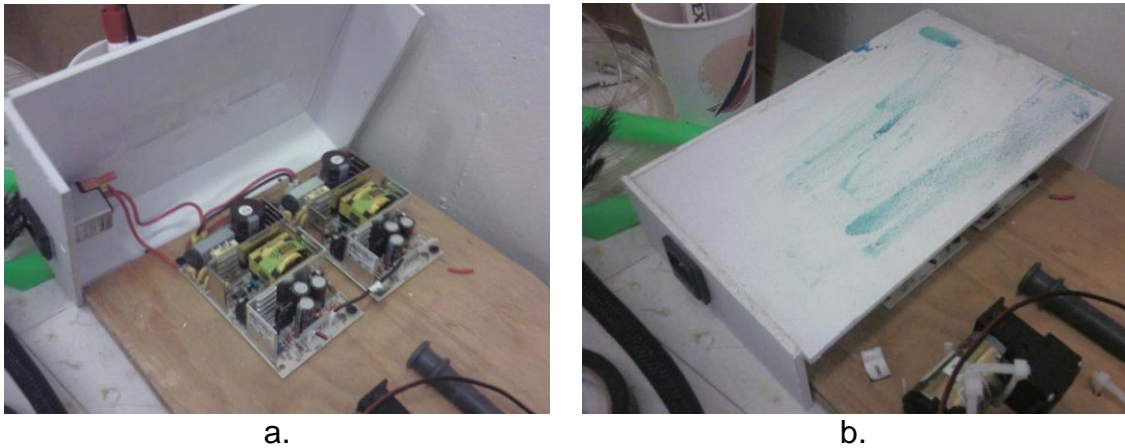
A deflated air muscle was fairly long. In order to operate correctly and generate pull, the muscle needs to be in a stretched position while deflated. Since there was plenty of vertical space on Tedde's wheelchair behind her, sketching was done with the muscle in this location. The device would have to have a rigid support structure so the force of the muscle pulling wouldn't bend or give. The most feasible solution at this point was a structure that securely attached to the back of the right side of Tedde's chair, came vertically up to the back of her shoulder, and then horizontally past her head the length of her arm. Tedde already had a hollow steel tube with a flat plate at the bottom that was previously used for a makeshift painting device. The tube was secured with two bolts to the back of her chair. Another 90 degree bent piece connected to the mounted tube and came horizontally over her shoulder. The mounting tube would make an ideal bracket to secure prototypes to the chair. With other prototypes in mind to use the same female pole connection, it only rose up to her shoulder. It was drilled and tapped near the top, with a screw in knob to fasten the male component into place.

In order to test devices without Tedde present, a testing rig was built. This rig consisted of a few pieces of plywood attached perpendicularly. It accepted the female anchoring tube that connects to the back of Tedde's chair with the same two bolts (see Figure 31). Moving this between the powerchair and the testing rig was fast and painless. An "L" shaped length of aluminum with holes in it was attached vertically along the rig to give numerous attaching points for the muscle.



*Figure 31.* Testing rig with female mounting bracket attached.

In order to power the device while on the rig, the pump and release valve had to be attached to something other than the wheelchair battery. An electrical engineer helped to lay out two circuit boards in series that converted regular wall outlet voltage (120V) to replicate the battery's 24V system (see Figure 32a). A cover was made out of ABS plastic to prevent accidental electrocution by touching any live wires on the circuit board (see Figure 32b). This outlet powered set up proved to be not only valuable for the testing rig use, but also when the device was tested on Tedde's chair. It was easier and faster to just plug this device into the wall than to take apart the battery compartment on the wheelchair and connect to the actual battery each time.



*Figure 32. 120V Outlet-powered box and circuitry to control air pump and valve.*

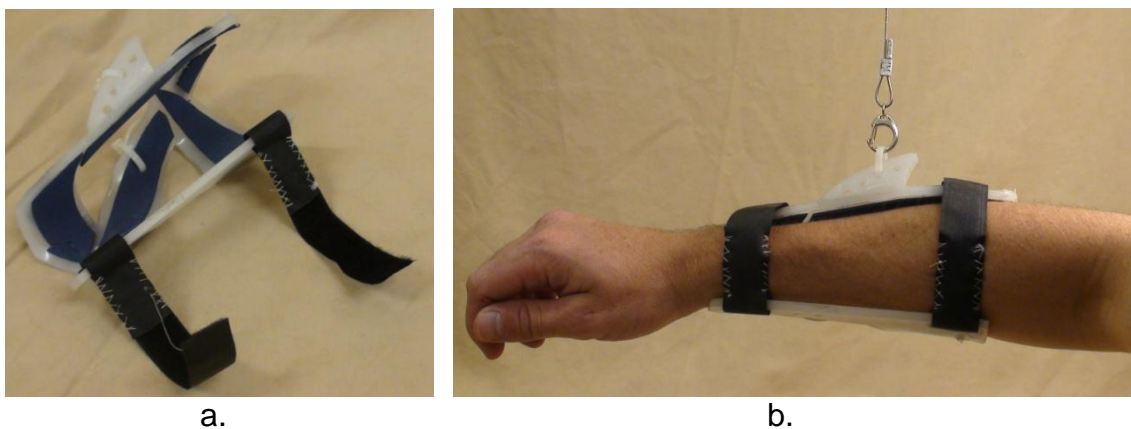
The testing rig and electronic control box were the solution to the second design objective (see Table 4, p 78). This objective needed to be addressed first so the prototypes could be powered and tested in the lab.

### *Arm Cuff*

Every prototype that was made would have to connect to Tedde's arm in order to lift it up to her face. Human factors guidelines were considered for this important component. It would have to be as lightweight as possible to not impede the air muscle or feel cumbersome to the user. It would also have to be durable enough to hold its shape while supporting an 8 pound arm. A caregiver would have to put the cuff on and take off, so it needed to be easy to slide the arm in and fasten. It also needed to be comfortable to wear for extended periods of time.

Quarter-inch sheet polypropylene was the material used to make the arm cuff. The cuff featured a one piece design, with holes cut out for breathability and

weight reduction while still maintaining rigidity. These holes also gave the cuff a stylish look. The cuff was designed so the arm would slide in from the side (C shaped), and be secured by two Velcro straps. The styrene material was rigid enough to support the arm weight, but flexible enough to allow for easy entry and exit. The human factors lab happened to have a plaster cast of a forearm approximately the size of Tedde's. This was used as a mold to bend the cut out styrene around after heated with a heat gun. Thin foam padding was glued onto the inside for comfort (See figure 33a and b).



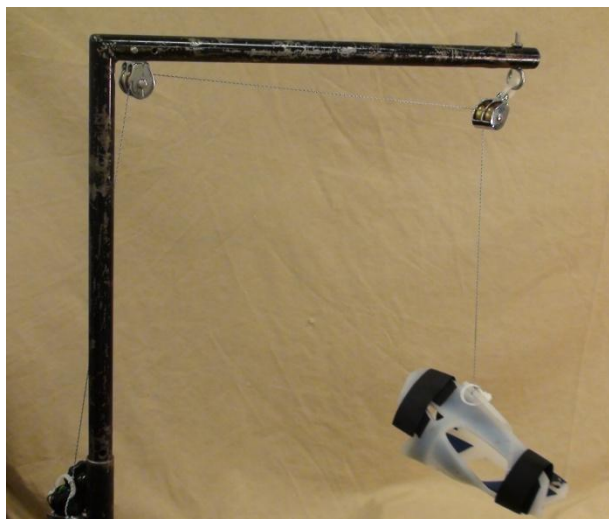
*Figure 33. Arm cuff; correct positioning of cuff on arm.*

The arm cuff design addressed design objective 6 (see Table 4, p. 78). This will be discussed further in this chapter.

### *Prototype 1*

Because of the air-driven mechanism to control the device, it was dubbed the PAL (Pneumatic Arm Lift). The original working design featured a round steel pole at a 90 degree angle. One end of the pole was secured into the female tube already anchored to the chair. Two pulleys were used to transfer the downward

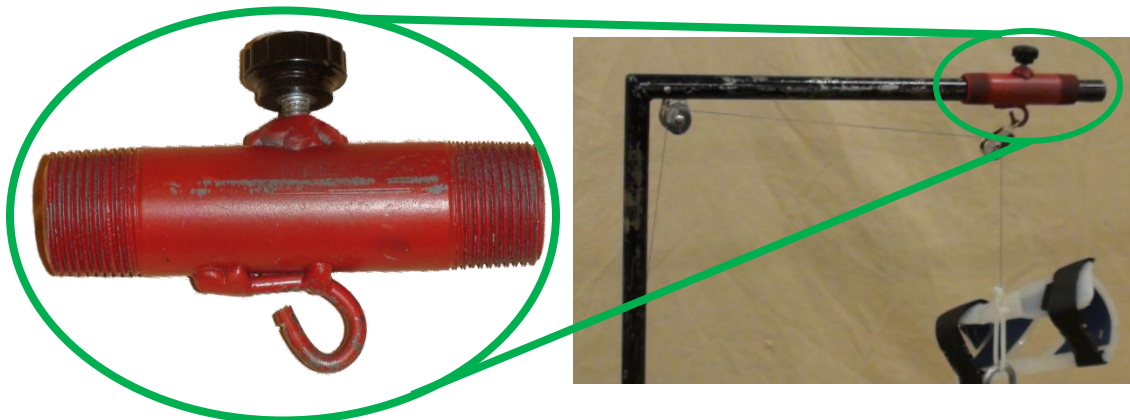
pull of the muscle to an upward lift on the other end. One pulley was located at the 90 degree bend, the other on an eye bolt directly above her wrist. The air muscle was secured to a rigid support on the lower back of the chair using zip ties. High pound test fishing line was tied to the top of the muscle and then strung through both pulleys. The other end of the string was attached to the top of the arm cuff (see Figure 34).



*Figure 34. Prototype I*

When the device was tested on the rig, it seemed to work as expected. However, when it was attached to the wheelchair and tested by Tedde there were obvious flaws in the design. First and foremost, her arm lifted up to the anticipated height but her hand didn't reach her face. It was determined that the vertical point where the final pulley was positioned over her arm was too far away. This led to the fabrication of a movable pulley that could slide up and down the horizontal bar. A hollow piece of steel tubing was drilled and tapped to accept a screw in knob. A hook was welded on the bottom to hang a pulley from. When

tightened, the knob would secure the pulley mechanism at any point on the horizontal bar (see Figure 35).



*Figure 35. Adjustable pulley positioning piece.*

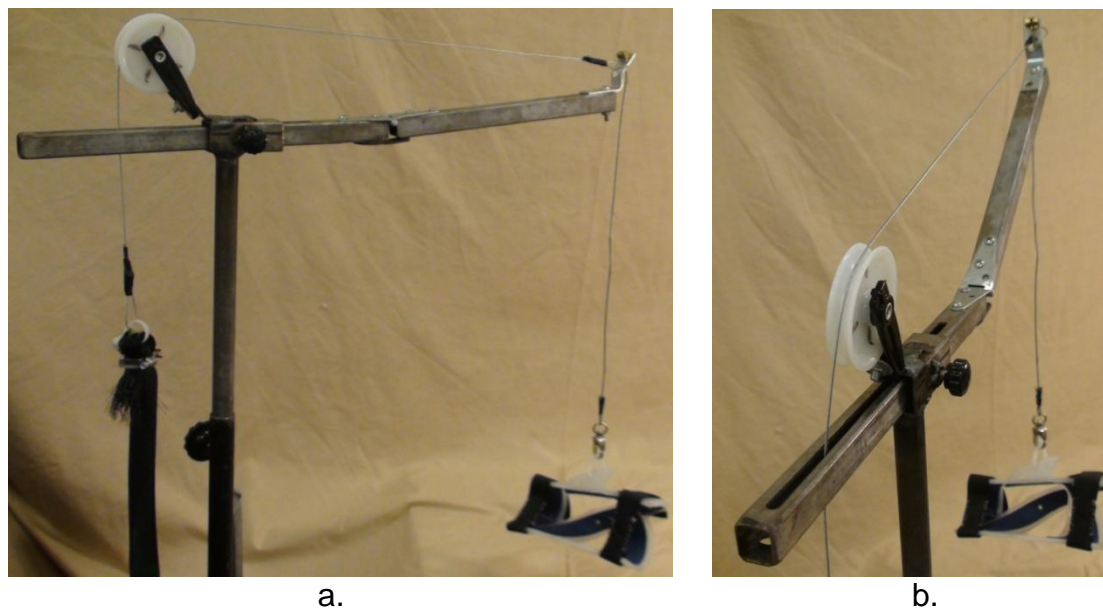
This adjustable piece allowed for testing of different front pulley positions to try and bring Tedde's arm closer to her face. Unfortunately, this didn't solve the problem. It was determined that there was too much movement in the hanging pulleys to accurately find an ideal front location. The small pulleys used also had subpar bearings. They didn't turn smoothly, and led to jerky action. The fishing line also stretched a bit when taut, resulting in an inefficient pull from the air muscle.

### *Prototype II*

The pitfalls of the first prototype were assessed, and more sketching and brainstorming was done. The fishing line was nixed in favor of a braided metal bicycle brake cable. This would eliminate the stretching of the line as the cable has no give at all when a force is applied. A larger plastic pulley was employed at the 90 degree bend. This was more durable, mounted better, and because of its

larger circumference there was less of a chance of the bearings sticking. The female vertical pole attached to the back of Tedde's chair remained as the mounting bracket. Once again, a 90 degree steel pole was inserted into this female mount and secured with a screw knob.

On this second prototype, it wasn't all round tubing like before. The vertical piece that fit into the mount was round, but a square steel tube was welded as the horizontal piece. The reason behind this was a change in the way the device lifted up. In an effort to bring Tedde's arm closer to her face, a new top-hinged design eliminated the need for a second pulley above her arm. The air muscle, still anchored at the bottom back of the wheelchair, was attached at the top with the brake cable. This cable was wound around the larger pulley, then attached to an anchor point on the top of the horizontal arm (see Figure 36a). As the muscle inflates, vertical pull is transferred to horizontal pull through the pulley. This force then makes the hinge flip upward, lifting the horizontal bar. Another cable dropped from the front of the bar is attached to the arm cuff with a hook. The reasoning behind using the hinged design is that it not only lifts in the y direction. As the top piece hinges upward, it also moves in the x direction back toward Tedde's body (see Figure 36b). The ideal positioning of the hinge was determined by making the length of the horizontal steel tubing adjustable. This was done through the use of a screw knob and a male-female connection on the horizontal bar. The back part of the horizontal bar was milled to allow the cable to pass through unabated.



*Figure 36. Prototype II*

After several tests on the rig, the prototype was in good working order. It was attached to the mounting bracket on the back of Tedde's chair for user testing. Using one large pulley and the metal cable made the 90 degree corner transition work much smoother. She immediately noticed a difference in her hand moving closer to her body. The hinge position that achieved the most reliable results was about four inches from the rear of the horizontal bar. However, this straight bar lifted her hand and utensil closer to her shoulder than her face. In order to tackle this new problem, a revision was made to this prototype.

In an attempt to bring Tedde's hand close to her face instead of her shoulder, the point from which the cable dropped to the arm cuff was changed. This was done by adding an adjustable sliding square tube to the front hinging piece. Another smaller piece of square tubing was welded at a 45 degree angle off the inside face of the slider. This angled tube had several holes drilled in it to

test various drop positions to connect to the arm cuff (see figure 37a and b). The idea was that if the drop point was moved inward, it would result in her hand reaching her face. More testing was done with Tedde, and the drop position that yielded the best results was selected.

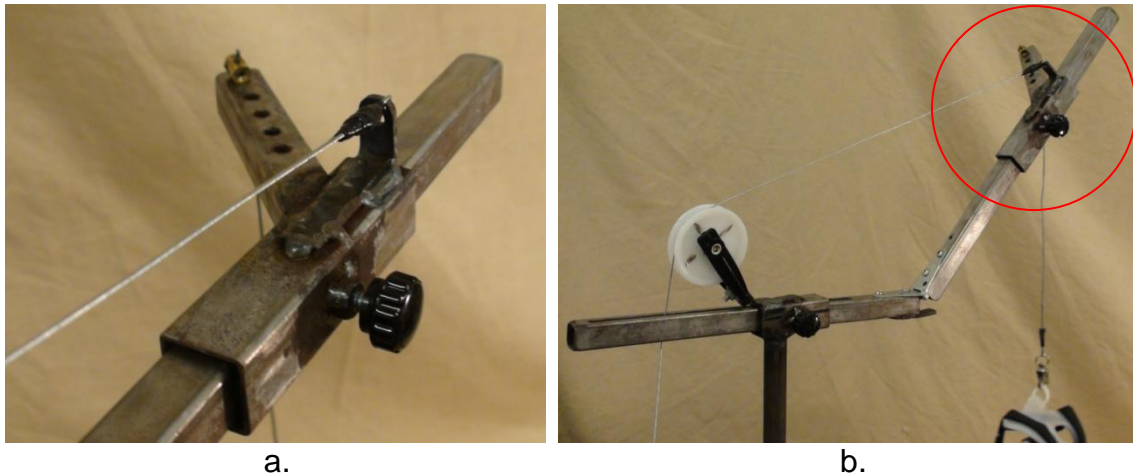
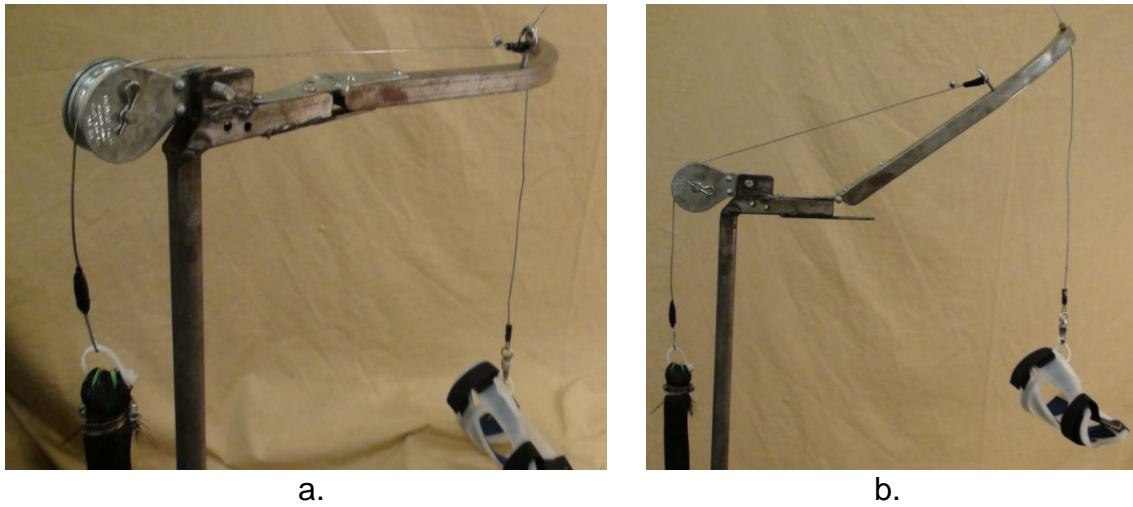


Figure 37. Angled, sliding drop position bar.

### *Prototype III*

The third prototype was a much more refined version of prototype II. All of the adjustable pieces from II were used to determine proper length, hinge location, and drop point for this iteration. For a better looking part with fewer pieces, the hinging front bar and the angled bar were replaced with one piece of bent aluminum square tubing. A template was made, and a smooth curve was achieved by bending the tube around a mandrel. An eye hook was added on the top right before the bend so the cable still pulled in a straight line. A sturdier metal quick clip was attached to the end of the drop line for fast and easy connection to the arm cuff. The large plastic pulley was replaced with a large

metal pulley for durability, fluidity, and visual cohesion (see figure 38a). Once again, this device was tested several times on the rig with weights attached to replicate the weight of the subject's arm (see Figure 38b). Once calibrated correctly, Tedde came in for another testing session.



*Figure 38. Prototype III in resting state; being lifted.*

Tedde was impressed at the refinement of the device up to this point. When tested, the curved horizontal bar clearly brought her hand within inches of her mouth. She was able to reach her mouth with a utensil as well as adjust her glasses with her finger. The device was successful in producing both the necessary arm lift and proper hand position to complete several face related activities. Unfortunately, there were still a few snags that could not be overlooked. Although the muscle was producing enough pulling force to get the arm there, the motion was a bit jerky. As the air muscle inflated, it pulled on the metal cable. As the cable pulled tight, there was a few second delay in the hinge swinging the bar upward. This resulted in a slower than acceptable time to lift the

arm to the face. This delay also caused a built up amount of torque to be placed on the mounting bracket. It was clearly moving the area of the chair it was attached to. The large pulley and the hinge location also impeded Tedde's view to the right when the device was in use.

At this point in the research, mechanical engineering expertise was needed. Dr. Thomas Sugar is a professor of mechanical engineering and an advisor to the robotics lab at Arizona State University. He has prior experience working with air muscles so he was asked to consult in the design of this device. Dr. Sugar immediately noticed mechanical flaws in the design of the PAL. Although the hinge design worked well to bring Tedde's arm closer to her face, the pulling force of the muscle was being wasted. The cable was running parallel to the hinging arm, requiring a build-up of power at the hinge before it popped upward. This explained the slight delay and then jerky action of the horizontal bar. This energy was also causing a slight failure in the mounting bracket. Because the cable was going around the 90 degree turn on the pulley, the muscle was actually pulling the mounting bracket (and the whole device with it) away from the back of the chair. Dr. Sugar suggested a more efficient mechanical principle that would fully utilize the power of the air muscle. A cantilevered moment arm with a pivot point located at the top of the vertical mounting pole would eliminate the hinge, the pulley, and the long cable. All of the vertically downward pulling force would be directly transferred to upward lift on the other end of the horizontal bar. Dr. Sugar's intuitive suggestions would

require a complete redesign of both the device and how it mounted onto Tedde's chair.

#### *Prototype IV*

All previous prototypes had been made of steel or aluminum as the force of the muscle put too much strain on the device. The downside to this was that metal fabrication and welding were time consuming and labor intensive. It was also hard to make small changes at the same time the device was being tested. Since the new cantilevered design would be less physically taxing on the device arm and support, plastic became the prototype material. The addition of a band saw, drill press and disc sander to the Human Factors lab allowed for quick fabrication and modification of test parts.

Sketching and ideation was required to rethink the logistics of both the device and its connection point to the power chair. On her first visit back to the lab after the meeting with Dr. Sugar, Tedde's chair was inspected once again to determine a more sturdy location to mount the revamped device to. Near the bottom of the right side of the seat pan, there was a piece of steel that had three exposed holes already tapped into it. This was on the frame of the chair, so it was meant to be load bearing and could definitely handle the pressures of the PAL. This low area would also make a great bottom connection point for the air muscle. The vertical rod with the pivot point on top would have to run the length of the back of Tedde's chair to connect to this rigid frame. Because of its length, it needed an extra stabilizing connection half way up. The right arm rest on the wheelchair connects to the rest of the chair in an ideal spot for this stabilizer. The

stabilizing bracket was designed to hold the vertical bar in position, but slid up and down if Tedde reclined the back of her powerchair.

Thin styrene was used as a mock-up material to create the new mounting bracket and stabilizer. Over two visits to the lab, the styrene was measured, cut, and fitted to Tedde's chair. Having her and shop tools in the same room made this process very easy since there was continual testing and trial fittings to get the dimensions exact. Once the styrene mock ups were finished, stronger and thicker ABS plastic working models were created from them (see figure 39a). Based on sketches of how the new PAL should look, one inch diameter PVC pipes were used to create both the vertical support bar and the moment arm. The "quick and dirty" method of using PVC let the project team test out different lengths and configurations (see Figure 40a). The PVC elbows (connection pieces) of different angles made the process of joining the pipes easy. It was fast and easy to cut a piece to length, connect with elbows, test, re-cut, and test again. The elbows also gave the team the option to modify angles and test configurations that wrapped around chair constraints (see Figure 40b).

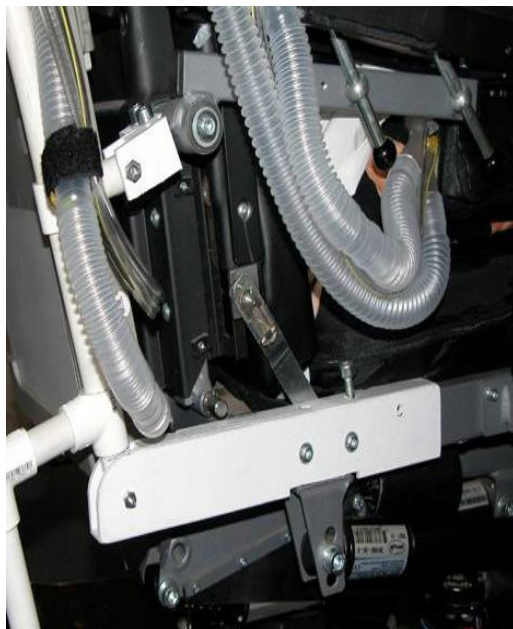
A modified PVC end cap served as the hinge. Tedde had criticized that prototypes I through III impeded her lateral vision. With this in mind, the pivot point was positioned just behind and slightly higher than her right shoulder. The muscle was attached directly to the back of the horizontal bar.

The use of PVC let the team test the best place along the bar to connect the muscle. The eyebolt the air muscle attached to could be moved by simple drilling a new hole with the cordless power drill and moving it. Modifications like

this that could be performed with the device still attached to the chair saved valuable time and resources.

The pivot arm was bent using PVC elbows to drop down slightly after crossing her shoulder and then inward. This was based on the curved modification to prototype III that brought her hand closer to her face (see Figure 39b). The project team used elbows and quick modifications to tube lengths to try many angle configurations. The bar was curving in the x, y and z directions. The elbows could also be rotated once connected for more fine-tuned adjustments.

A bungee cord was connected at the same point as the air muscle. This added a bit more pulling force to the air muscle to speed up the lift of Tedde's arm. After several testing sessions, the plastic device was the most successful so far. Tedde was able to lift a fork to her mouth for eating-related ADLs.



a.



b.

*Figure 39. Two ABS mounting brackets; plastic PAL in use.*

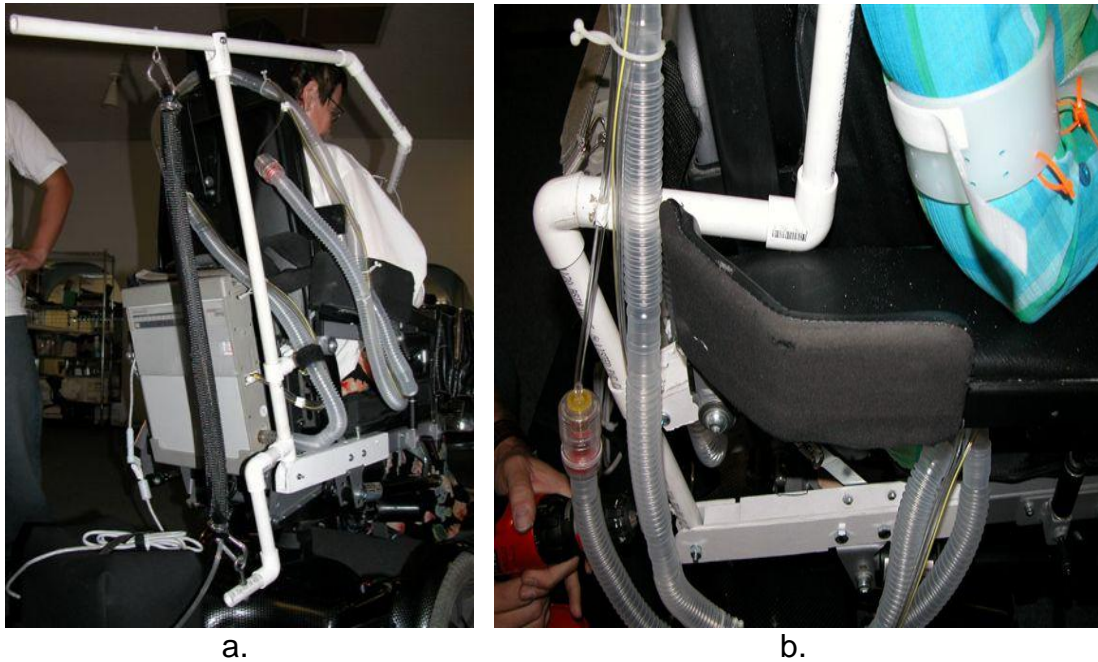
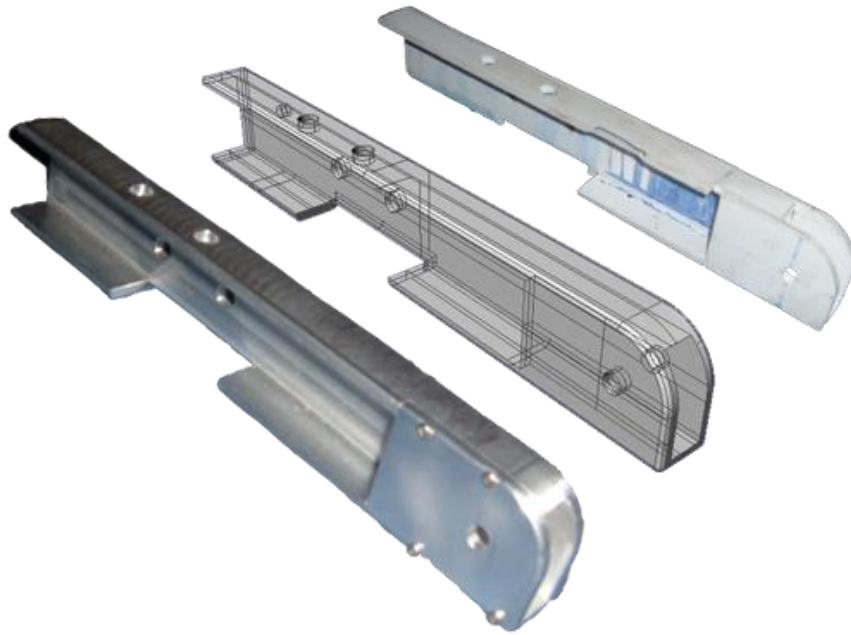


Figure 40. Long PVC could be easily trimmed or angles changed using elbows.

#### *Prototype V (Final)*

Although the PVC device was functional, the final device needed to be fabricated out of metal. 3D models of the mounting bracket, the stabilizing bracket, and the top pivoting piece were created using SolidWorks. These 3D CAD files were sent to the robotics lab to be professionally fabricated. The pieces were CNC milled out of block aluminum to be lightweight and extremely durable (see figure 41).



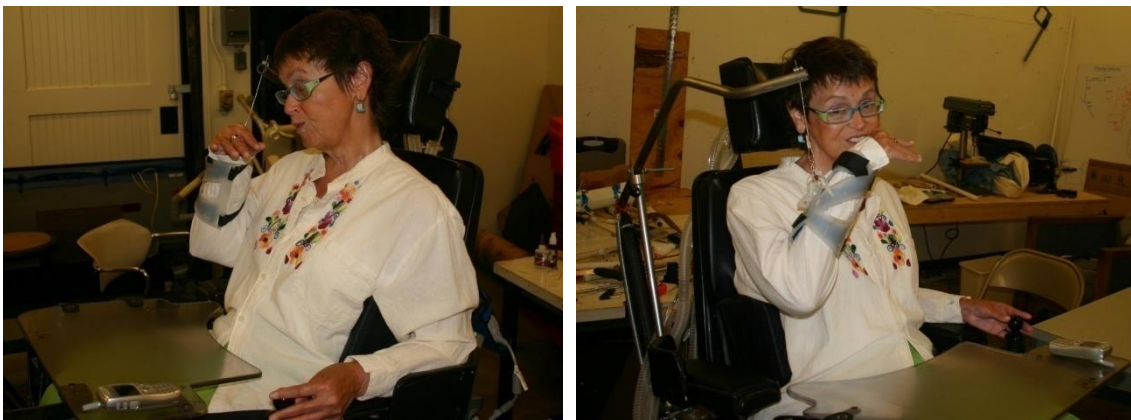
*Figure 41* (From right to left): Mock-up, 3D model, fabricated metal prototype.

The vertical support and horizontal cantilevering bar were fabricated out of steel conduit. It is thin and lightweight but durable. The horizontal bar was bent on a mandrel to match the bend in the previous PVC mock-up. A heavy duty metal spring replaced the bungee cord used in the previous version. This spring acted as a counterbalance to Tedde's arm weight. It reduced the load the air muscle would have to lift, thus speeding up the PAL (see images 42, 43).

As a safety precaution, an electrical engineer from the robotics lab helped oversee the final connection of the air pump to her powerchair batteries. A mini five amp inline fuse was added to the positive wire in case the pump failed.



*Figure 42.* Final prototype attached and ready to use.



*Figure 43.* PAL lifting Tedde's arm to her face.



*Figure 44.* Side view of device in use.

### *Design Objectives Revisited*

The main design objective of the iterative process was to lift Tedde's arm and hand to her face to aid in eating-related ADLs (Objective 1, Table 6). The DSC 544 project team broke this main goal down into smaller tasks. These tasks were introduced in Table 4 (p. 78) with a description and possible materials that could be used. Table 6 revisits that previous table with the solution for each now included.

<b>Design Objectives</b>	<b>Description</b>	<b>Solution</b>
1. lift Tedde's arm to her face for eating tasks	This is the main design objective of the project	(see below)
2. design of testing rig and testing electronics	important to test prototypes while using outlet power when subject was not present	Rigid wooden plywood frame, vertical angled steel bar with multiple holes to attach device and muscle. 2 12V circuits wired in series to power source and covered with plastic for safety.
3. mechanics to lift arm up	find out the best solution to achieve optimal lift	Pivoting arm takes advantage of linear muscle action. Direct pull on the back of the device generates smooth lift in front, resulting in hand lifted to face.
4. mounting device to chair	find the strongest and best placed location on powerchair to attach device	Custom made aluminum components. Two-part system created that anchors to the frame and arm rest. Mount allows chair to fully recline while attached.
5. mounting air muscle to device/chair	find the most efficient method and place to attach the air muscle	Air muscle and spring are attached via zip tie to a hole in the back arm. The bottom of the spring and muscle slip over a screw at the lower end of the vertical pole, making it easy to attach.
6. design of arm cuff	create strong, lightweight, and comfortable supporting brace for arm	Molded cut polypropylene sheet. Flexible yet strong; Velcro for easy fastening and foam for comfort.
7. design of arm-lifting device	develop prototypes that explore functionality and aesthetics.	Culmination of solutions to objectives 3-10
8. user controls	type, location and configuration of user input control device	DPDT toggle switch with plastic paddle controls the pump and valve. Mounted near other user controls at an angle for easy reach.
9. mounting of air pump and release valve	find the ideal location for electronic components, and best way to manage wires and air tubes	Air pump and valve Velcro-ed to inner chair cavity. Tubes and wires mostly hidden under plastic. Electrical tape wrap keeps wires together that run to control switch.
10. connecting electronics to power source	find the safest means to connect pump and valve to wheelchair battery system	terminal connectors bolt onto the +lead of one battery and the -lead of the other. Fuse added to the positive wire between battery and pump.

*Table 6.* Solutions to design objectives.

Objective 1 was solved through the break down and completion of the other tasks. These objectives will be examined individually for further explanation.

The testing rig and outlet-powered electric circuitry was built prior to any device prototypes. It was important to tackle Objective 2 first so the testing equipment could be utilized throughout the duration of the design process. The testing rig was built using plywood and a long steel L-bracket. Holes in the bracket gave the team many mounting options for different sized devices and muscles. This rig is explained in detail on pages 106-107 (see Figure 31). The electric box was made by wiring two 12V circuits together in series. A plastic housing was made for safety purposes (see Figure 32).

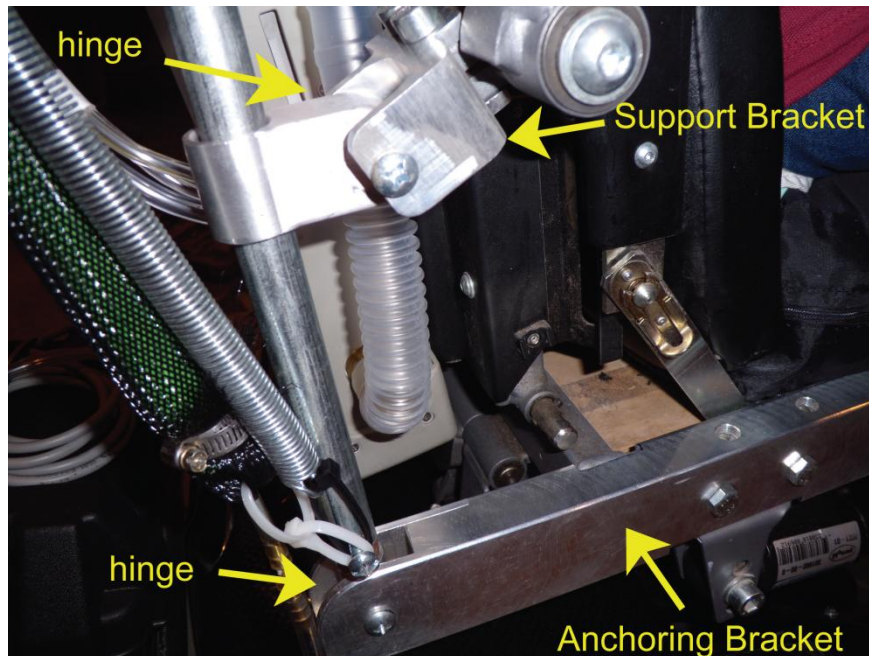
The purpose of Objective 3 was to find the best mechanical solution to obtain optimal lift from the device. It was established early on that the device would consist of a vertical metal bar running up the back of the chair, with a horizontal bar running over Tedde's shoulder. The first mechanical solution was to use small pulleys attached to a stationary bent pole (see Prototype I, pages 109-111). The small pulleys were inefficient and lift was not adequately generated. The second mechanical solution was explored in prototypes II and III (pages 111-115). It used one larger pulley (better bearings, less rotations needed) in conjunction with a hinging front arm. This design brought Tedde's hand close enough to her face, but the movement was jerky and the load on the mounting bracket was pulling the device off the chair. After collaborating with a mechanical engineering and robotics professor, the final solution was

established. There was no need to pull around a 90 degree bend and build up force. With a pivoting arm design, the vertical pull of the air muscle on the back of the horizontal arm would be directly transferred to lift on the front. This was explored through PVC prototypes and iterative user testing. The final pivoting hinge part consisted of an aluminum bracket on the top of the vertical pole with a bolt through it.

Objective 4 was to determine the best way to mount the AT device to Tedde's wheelchair. Prototypes I through III used an existing aftermarket hollow steel tube that bolted onto the backrest of the chair on the right hand side. The tube was easy to install and quick to switch between the wheelchair and testing rig. However, the force of the inflating air muscle moved the pole backwards away from the chair. It was not a sturdy enough location to handle the load. The best mounting area was not fully explored until the prototype material switched to plastic. The constraints faced in Objective 4 were keeping the device inside the footprint of the chair, avoiding the armrest, and allowing the chair to fully recline and lift with the PAL attached.

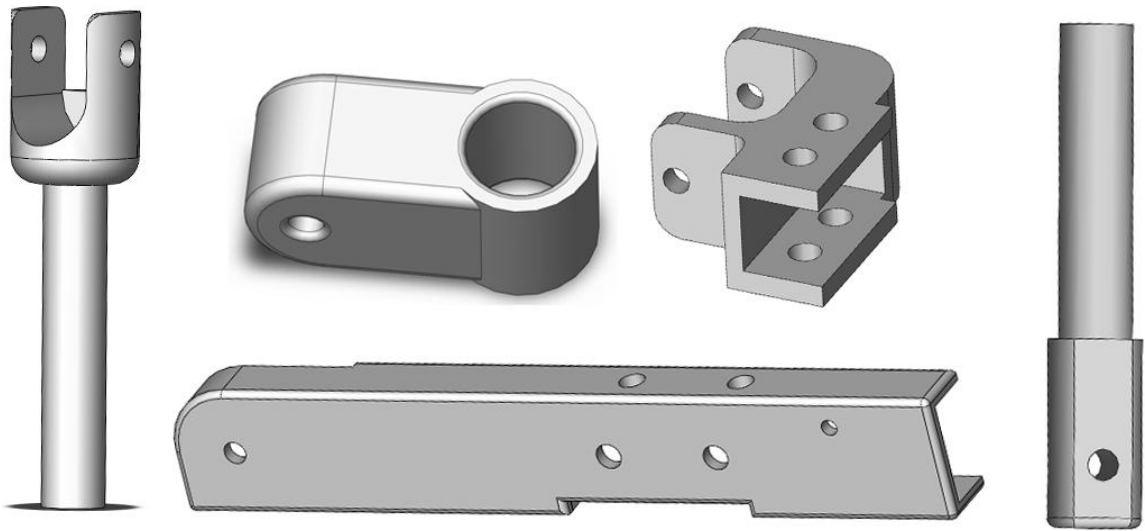
Upon closer inspection of Tedde's chair, pre-tapped holes were found on the rigid frame of the seat pan. After sketching and ideation, the idea was to make a long anchoring bracket that attached to this spot with two bolts (see Figure 45). The vertical pole of the device would hinge onto the back of the bracket with a bolt so the device would tilt as the chair did. Since this bracket was at the bottom of the long vertical pole, another bracket was needed to stabilize the device. This secondary support bracket was made of two components, also

hinging on a bolt (see Figure 45). The first component attached to the right armrest mount. The second component hinged to the first, and had a hole in it slightly larger than the diameter of the vertical pole. This design would keep the entire device inside the width of the chair (the more worrisome dimension for fitting through doorways).



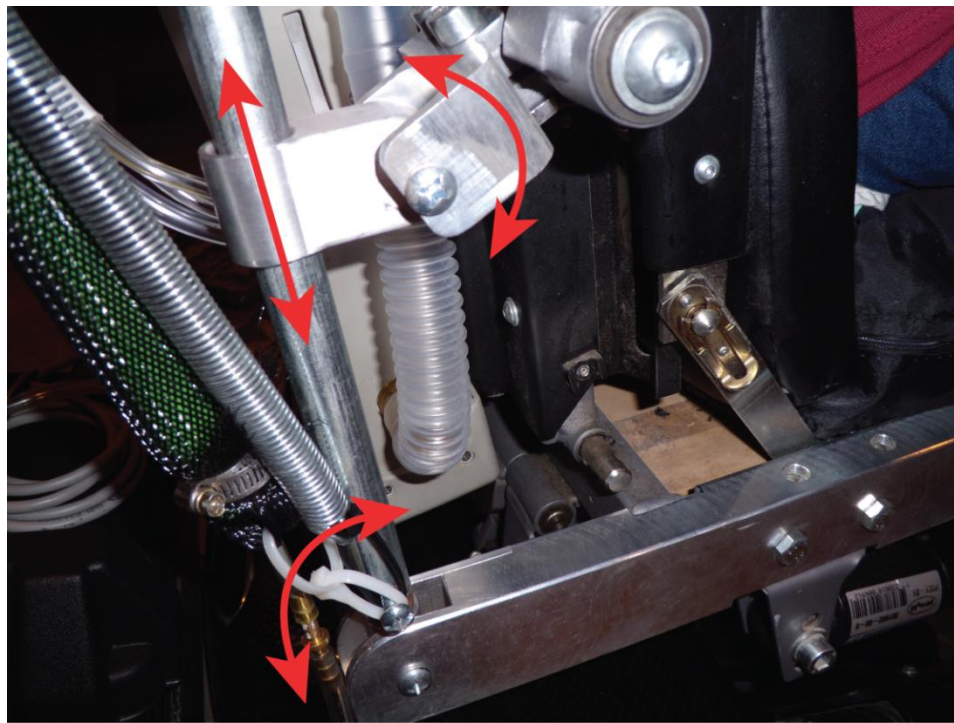
*Figure 45.* Explanation of mounting brackets.

Paper mock-ups were used to get dimensions and hole locations correct. These were transferred to and fabricated out of ABS plastic so we could have working prototypes (see Figures 39, 40, 41). 3D models were made from these prototypes (see Figure 46), and they were manufactured by the machine shop in the Ira A. Fulton College of Engineering at ASU. Aluminum was the chosen material for its strength, low weight, and resistance to corrosion.



*Figure 46.* SolidWorks 3D models.

The design of the mounting brackets securely supported the PAL. The constraints of getting the vertical pole past the armrest and allowing the chair to recline while attached were solved through the hinging mechanics.



*Figure 47.* Diagram explaining allowable movements of the bracket.

These hinging and sliding movements are shown in Figure 47. As Tedde reclines, the bottom hinge allows the main support pole of the device to move backwards parallel to the chair back. The support bracket slides up and down along this pole as it moves with the reclining action. The second hinge lets the angle of this bracket change relative to the angle of the chair back (see Figure 48). Tedde is fully capable of reclining or tilting the chair (see Figure 49).



*Figure 48.* Incremental images of angle change during wheelchair recline.



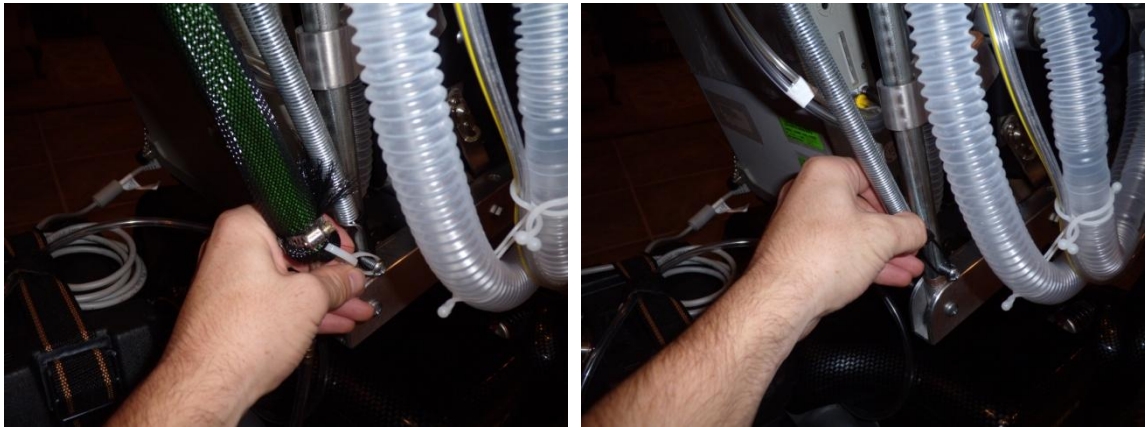
*Figure 49.* With PAL attached, wheelchair can still recline and tilt back.

The goal of Objective 5 was find the most suitable method and location to attach the air muscle (and weight compensation spring). Zip ties were the chosen method of attachment as they are very strong and can be quickly added or removed. They also allow for quick adjustability in tightening. There was a hole cut in the back of the horizontal bar to attach the top of the muscle and spring to. This location was explored during the PVC prototype stage. On the bottom, the spring and air muscle have a zip tie loop at the end of them. When the device is attached, the bottom of the spring and the muscle are stretched. The loops slip over a large screw at the bottom of the pole.

A secondary goal of Objective 5 was to make the muscle, spring, and pivoting arm removable and easily stored when not in use. This had direct implications on the constraint of Hoyer lift use for transfer out of the chair. This was accomplished with the use of a set screw knob that locked the pivot arm in place. The set screw is loosened, and the bottom loop of the muscle and spring are slipped off the screw they attach to. This is illustrated in Figure 50 and 51.



*Figure 50.* Loosen set screw; lift pivot arm and hinge out of female support pole.



*Figure 51.* Remove air muscle loop; remove spring loop.

After this four step process, the muscle, spring and pivot arm are all still attached to each other but not the supporting frame. They are then easily stored parallel and attached to the vertical female pole with a Velcro strap (see Figure 52).



*Figure 52.* Air muscle, pivot arm, and spring neatly out of the way.

The purpose of Objective 6 was to design and fabricate an arm cuff to connect Tedde's arm to the PAL. A polypropylene sheet was cut, heated, and bent on a plaster mold of an arm. Velcro straps are used to secure the cuff to the arm. This was the original cuff made, and through the prototyping process proved to be the most effective. The way the arm is supported by the cuff has an impact on how close to the face the PAL will bring Tedde's hand. Other possibilities were explored by the design team throughout the iterations. A softer cloth arm sling (made by Gema Munoz Alarcon, see Figure 53a) and a styrene two part cuff were tested (see Figure 53b), but did not work as well as the original.

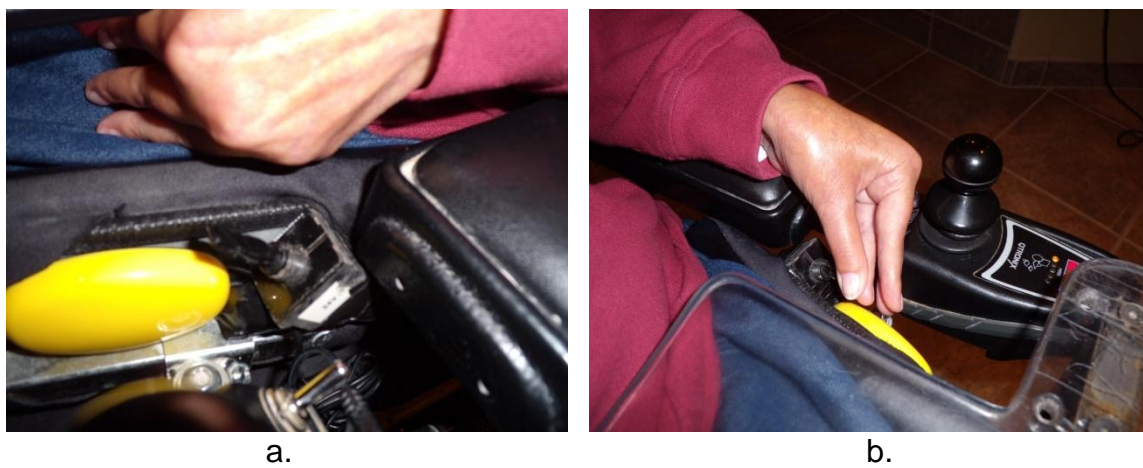


*Figure 53. Arm cuff variations.*

Objective 7 is the culmination of every other objective for the project. It is the design and iterative testing to make an arm lifting device. This solution is thoroughly covered in Chapter 4.

The goal of Objective 8 was to determine the best type of user input device that would control the air pump and release valve. The location and mounting of this device also needed to be considered. A momentary double pole

double throw (DPDT) switch with a center off position was chosen as an inherent match the electronics to be powered. There are two contacts (poles), and two throws (positions the switch can be in). The momentary (on)-off-(on) action of the switch reverts the paddle back to the center off position when it is not being pressed (Hewes, 2008). A plastic paddle was used for ease of operation, and a black housing was chosen to blend in with the color of the wheelchair. The area where the switch mounts to is located near all the other controls for the wheelchair. This posed a design constraint as there was not much room for additional equipment, especially to be close enough for Tedde's limited reach. There was a small area between the joystick and the armrest that proved to be the ideal location (see Figure 54a). It was fastened to a flat frame piece of the wheelchair with industrial strength Velcro for easy removal. This location could be reached with Tedde's arm on the armrest (see Figure 54b). The switch leads and associated wiring was wrapped tightly in black electrical tape for safety and to match the chair.



*Figure 54.* DPDT switch location; switch in use.

Objective 9 was to find a location to mount the air pump and the air release valve. When the plastic piece is removed that covers the battery, it exposes an open cavity near the bottom front of the chair. There was plenty of room inside this cavity to mount the pump and the valve with adhesive Velcro. The air hose leading to the muscle exited out a small hole near the back of the chair. The wiring for the control switch exited through a similar space on the top of the panel where the wires for the other electronics ran.

The purpose of Objective 10 was to safely connect the electronic components and controls to the wheelchair's 24V power supply. Jeffrey Ward, an electrical engineer at the Robotics Lab at ASU, came to the human factors lab to consult on possible connections. His recommendation was to connect the positive wire from the PAL to the positive lead on one 12V battery and the negative wire to the negative lead on the other battery. Because the batteries were in series, this would produce the 24V required to power the PAL. Eye terminal connectors were used for this purpose. A 5 amp inline fuse was tied into to the PAL's positive wire for safety precautions incase the pump failed.

All of the given elements and design constraints were considered during the development process of the PAL. The objectives of the project were broken down and systematically resolved through testing and user input. Many of the objectives were not fully resolved until the final iteration, prototype V.

### *Final Observation and In-home Trial*

Once prototype V was completed, the researcher drove to Tedde's new home in Tubac, Arizona to fit the PAL to her chair. The device and all necessary components were assembled, mounted, and tested to make sure they worked properly. Photo and video was then used to document Tedde using the device for the day. Tedde's mother and two caregivers were trained in basic troubleshooting and assembly/disassembly. They were shown how to easily remove the air muscle, spring, and pivot arm and attach it to the back of the device. This was an important consideration for the three to four times daily that the Hoyer lift was used to transfer Tedde to and from the chair.

Once the device was connected and the short training session concluded, Tedde was excited to try out the device in numerous ways. Since the main objective of the PAL was to lift Tedde's arm to her face to aid in eating-related ADLs, lunch was served by Tedde's mother.



*Figure 55.* Tedde using the PAL to eat.

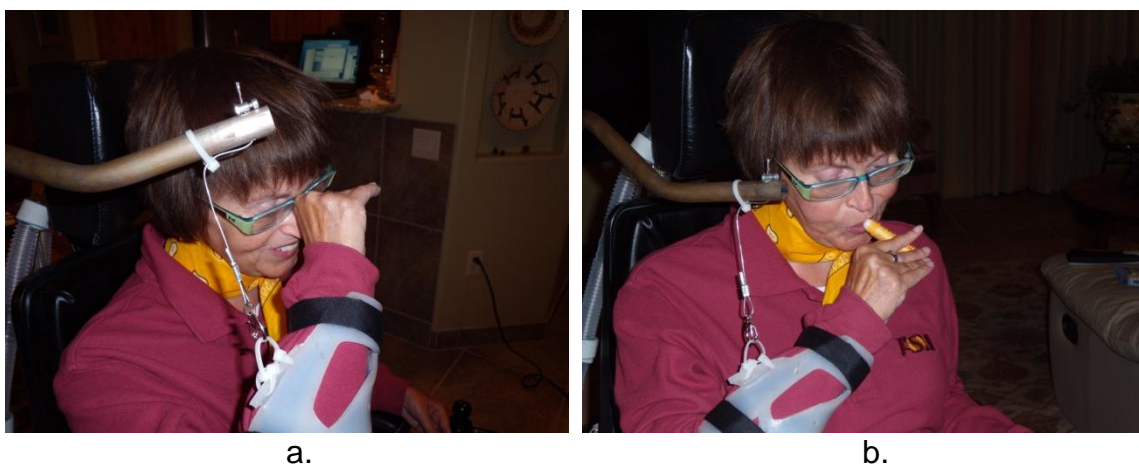
She was able to pull her wheelchair up directly to the table without the need for the additional lifting tray. This meant that Tedde could have her plate on the table instead of on her tray, and did not need to rest her eating arm at an unusual angle against the tray. She was able to manipulate food with her fork and use the PAL to bring her arm to her mouth to eat it (see Figure 55). Because she was sitting in an upright position instead of leaning forward, there was no need to recline in order to swallow. Previously, her respirator would inhibit swallowing in this position as it took away her breath. She had to move the chair recline the chair a little after every bite. Tedde also immediately noticed that not having to lean forward made her nose run less. Usually when she ate, her nose would run because of her position in the chair.

Tedde wanted to test the PAL's capacity to help her in other ways. There are many ADLs besides from eating that require a hand to be brought close to the face. Before using the PAL, when her nose ran someone else had to wipe it for her. This was admittedly frustrating for her and a tedious task for her caregivers. She normally keeps a few tissues on her main tray for this purpose. Tedde put the PAL to the test. She was able to pick up a tissue and bring her hand to her nose to wipe it (see Figure 56).



*Figure 56. Tedde using the PAL to wipe her own nose.*

There were two other activities that Tedde needed a caregiver to do for her several times a day. The first was adjusting her glasses (see Figure 57a), and the second was applying lip gloss (see Figure 57b). She successfully used the PAL to do both.



*Figure 57. Tedde using pal to adjust her glasses and apply lip gloss.*

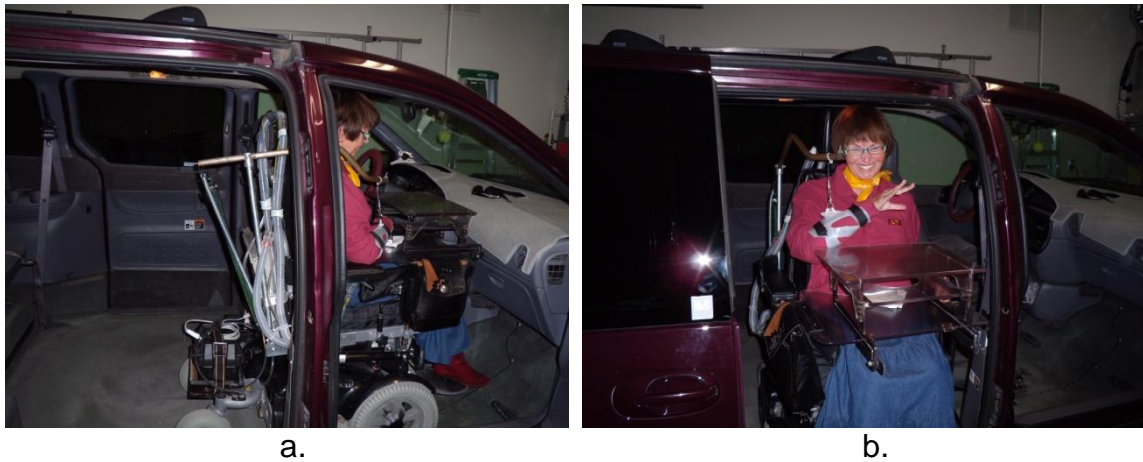
Tedde also tried out using the PAL in her home office area. In order to previously answer the speakerphone, she had to drive to the desk, switch the chair from drive mode to lift mode, and then crawl her hand to the phone button. She complained about frequently missing calls because she could not get to the button in time. With the PAL, she was able to get to the button much faster (see Figure 58a). She also discovered she could pick up a pen and write a note more easily with the PAL (Figure 58b).



*Figure 58.* Tedde using the PAL to answer speakerphone and write a note.

One environmental constraint discovered during the front-end task analysis was Tedde's modified minivan for travel. The powerchair barely fit through the vertical clearance of the sliding door (see Figure 24b, p. 97). At the request of the researcher, Tedde drove her chair into the garage make sure she could still maneuver into the van. With the Pal attached, she successfully drove her chair up the ramp, made the turn in the van and locked her chair into position (see Figure 59). The locking mechanism was released, and she backed up,

turned back towards the door and exited down the ramp with the device in working position. With a big smile on her face, Tedde was able to wave goodbye.



*Figure 59.* Tedde entering the van; exiting the van while waving.

One activity that Tedde brought up in the pre-design interview was shaking hands. Her inability to lift her arm up frustrates her when meeting people. She wants to shake their hand, but there is awkwardness felt because of her physical condition. They are afraid to reach over and pick her hand up off her tray. While using the PAL, she simulated shaking hands with her mother (see Figure 60a).

Finally, environmental constraints in Tedde's house were considered. She drove her wheelchair with the PAL attached through various doorways in her home (see Figure 60b). This was done to make sure the device did not impede her regular routine of daily travel from room to room. The PAL passed this final test on every hallway and doorway throughout the home.

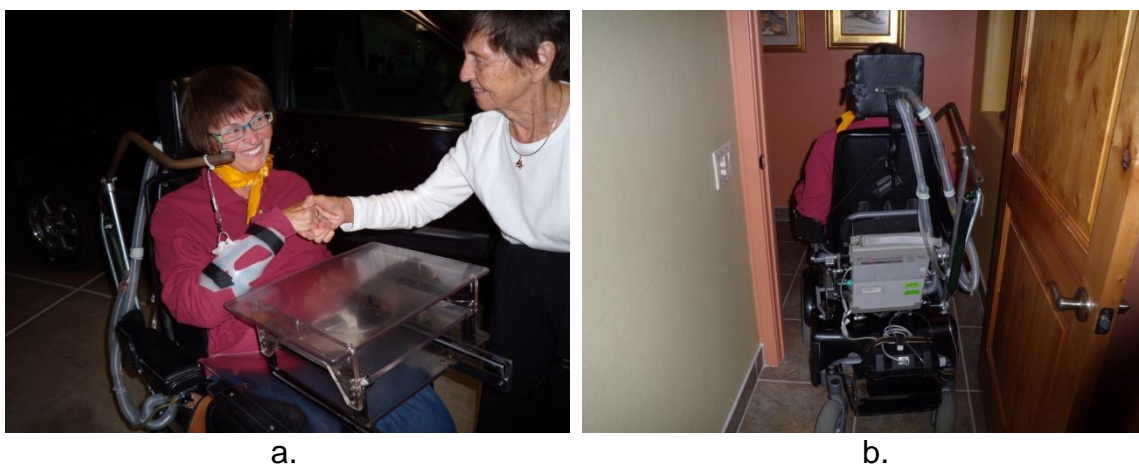


Figure 60. Tedde using the PAL to shake hands; driving through the home.

### *User Evaluation*

After a week of having the device attached to her powerchair and testing it out day to day, Tedde submitted a user evaluation of the PAL. In this document (see Appendix B), Tedde explains her current condition and how it affects her on a daily basis. She also explains her particularly troublesome ADLs and IADLs. She reviews the pros and the cons found, and then gives recommendations on possible improvements. Her main comments are listed below.

#### Pros:

- Able to raise and lower my hand/arm up to my face.
- Able to feed self in upright position without cutting off my air supply.
- Able to wipe my own nose!
- Able to adjust my glasses.
- Able to answer the phone more quickly and with ease.
- Able to reach things on my desk.

- Able to shake hands and wave.

Cons:

- Unable to type on my special computer keyboard due to angle of arm in the sling; unable to move arm laterally.
- Assembly is not difficult, but needs to be disassembled and reassembled every time I have to use bathroom or when going to bed (about 4 times a day). (Note: we use a sling and patient lift to take me in and out of the wheelchair; the arm-raiser impedes this process.)
- Sling is uncomfortable after long use and trying to move my arm laterally.

Suggested improvements:

- Drill a second hole for positioning the arm-raiser out to the side for easy access to a computer keyboard. It would have to be repositioned by a care-giver, but would be very simple to do.
- Cut and hinge the lateral pipe in front of the vertical rod that holds the assembly so that it can be folded up and out of the way for egress to and from the wheelchair. This would require temporary release of the spring and artificial muscle which is much easier than complete disassembly of the whole apparatus.
- To reduce stress on the wrist, hand and arm, design a sling that has more stability (e.g., metal or rigid plastic bars) across the top of the forearm with durable nylon sling under and around the arm, closed at the elbow, so that the arm is supported but not tightly bound.

In summary of the project, Tedde wrote,

This is a great project that works very well. It is still rough, but it is a well thought-out project that has real potential for thousands of people with muscular dystrophy and other debilitating disabilities. I can hardly wait to demonstrate it for the Muscular Dystrophy Association. (T. Scharf, personal communication, 2008)

*Cost Analysis of PAL*

<b>PAL Components</b>	<b>Price</b>	<b>Qty</b>	<b>Total</b>
<b>Air Muscle Components</b>			
Outer braided mesh	\$1 per foot	3	\$3
Inner bladder	\$1 per foot	3	\$3
Air tube	\$0.50 per foot	5	\$2.50
End Plugs	\$4	2	\$8
Air fittings	\$0.75	4	\$3
electronic release valve	\$20	1	\$20
air pump	\$25	1	\$25
hose clamp	\$1	2	\$2
wire	\$0.25 per foot	6	\$1.50
<b>Arm Cuff Components</b>			
1/4"x12"x12" polypropylene	\$5	1	\$5
1/8"x12"x12" foam padding	\$2	1	\$2
bicycle brake cable	\$6	1	\$6
quick release clip	\$1	1	\$1
<b>Other components</b>			
steel conduit 1"x10'	\$11	1	\$11
zip ties (pack of 100)	\$2	1	\$2
<b>Bracket Components (custom made)</b>			
anchoring bracket	\$35	1	\$35
support bracket part 1	\$20	1	\$20
support bracket part 2	\$20	1	\$20
top pivot hinge	\$30	1	\$30
bottom slide-in	\$15	1	\$15
<b>Total</b>			<b>\$215</b>

*Table 7. Cost Analysis of PAL*

All of the components used to make this prototype were organized and put into table form (see Table 7). The individual price, the quantity of parts bought, and the total for each listed. Since the custom-made parts were done free of charge by the ASU machine shop, an estimate was given at a local machine shop on a price for each part to be milled out of block aluminum.

The total of parts was \$215.00. This is relatively cheap considering that the device is in the high-tech bracket on the AT continuum. This price does not take into consideration that over half the cost is in one-off custom prototyped parts. It also does not show that all of the other store bought components were for very low quantities, meaning higher prices. If the device were to be manufactured with these parts bought in bulk and the custom parts made in higher quantity, the device could retail for less than half of the price shown in Table 7. A ballpark estimate would be \$99.00. Keeping a product like this under a hundred dollars would be a great selling point to the disabled community.

### *Part Two: Qualitative Research Findings*

#### *Survey*

Twelve individuals participated in an email based survey focused on the ADLs and IADLs of wheelchair users and their use of assistive technology. All of the participants use wheelchair at least part time on a daily basis, and could provide a better understanding of how functional limitations and other factors influence device use or non-use. The survey questions were designed to be open ended to promote descriptive responses and personal insights into the daily lives of wheelchair users. The goal of the survey was to provide answers to some of

the research questions that guided this study, and to find similarities and patterns in functionality, troublesome ADLs, device use, and personal adaptations.

### *Results of Survey*

#### *Question 1*

WHAT DISABILITY(IES) ARE YOU CURRENTLY LIVING WITH, AND HOW LONG HAVE YOU HAD THIS CONDITION?

Of the twelve participants, seven of the responses were neuromuscular diseases, four were trauma related, and one was due to age. Of the neuromuscular diseases, three respondents are living with Limb Girdle Muscular Dystrophy (LGMD), two are living with Multiple Sclerosis (MS), one has Charcot-Marie-Tooth disease (CMT), and one has Spinal Muscular Atrophy (SMA). Of the trauma related responses, three were spinal cord injuries (SCI) and one was a traumatic brain injury (TBI) due to massive head trauma. The age related respondent suffered from degenerated disks, pinched nerves, and arthritis (see Figure 61). The responses to this question showed a variety of ailments the participants were living with. The sample had neuromuscular, trauma and age related conditions that resulted in wheelchair use.

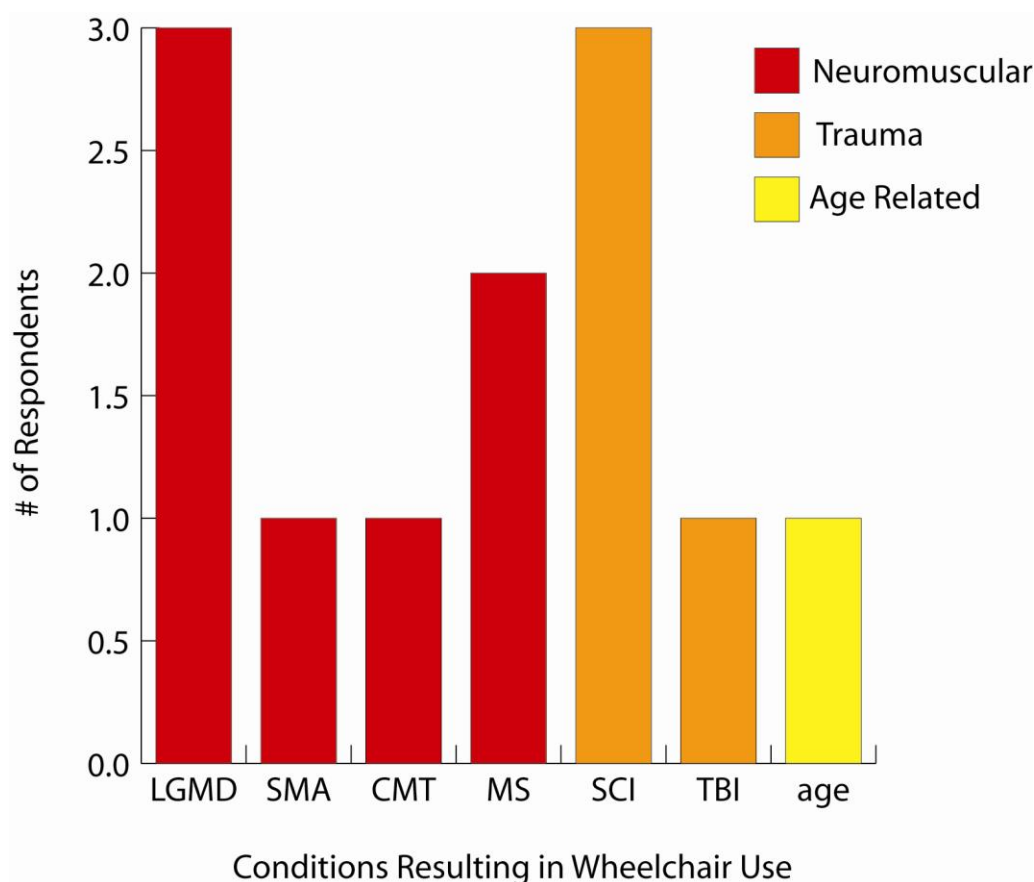


Figure 61. Survey responses to question 1.

### Question 2

HOW DOES THIS CONDITION AFFECT YOUR FUNCTIONALITY (LIMB AND BODY MOVEMENT)?

As expected, each one of these answers varied a bit depending on the severity of the condition they had. Everyone had some problems with muscle function and motor control in their legs. The most functionality of the legs was found in the head trauma respondent, the individual with MS, and the age related respondent. All could walk slowly for short distances with the aid of a cane or crutch, but tired very easily and suffered pain. This fatigue and constant pain

make wheelchair use a better alternative. The SCI and the SMA respondents have no functional ability at all in their legs, and have limited arm and upper torso movement. Depending on the individual, it seems that one arm is usually more functional than the other. The worst functionality was found in the advanced LGMD respondent and the CMT respondent. This is the extreme case where majority of muscle function throughout the entire body is lost. A caregiver is a necessity to accomplish almost all daily tasks.

### *Question 3*

DO YOU REQUIRE SPECIAL ASSISTANCE, AND IF SO, FOR WHAT TASKS?

This question was aimed at seeing how many of the respondents required the use of a caregiver in addition to any assistive devices they may use. One purpose of the question was to see if people with severe disabilities used AT devices less because the caregiver was there to help them with their ADLs. As expected, the individuals with the most severe disabilities used caregivers. They needed help with all of their ADLs associated with self care, including eating, grooming, dressing, using the toilet, and bathing. The two most severely disabled people simply responded, “for everything”.

Another purpose was to see if many of the respondents needed assistance for various IADLs, which are tasks done daily but not specifically required for functioning. These also do not require a caregiver necessarily, but someone hired to do a specific task. The most common tasks needing this type of assistance were housework, driving places, carrying things, and shopping.

*Question 4*

HOW DOES YOUR LIMITED FUNCTIONALITY AFFECT YOUR DAILY TASKS?  
ARE THERE CERTAIN TASKS YOU PERFORM EACH DAY THAT ARE  
PARTICULARLY TROUBLESOME?

This question was aimed at finding commonalities between all the survey respondents in tasks that they find particularly difficult. Again, it was expected that the severely disabled would find difficulty in most all tasks. One such respondent said, "I have to depend on other people for everything and that is incredibly frustrating." Another wrote, "I need help with everything I do." This question was more aimed at people who still had limited functionality in their arms and hands but still found things to be difficult. Most of the respondents listed a few activities in their answer. Things that able bodied people take for granted were common answers for this question. Getting dressed was listed on eight of the twelve responses. This activity requires good grip and dexterity, and lots of bending. Showering was listed on six of the surveys. Four listed getting out of bed, while 3 mentioned housework. Other activities that require two arms and hands to complete, such as carrying things or opening jars, were also listed.

*Question 5*

THINK OF THE TOP 5 DAILY TASKS THAT ARE THE HARDEST FOR YOU TO  
PERFORM ON YOUR OWN. (RANK THEM FROM 1 TO 5, WITH 1 BEING THE  
HARDEST).

This question was basically a reiteration of the last, but the wording was changed to stimulate a more quality response. Respondents gave several

answers to question four, but it was hard to see which ones they personally found the most difficult. By suggesting they give five answers and rank them, more tasks were listed and it was easier to see what ones were the most problematic. Three of the twelve respondents did not answer this question because they felt it to be non-applicable. Because of their severe disabilities and almost no muscle moment or control, every task to them was equally difficult.

Of those that did answer the question, showering and dressing were the first or second most difficult activity for seven of the nine respondents. Some other responses that made the top two were feeding one's self, reaching for things or carrying things, and cooking. A few responses were individual to one respondent. One person put "walking" as the most difficult task. Seemingly pretty obvious that if you were in a wheelchair walking would be difficult, he was the only one who put this answer. Although not statistically significant, one respondent put "paying bills because of my lower income status" as the number one difficult task. This answer showed that physical functioning is not the only thing that being disabled effects. Because of the disability, this person was unable to work, and had a difficult time making ends meet because of it. This same respondent listed "depression often" as an answer to question two (how does your condition affect your limb and body functionality?) This ties into the emotional strains that a disability can bring with it.

### Question 6

DO YOU OWN ANY SORT OF ASSISTIVE DEVICES (NO MATTER HOW SIMPLE OR COMPLEX) THAT ALLOW YOU TO COMPLETE YOUR ACTIVITIES OF DAILY LIVING (ADLS) FASTER OR EASIER?)

This question was answered by all of the respondents. Some listed more devices than others. The devices were broken down into ADL or IADL specific to see if an activity had more devices associated with it than others.

*Movement related:* Power wheelchair, scooter, quad cane, pillow to sit on

*Showering, bathing:* bathtub seat, shower chair, bathtub bars

*Grooming:* electric toothbrush, long lipstick

*Eating:* long straws, ergonomic kitchen tools, plasticware (silverware too heavy), big handled utensils, bent handled utensils, wheelchair tray, electric can opener

*Reaching, carrying:* gripper, reaching pole with hook, pole to turn on lights

*Getting dressed:* extending shoe horn, button hook

*Going to the bathroom:* Hoyer lift, condom catheter, pole for wiping

*Computer related:* head controlled mouse, track ball, ergonomic keyboard, mouse controlled keyboard, voice recognition input device, speakerphone, Point & Click and Wivik (software)

*Transferring to/from chair:* Hoyer lift, caregiver

*Other:* service dog, Bipap machine (breathing), Tens unit (pain), suction machine to clear mouth

The most prevalent single device listed was a powerchair, with seven respondents mentioning it in their answer. The most devices listed for a given activity were computer related. There is a plethora of technological devices available to help disabled people with using computer. Surprisingly, the activities

the respondents found the most difficult in questions 4 and 5 (dressing and showering) did not have many devices to go along with them. After listing devices used, one respondent wrote, “Devices may help, but one must have the money to buy them.” This is an important consideration that a designed device should be affordable. According the assistive technology documentary *Freedom Machines*, 70% of working age disabled are unemployed (Stobie, 2005). In the demographics question at the end of the survey, six people responded that they were unemployed, and two were retired. Designing cheap devices makes them more accessible to a larger population, in turn helping more people.

#### *Question 7*

ARE THESE DEVICES BEING USED FOR THEIR INTENDED PURPOSE OR  
HAVE YOU ADAPTED THEM TO FIT YOUR SPECIFIC NEEDS IN ANY WAY?

This question was designed to find out if this sample of AT users has modified any assistive devices they have purchased. This could happen because the device was poorly designed and doesn’t do exactly what it is meant to. It could also happen when a device is designed for a larger population and doesn’t quite fit the needs of a specific user. If a user has a degenerative condition, the device may have worked properly at one time but worsening functionality required some modifications.

Three respondents left this question blank. Four responded that they use their devices for their intended purpose. Two participants said they use their devices for the purpose they were intended for, but modify them to fit them better. Three people gave specific details on modifying an existing device. One

respondent extended the joystick on his powerchair by taping a ballpoint pen to it. This allowed him to control the chair much easier. Another uses the sucking machine that clears his mouth while he brushes his teeth so he doesn't have to lean over to spit. A third modified a device for recreational purposes. He plays Power soccer, and needed to weld steel tubing and metal guards onto the front and sides of his chair. This prevents injury and damage to the device.

### *Question 8*

OF THE DEVICES YOU OWN, DO ANY SELDOM OR NEVER GET USED?

The intent of this question was to see if anyone in this sample had abandoned an AT device. Three participants responded "No," and two left it blank. Three participants no longer use a certain device because of their degenerative physical condition. Two people have a manual wheelchair that they can no longer propel so it doesn't get used. One respondent had orthotics, but can no longer walk. A few participants though listed devices that they purchased, and don't use because they don't work well or they are a hassle to use. One person had a device that just did not work well. Their response to this question was, "I used to have a box that did things like turn lights on/off, turn channels, etc. I don't remember the name of it but it was a piece of crap...needless to say, I didn't have it very long." Two participants listed the Hoyer lift as a device that seldom gets used. Both find it easier to have a caregiver lift them for transferring than bother with the time and hassle of the Hoyer lift. Another participant had a device that she had to abandon because it was painful to use. This device was made specifically for her, and she had high hopes for it but after using it for a

short time realized it wouldn't work. "I had a brace made last year but the design, although it sounded good, put too much pressure on my shoulder and I am no longer able to use it." In this small sample of AT users, over half had abandoned a device before.

### *Question 9*

HAVE YOU EVER CREATED YOUR OWN ASSISTIVE DEVICE (IF YES, TO HELP WITH WHAT SPECIFIC ACTIVITIES?)

The purpose of question nine was to determine if device creation was common among AT users. This would signify that there are plenty of opportunities for designers in this wide open market. There are obvious needs in the disabled community that are not being met if they are creating their own products to help them. The devices that the respondents created will be organized by activity they are needed for.

*Reaching:* 5 ft pole with hook on it for grabbing things on the floor and in cupboards; broomstick for turning on and off lights; Swiffer Duster with hook or old cane for reaching and grabbing.

*Showering:* plastic patio chair with one arm cut off for side access.

*Swimming:* mesh seat with "floaties" all around it.

*Gaming, recreation:* homemade joystick to play computer games; glove with finger and thumb sewn together to pull back on wheelchair joystick during power soccer (can't normally do because of limited grip strength); homemade fishing rod holder out of broomstick and electrical tape; bent aluminum and electrical tape cue stick handle to play billiards from a powerchair.

*Cooking, eating:* an empty jelly jar shaken to beat eggs and mix things, elevated wheelchair tray to aid in eating.

*Computing:* wrist support for typing

*Opening locks:* T-shaped key holder out of a broomstick and bolt

*Transferring* (in the respondent's words): Invented, Designed, and built with help, a large square frame over my bed. Supported at each corner by 4x4 wooden posts. Within the frame are three ropes extending from head to foot of the bed. There are another three ropes from left to right side of bed. All ropes are spaced about 2 feet apart. The frame is extends wider than the bed on one side including the ropes. I use this for transferring in and out of bed. I also use it for turning over at night. The ropes are within arm reach over my bed while lying on my back. It helps tremendously especially helping me to transfer by having something to hook my arms or wrists on in case of spasms or loss of balance." (This device is copyrighted by Daniel T. Kolston, © permission was given to use name and device).

All but one of the respondents gave at least one device they have created to help with ADLs or IADLs. Some devices are more complicated than others, but the sheer number of homemade devices in a sample size of twelve people is incredible. Almost every activity mentioned in question four has a device listed above made for it. Adaptation is a big part of adjusting to life in a wheelchair. Sometimes homemade devices are cheaper and work better than store bought ones. In some cases, there is no device out there that can fulfill the need of a specific individual. Specific functionality and wants and needs will differ among

every chair user. However, much of the time these AT users are not asked this. Products are mass manufactured without the disabled community involved throughout the process. In order to improve their own quality of life, many AT users will create such products as listed above to help them achieve their goals.

*Question 10*

IS THERE ANY PARTICULAR ACTIVITY THAT IS PERSONAL AND IMPORTANT TO SPECIFICALLY YOU THAT YOU FIND YOURSELF UNABLE TO DO?

This question is significant because it is what started the research on the PAL device. Tedde had a specific thing she wanted, and a device was designed around that activity. As expected, most had a different answer for this question. They are as follows:

Operating the TV/DVR, cleaning after a bowel movement, driving, horseback riding, hiking, cross country skiing, photography, home repairs, drawing and painting, tying shoes and putting socks on, and 'most things'.

Question ten shows that possibilities are endless for device design. Each disabled person across the globe has needs and wants that are important to them. These are the things that improve a person's quality of life and let them become more independent.

*Question 11*

IF YOU WERE TO GO OUT TOMORROW AND PURCHASE A NEW ASSISTIVE DEVICE, WHAT WOULD IT BE AND WHAT TASK WOULD IT HELP YOU WITH?

The final question on the survey was attempting to uncover unarticulated needs of the participants. Some people may be so used to adaptation and how they are currently accomplishing their daily activities that they do not think of devices regularly. Others may try to avoid them at all costs in order to try to look “normal.” Some devices may be too expensive for them to attain so they wouldn’t ever think of buying one. Like the previous question, it was expected that the answers would be mostly different. They are as follows:

A blonde (haha), a page turning device, a computer voice system, an accessible corvette, an auto door opener for all doors in home, a device to hold the head up, a larger bathtub, something that would help to carry an object, help with raising my arms for eating, an iBOT®, maybe, and no idea.

Many of these responses were indeed things that would be expensive to purchase. The first respondent showed a good sense of humor with his answer, and the last two were vague. The rest of the responses show that there is a consumer market for the millions of disabled people on this planet. Designers need to harness this untapped resource and help people who really need it.

Overall, this qualitative survey provided a rich diversity in answers even though the sample size was small. The data gathered was not like any available in the review of the literature for this research project. There were a lot of commonalities in functional limitation across a variety of disabling conditions. Many specific activities were found to be particularly troublesome across the board, including dressing and bathing. All of the respondents used assistive

technology on a regular basis, and all had made or modified their own device(s) to suit their individual needs. The intuitiveness of the participants and ingenuity in the devices they created to help themselves was astounding. More so, this shows that individuals with disabilities need to be involved in the development process of assistive technology. It became clear that there is a disconnect between devices available on the market and devices that people actually need or want. There is a large gap to fill by product designers and engineers that has the potential to change lives for the better.

### *Internet Chat Sessions*

The second qualitative research method employed was the internet chat room on the Muscular Dystrophy Association website, mda.org. The idea was that in a less formal environment, people would be more willing to open up about their disabilities and their use/ nonuse of assistive technology. The original research questions as well as the questions used in the survey guided the chat. An internet chat is also a dynamic environment. Chat participants are there to make friends with one another and offer support to others who are dealing with the same physical and social issues. The style of research is similar to a focus group, where a bunch of people are present to openly discuss an issue. Unlike a focus group however, the internet lets people from around the world meet in a centralized virtual space. This is vastly different from the physical and environmental barriers faced by the disabled on a daily basis. They can be themselves with others who are experiencing similar tribulations in life without the stigma of feeling like an outsider. Internet chats are generally informal, with

participants using shorthand slang. “LOL” means laugh out loud, “tc” means take care, “np” means no problem, etc. From many years of internet tinkering, the researcher was very familiar with this style of chat and used it as well. They are dynamic in the sense that many people are typing at once, and the topic of the conversation can shift rapidly. There were two two-hour long internet chat sessions conducted for this research.

Mda.org has specific meeting times weekly for various groups. The two thought to be most prevalent to this research were *Wheelchair Gang* and *LGMD Support Group*. As explained in the methodologies chapter, the researcher requested a username and password to their chat rooms as they are not open to the public. This provides a level of security and protection for their disabled users. MDA also retains public records of the internet chat sessions accessible to anyone online, so saving a copy of the transcriptions was very easy.

The first chat joined was Wednesday’s *Wheelchair Gang*. As the name implied, the members who meet here all use wheelchairs on a regular basis. The second chat was *LGMD Support Group* the following Friday. About half of the users from the first chat were also present in the second chat, even those without LGMD. This should that the MDA chats were a close knit social environment for the disabled. There is a small table on the right of the chat window that shows who has entered and exited the room. This was a convenient way of keeping track of how many people joined the discussion. It also showed the members that the researcher had joined the group, so right away the ice was broken. An introduction was made and the research project was described. The researcher

apologized for dropping in unannounced, and asked for their help in answering questions about ADLs and assistive technology. Immediately, some members of the group asked how they could help, and explained how to change the icon associate with a username in the chat room. As the research project was being explained, a participant pointed out that Chris-ASU “sure did type fast”. It was important to remember that many of these people were using alternative input devices such as onscreen mouse controlled keyboards and voice recognition software. In order to not overwhelm them with information, the typing speed was slowed.

The following excerpts were pieced together from both chats. The initial question asked was about activities they find particularly troublesome. A lighthearted vibe was immediately apparent when the first answer received was, “Chris first thing that is hard to do in my wheelchair is.... (45 second delay) ...walking. And the other thing I can’t say in chat.” Right away, a participant had hinted at a device to help him with sexual gratification. This is something that may have been too embarrassing for respondents to talk about in interviews or even the survey. This is an important part of adulthood, and just because their bodies don’t work well doesn’t mean they don’t have the same needs and desires as the rest of us. This topic still seemed a bit taboo in the chat, as it wasn’t further discussed. User ken-t explained that he has difficulty lifting his arms to comb his hair, and eats with the help of arm cuffs that he slides his elbows in.

Every time a person entered the chat (users can come and go as they please for the two hour duration), they were greeted with hellos and “hugs.”

Since this was their personal space and time, other things were discussed like who had won American Idol and current weather in various cities throughout the country. It seemed like a tight knit group, as others had entered after the research project was explained. They immediately asked if Chris-ASU was new here, and were glad to provide insights once the project was explained again. User Rollerbetty explained that her father was creating her a go-cart type device so she could go on sand and in shallow waters at the beach. This was another example of a creative person making their own device because one was not readily available. Stephh1 added a very insightful comment that many of the chatters agreed with. She said, "Thing is you have to be inventive when you are disabled, if you pay the going price for everything you will pay an outrageous amount of money, so with ramps and stuff sometimes it is easier to have someone build it for you." User hen added, "and man is everything expensive, it's ridiculous." This is furthering the point that devices need to be inexpensive in order to get used by a larger population. Stephh1 created a device out of a stick and a rubber ball to turn on her computer and her monitor. One user said they just bought a ramp for 300\$, on sale from 600\$. Another user interjected they had just made homemade carpeted ramps for 50\$, and would never pay 300\$. The iBOT® was discussed as a ridiculously overpriced item, but one that everyone wanted. Tim pointed out that it cost nearly 25 thousand, and no one he knew could ever afford that.

Ken-T mentioned that some of the cheaper devices he does buy don't hold up to everyday use. He said he needs an industrial grabber he can't destroy,

as he regularly breaks the ones he buys. He said he is hard on his equipment, as just that day he broke one of the back wheels off his powerchair trying to go over a curb. This reiterates another human factors consideration in device design-durability.

As the conversation shifted, users were pointing out devices they had and devices they wanted. Larry-e uses a sip and puff device to control his chair. By sipping or blowing into a straw like device, users with no arm or leg control can still drive their chair around. No other research respondent had mentioned this technology. Larr-e said his wife has a universal switch to control all her lights, TV etc. A device like this that simplifies many actions into one action is appreciated. He said that his friend in Canada has ceiling lifts in many rooms, that work on a track system to transfer him without the need of a caregiver. Remote controlled lights and doors were also discussed, but losing the remote was considered a negative. User Hen wished that he had something to help him turn over in bed. Other respondents in this study had mentioned creating similar devices to help them with that task.

Cost of devices was reiterated again by Hen, Stephh1 and Rollerbetty. "Everything costs so much, and insurance doesn't want to pay for 95% of it. Over the bed table, shower chair, porta potty, grab bars, reachers, all out of pocket expenses."

Other topics important to the disabled community were discussed. The need for places to be more accessible is a common issue for most chatters. Some discussed their chairs not fitting through doorways, or getting stuck in tight

places. They also discussed the stigma of being handicapped, and how people assume mental incapacity when they see physical incapacity. Sometimes they get talked to like they are children, or people avoid eye contact or talking to them all together.

The participants in both sessions were asked the conditions they had. Since this was MDA chat, all of them were neuromuscular, though varying types and degrees of degeneration. There were users with DMD, LGMD, ALS, BMD and SMA.

### *Yahoo!® Messenger Chat*

As the first chat session was expiring, a user named Sunny signed on. Since the MDA window was about to close, he suggested furthering our conversation through an instant messaging client. The software was free, so the researcher downloaded it and installed the client on his home computer. Sunny had given his Yahoo! ID, and the conversation was continued one on one.

A few aspects to this interview were unique. It was amazing that a last minute chat in the MDA window had spawned a spur of the moment interview with a man half way around the globe. Sunny lives in New Delhi, India, and shared some insights of having a disability in a foreign country. He immediately shared that both he and his brother suffer from MD, and neither can afford a power chair although both really need one. They can't afford a caregiver either, and rely on their parents (in their late sixty's and early 70's) to care for them and push them in their manual chairs.

His BMD is progressive, and he has a difficult time lifting his hands and arms. He noticed that brushing his teeth and grooming have become increasingly difficult in the last year. He uses long spoons and straws to eat, and an on bed table. He also uses the table with a wash basin on it for cleaning and teeth brushing. In order to type, he uses a sensitive mouse and an onscreen keyboard. Because of this, much of what he typed was in shorthand, but surprisingly easy to understand. A lot of vowels were left out, but the words were still readable. He said that there is no state help or insurance for people that are disabled. He has no store bought assistive devices; everything that he and his brother use day to day is homemade. As far as he knows, it is like this in most developing countries as people who are disabled cannot afford to buy AT. He is very grateful to have access to a computer. Midway through the interview, Sunny said that his hand was giving way, as he tires very easily and he needed to go.

This chat interview put AT design for developing countries into perspective. Many of these people are poor to begin with, and having a disability means they cannot work at all. This should be an eye opener for aspiring designers to create devices out of readily available local materials. There are programs that do this, but with the amount of disabled people around the world, there can never be enough to help everyone. Simple and cheap solutions that could be fabricated on location could literally change lives.

### *Qualitative Analysis*

General comments and concerns given by the Part Two data samples were analyzed and abstracted. Transcripts of the chats, surveys, and interviews

were reviewed by the researcher for commonalities in AT use and troublesome ADLs. An editing approach was used because it is interpretive and flexible. The textual data was scanned and coded in an attempt to find similarities in phrases and dialogue (Robson, 2002). The coding is based on the researcher's interpretive meaning of these found language patterns in relation to general knowledge brought forward in the literature review.

It is important to note that this analysis only applies to the sample of wheelchair users involved in this research project. The generalizations made do not reflect the views and feelings of the entire disabled community.

The coded data was grouped and simplified to gain a better understanding of the types of individuals who use, abandon, modify, or create assistive devices. Three types emerged from this analysis: the Worriers, the Survivors, and the Inventors.

*Worriers*

“Disability income just does not help you with quality of life.”

“Devices may help, but one must have the money to buy them”

“If I did need something like that I’d have to go without”

- frustrated with not being able to accomplish tasks
- hate relying on people
- depressed
- low income
- little to no support network
- not many AT devices because of cost
- buy AT when they can afford it; hire people to do simple tasks
- disheartened by broken devices
- bad disability experience, low quality of life
- feel stuck

*Survivors*

“If we don’t help each other, who will?”

“It’s the friends we have that know us more and the love we have for each other that has the ability to keep us safe.”

“I give away (unused AT devices) or sell them cheap to others.”

- open to change
- good support network
- never give up
- social; friends are important
- family assistance
- willing to use AT for independence; purchase used devices
- family help with fixing broken devices or low-tech modifications
- good disability experience because of friendship and support

*Inventors*

“Thing is you have to be inventive when you are disabled. If you pay the going rate for everything you will pay an outrageous amount of money.”

Invented, designed, and built with help, a large square frame over my bed...it helped tremendously.”

- creator; handy
- necessity driven; if there isn't a device for a task they will make one
- lofty goals; conquers challenges
- many devices, mostly homemade
- Fixes broken devices
- AT is key to independence
- Friends and family assist when necessary
- good disability experience and quality of life

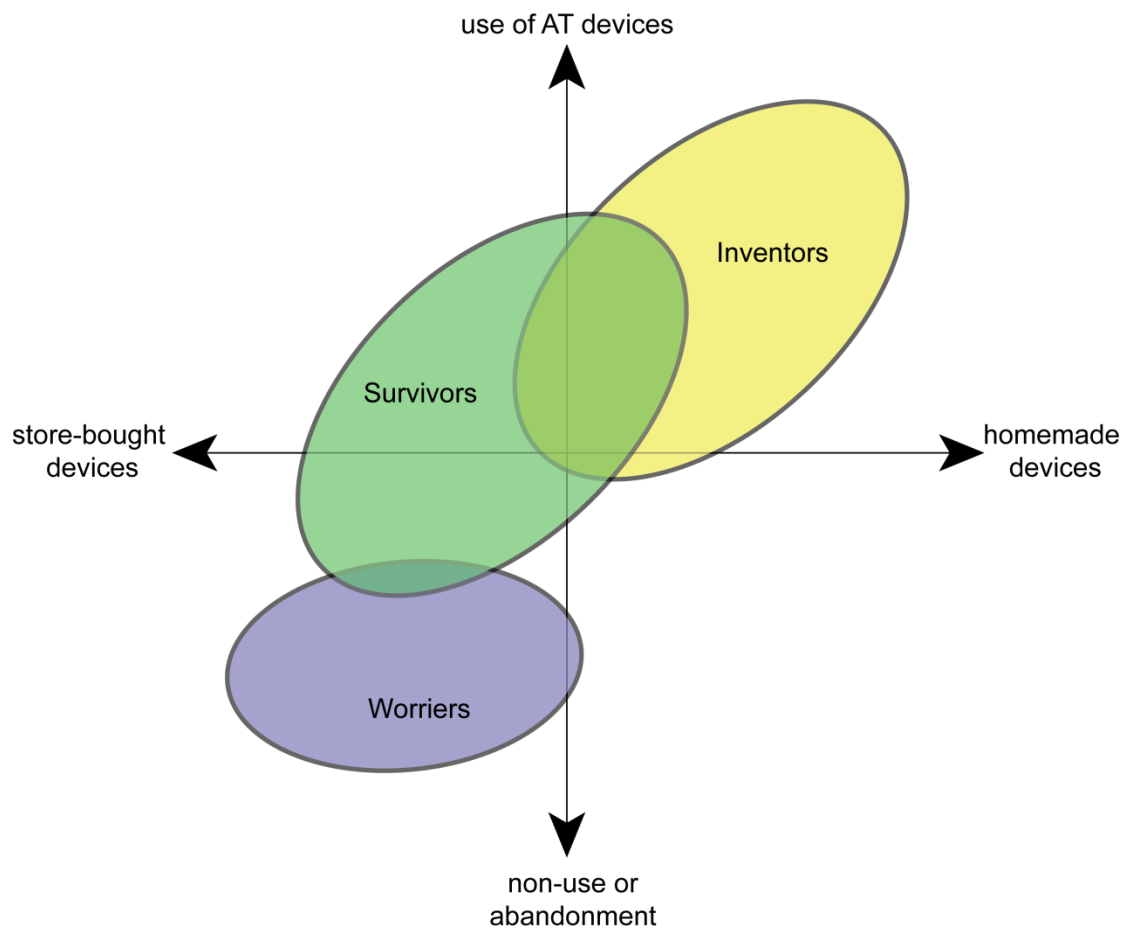
These three categories of wheelchair users provide a glimpse (however limited) into the types of people in the consumer market of AT devices. They share a common thread in that cost of devices is a driving force. For the Worriers, the price of assistive technology is too high for their limited income. Because of a poor support network, they have no means to acquire new devices. This leaves them frustrated, depressed, and less independent. For the Survivors, cost also keeps them from buying higher end devices. They turn to family, friends, and organizations to get used devices. Having a good support network and relying on others increases quality of life. For the Inventors, the high cost of off-the-shelf products and lack of satisfactory devices fuels their creativity. Challenges can be overcome with some household items and ingenuity. They may need help with assembly or fabrication but have friends or family for assistance. Building devices means greater independence, which directly leads to a higher quality of life.

Another common bond in the groups is durability of devices. When AT breaks down, it can be a disaster for the Worriers. With no spare income to purchase new devices and no support network to help, devices get abandoned. The Survivors will look to organizations for another used device or get help from family to repair the item. The Inventors will fix the device themselves or make a new one to overcome the obstacle.

Functionality is also an important quality of assistive devices for all three groups. AT is task driven in that they aid in specific ADLs and IADLs. An efficient device will solve daily challenges, require few modifications, and rarely break

down. Devices that work properly will be abandoned much less frequently and lead to increased independence.

There is an untapped market for the development of new AT devices for wheelchair users. Figure 62 is a graphical representation of where these potential consumers sit. There is a correlation between the use of AT devices and the devices being homemade. The Inventors, who make many of their devices, have the highest rate of AT use. If useful AT was inexpensive and of better quality, the modest Inventor would lean toward buying some devices instead of making all of them. The Survivors sit somewhere in the middle, with mostly store-bought and some homemade devices. They use AT, but would use it more if devices were less expensive. They would prefer new items over used ones if the cost was comparable. The Worriers have the lowest rate of AT use. Because of their limited budget, any device that is a good bargain would be marketable to this group. They want new devices but just do not have the funds to spare for the expensive products currently on the market.



*Figure 62.* The three user groups in relation to their use/non-use of AT, and tendency to buy or make devices.

Cost, durability, and functionality are the three most relevant factors to the development of new products for this sample of disabled individuals. A new AT device that fits into all three categories can be successful in this type of market. The Worriers, the Survivors, and the Inventors would be willing to purchase new devices if they were affordable, long lasting, and did what they were supposed to do. Cost is by far the most important to all three groups. Durability and functionality are also concerns based on the findings of the qualitative analysis.

## Chapter 5

### Conclusion

#### *Assistive Technology and Activities of Daily Living*

The purpose of this study was to explore the use of assistive technology and activities of daily living of wheelchair users. It aimed to use an iterative design process and a user centered approach to product design to develop an assistive device. The design was based on core human factors principles and focused on the needs of the end user of the product. Her input and presence from the onset of the product's development were critical. The design of a tangible device was paired with a flexible, mixed methods qualitative approach to better understand the needs of a larger population wheelchair users. The goal of the research was to explore similarities in functionality, problematic ADLs and IADLs, and assistive device use/ non use. The end result would be a usable prototype of an AT device as well as recommendations to help designers make better and less abandoned assistive technology devices. A well designed device has the potential to promote independence and improve the quality of life for millions of people worldwide.

#### *The Impact of Assistive Technology on Industrial Design*

The study provided valuable results to product designers and rehabilitation engineers who want to learn about the necessary steps to creating successful AT. The use of an extensive literature review covered many areas of interest that could be an asset in the development process. It served as a benchmark of available information about wheelchairs, the disabilities that result in the need for them, and the lifelong changes and struggles of living with a disability. It also

contains recommendations and guidelines of human factors considerations specific to the development of assistive technology and the reduction of device abandonment. An assessment of the levels of AT was done, as well as research into current technology available to aid in arm lifting and eating.

The process of developing a successful device is an arduous task. All too often, manufacturers make a critical mistake in the assumption that a device will be widely accepted. The truth is every disabled person has individual needs, wants, and desires. There are hundreds of thousands of people who live with a certain condition and share similar levels of functionality. However, a person's age, gender, education, socioeconomic status, upbringing, medical coverage, previous experiences, and personal goals for quality of life are vastly different. They have differing views on the use of gadgets and emerging technologies. Some disabled people are open to using assistive equipment to become more independent, while others would rather struggle to get by without their help as they see AT as a stigma to being disabled and different. The key to creating a breakthrough product in this largely untapped market is to treat people with disabilities as consumers and not as patients. There should be a focus on both functionality and aesthetics, and research should be done into current design trends. Like any consumer, disabled people want products that are in tune with their individuality but also can help them become more independent. Design based qualitative research can provide developers with the unarticulated needs of the disabled community.

### *Evaluation of the PAL*

Qualitative research in the form of a face to face interview and a video observation were done to better understand the end user. The interview provided insights into Tedde's personal disability experience. The onset of her disease at a young age meant that she has grown accustomed to life in a wheelchair. The fact that she was still working and using other forms of AT to complete her daily tasks showed that she was willing to try new things. She had a positive and friendly attitude toward the research at hand and clearly wanted to improve her quality of life. According to Marcia Scherer, these qualities made Tedde an ideal candidate for the development of a new device. The video was able to provide necessary information on her specific functionality and current means of completing daily tasks.

Human factors guidelines were constantly referenced during the development process. In order to be considered successful, the device needed to be cost effective, easy to use, durable, easy to maintain and to fix, safe during use and in case of failure, and be aesthetically pleasing. Ease of manufacturability and of assembly was also considered. Above all, it needed to fulfill its intended purpose to aid in face related activities and make Tedde more independent. The decision to use an air muscle as the means of power meshed well with these guidelines. They are cheap, durable, and easy to make and to fix. They have a built in fail safe that would not result in injury in case the device was overexerted.

Tedde's presence and input during the entire design process was essential to the success of the essential device. When tested on the rig, many of the working prototypes seemed to be a viable solution. Once actually tested on Tedde's chairs, the many flaws of each design truly unfolded. Each flaw created new design challenges that had to be overcome. The invaluable collaborative input of an engineer led to a much more mechanically sound design. It also led to the ability to use plastic as a prototyping solution, which saved valuable time and material costs. Instead of designing devices on the rig and having Tedde come to test them, design alternatives could be changed on the fly and immediately tested with her present. A much more stable and better designed mounting bracket was also an added benefit of using plastic first. The use of 3D software and a collaboration with the robotics lab meant that key components could be precisely and repeatedly manufactured using strong yet lightweight aluminum. This was an important consideration if the device were to go mainstream.

The main design objective throughout the development of the PAL was to lift Tedde's arm to her face to aid in eating related tasks. The device was successful in accomplishing this goal as well as many other arm and face-related ADLS. It inadvertently solved her nose running problem while eating, and let her eat in a more upright position as to not cut off her air supply. The device was left with Tedde for a week-long in home trial period, and then she submitted a written evaluation of the PAL. Overall, she is very happy with its performance and it has increased her independence in many tasks. These included wiping her nose, scratching her face, adjusting her glasses, and applying lip gloss, answering her

phone easier, writing notes and getting to objects easier on her desk, shaking hands, and waving. There are other undiscovered activities that it could also benefit with continued use.

She had a few recommendations for improvement on the devices. These were more lateral movement, a possible hinge to quickly move the device out of the way, and a more comfortable arm cuff for extended use. Tedde was excited to show the device off at the MDA office in Tucson near her home. She believes that the device could benefit many people with similar neuromuscular degenerative conditions, and is more than willing to be a spokesperson for the device to try and get a grant for continued research.

The PAL offered a unique insight into designing for someone with special needs. Working with the disabled in this capacity was both humbling and gratifying. It showed that industrial design does have the capacity to change lives for the better.

### *Qualitative Research of Assistive Technology*

The three qualitative methods employed in this project gave the researcher a much better understanding of the challenges of having a disability. Invaluable data that could not be found in the review of the literature was collected and analyzed. The diversity of the population became apparent in all three methods. Common trends were found in both functionality and problematic ADLs/IADLs. There was a diverse cross section of people who were in a wheelchair because of trauma, neuromuscular diseases, and age related degeneration. The participants ranged from 18 years of age to 67. Their level of

functionality also greatly varied from those who could still walk occasionally and live without outside help to those who had no muscle movement at all and needed a caregiver for all tasks.

Although only twelve people responded to the survey, it offered valuable information to designers of new assistive technology. Getting dressed and showering proved to be the two most common daily activities that were problematic. These are certainly two areas that designers could research further to help a large amount of people with a usable device. The language used in the surveys had different emotional overtones to it. Some people seemed frustrated that they couldn't afford a device or could no longer do things that they wanted to. Others seemed very open to discuss the many changes they have personally brought about to better their lives. Despite these differences, they all were ready and willing to discuss personal issues of health and functionality in a research study aimed to further the development of AT. The amount of homemade devices created by this relatively small group of twelve people was amazing. This could be seen as evidence that their needs are not being met by designers and rehabilitation engineers. It also showed the ingenuity and creativity of people who want to be independent and improve their quality of life.

The internet chat brought the research to a more personal level. This is a relatively new means of acquiring research data in the design of assistive technology. No literature could be found on another study conducted in this nature. The method itself is one that can be explored further for future research dealing with anything related to the disabled community. The twenty five

individuals who contributed to the chat were all very friendly and open to discuss functionality and assistive device use. The use of an internet chat coupled the dynamic energy of a focus group with the ability to interview many disabled people from around the globe at the same time.

The informal nature of the chat mixed with the emotional ties of a support group immediately made the researcher feel comfortable. Many of the participants felt that the research was for the greater good, and wanted to help in any way possible. It was a good place to discuss emerging technology and the use of assistive devices. Each person was able to be there because of varying devices utilizing technology. These included voice recognition software, on screen keyboards, special data pads and mice, and other assistive input devices. Several of these participants also shared information on devices they had modified or created. A discerning conversation was sparked about the cost of purchasing assistive technology weighed against creating homemade devices. It is clear that even with great medical coverage, many devices are still paid for with out-of-pocket expenses. Many wish they had the latest and greatest technology, like the iBOT® or the Arm® (see pages 35, 62), but could never afford the high price tag. The human factors consideration of keeping the price affordable is an important one.

The instant messenger interview was an unexpected qualitative method. It was an idea of a participant in the chat room who wanted to share his experiences but couldn't because of time constraints. This led to an interview with a disabled man half way around the world in India. The conversation shed

light on the need for cheap alternatives of AT in developing countries. With no state support or medical coverage, he and his disabled brother have no store bought devices aside from a manual wheelchair. They use modified household goods to accomplish their ADLs. Devices that are designed to be easily manufactured out of cheap local fare could change the lives of people throughout the world. The future implications for research in this area are endless. The analysis of the qualitative data suggests that there is an unmet need for affordable, durable, and functional new AT devices. These factors were the commonalities among the three categories of wheelchair users with MD who participated in the study. The Worriers, The Survivors, and the Inventors all could be potential buyers of such devices.

#### *Design of PAL Relative to Qualitative Analysis*

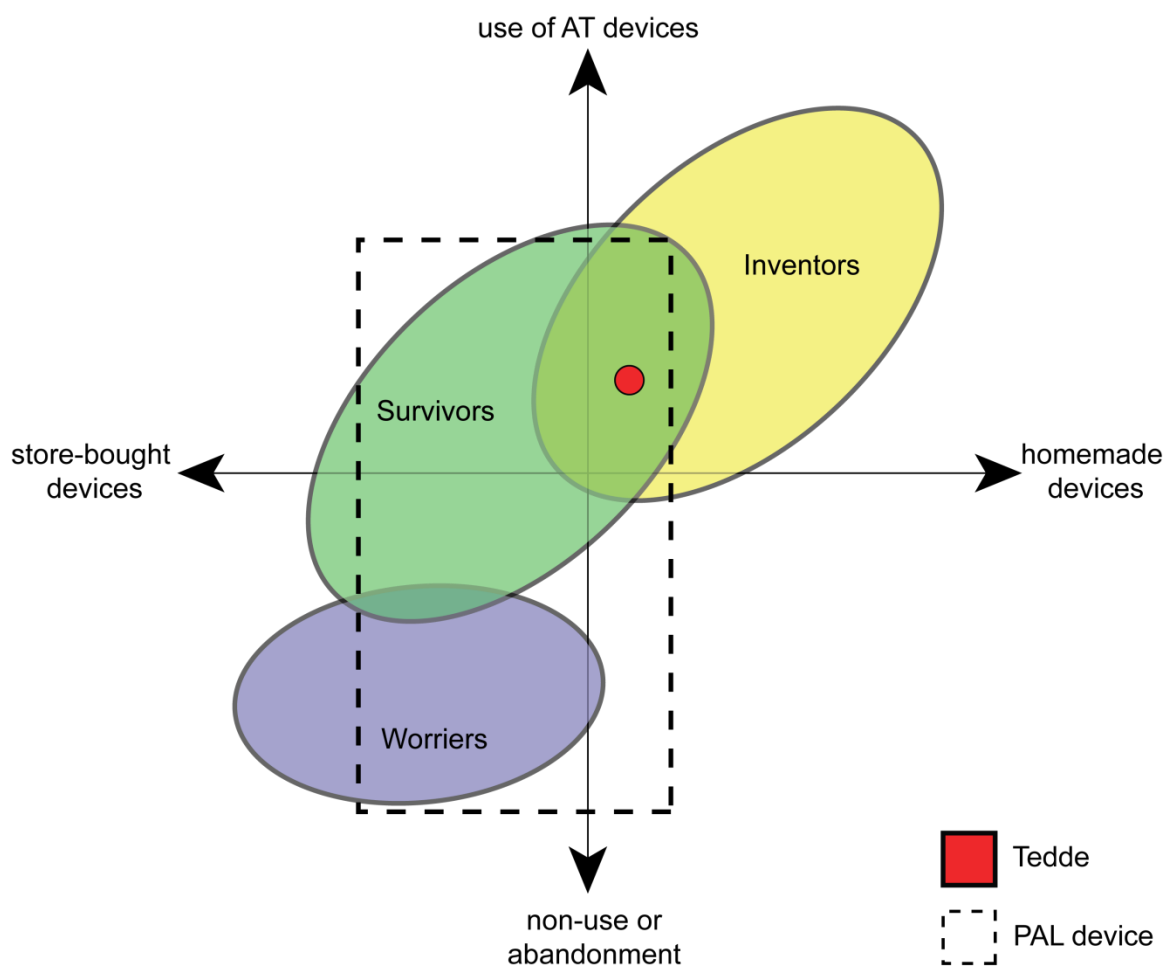
It was important to compare the design of the PAL to the results of the qualitative analysis for validity in this study. Because the PAL was designed around one woman's needs, one goal of the qualitative methods was to see if this kind of device could benefit a larger population.

The first comparison was to see if this specific device could help any users in the research population. Eating was the third most listed troublesome activity in the user surveys, and mentioned in the chat and instant messenger interview. This shows that this specific ADL is something that many other wheelchair users could use help with. Eating was the main problematic activity that the PAL was designed to assist in. There were other difficult activities listed throughout the qualitative study that the PAL could aid in. These include combing hair, teeth

brushing, applying make-up, and drinking. Drawing or painting could be accomplished for someone who cannot lift their arms by inflating the muscle half way, which will float the hand and arm above the tray. When asked if there was a specific activity they would want a device for, two survey respondents and two chat members listed eating. When asked if you were to go out tomorrow and purchase a new device what task would it help you with, one survey respondent answered, "Help with raising my arms for eating." This gentleman fit the exact criteria for an ideal user of the device. To find this answer in a sample of twelve wheelchair users with different disabilities considering their various levels of functional severity was amazing.

The second comparison was to see if the PAL device fit the criteria generated from the qualitative data. The qualitative results suggested that there was an unmet need for AT device design and a potential market niche. All of the user groups could benefit from a low-cost, durable and efficient new assistive device. Price was the biggest concern, as it drove the three groups away from purchasing new items. Instead, they did not use AT (the Worriers), got used products (the Survivors), or made their own devices (the Inventors). As seen in the PAL cost analysis section (p.142-143), the estimated cost of the manufactured device would be around one hundred dollars. A high-tech device at that price would have a high potential to sell in this market. The fact that the device is durable, easy to fix, and can aid in a variety of activities is also in tune with the qualitative results.

Figure 63 shows the correlation between Part One and Part Two of this research project. The red dot represents where Tedde falls in relation to the qualitative results. Her high use of AT mixed with her tech-savvy and creative personality put her in the overlap of a Survivor and an Inventor. The dotted black line represents where the PAL corresponds to the qualitative analysis.



*Figure 63.* The integration of Tedde and the potential of the PAL into the qualitative findings.

### *Future Research*

Assistive technology for the disabled community is an area of product design that needs to be explored much further. It is evident through this research that many of their needs regarding ADLs and IADLs are going largely unmet. Industrial design is a field dedicated to making people's lives easier through product innovation. People with disabilities face challenges in life everyday in activities that most others take for granted. With the emergence of new technology, new light weight materials, and more global connectivity, designers need to step up to the challenge and help those most in need of their skills.

A collaborative effort between researchers, designers, and engineers needs to take place in order for this to happen. It should start on the academic level with different departments joining their efforts and talents to teach students about the growth and importance of assistive technology. This should start as early as high school and continue to higher education. Collaborative research as a joint thesis project has unlimited potential to help millions of people.

### *Design Recommendations for Future Designers of AT*

- Involve end-user from the beginning
- Treat the disabled community as consumers, not patients
- Make a device that is cost effective and durable.
- The ADLs of showering, dressing and going to the bathroom need further exploration as there are limited devices in these areas.

- Collaborate with mechanical, electrical, and rehabilitation engineers throughout the design process.

#### *Future PAL Considerations*

- There is need for cataloguing all the existing power chairs and an identification of mounting points for the PAL.
- Look into possible funding for additional research, development and refinements.
- Develop more aesthetic forms for some of the system components
- Explore additional modifications to the system to provide added ranges to user motions to facilitate new ADL's.
- Develop a way to collapse the system easily when not needed or it is in the way of the caregiver or a chair repairman.
- Explore a larger pump to increase fill rates of the air muscle
- Investigate a way to store a spare air muscle, or other parts
- Explore redesign of the control unit used to fill and deflate the air muscle
- Find additional subjects to use and evaluate this system

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## APPENDIX A

### TRANSCRIPTION OF INTERVIEW WITH TEDDE

Tedde Interview

---

C: The first question is what condition do you have?

T: I have muscular dystrophy, limb girdle is the form.

C: How long have you had it as in when were you diagnosed with it?

T: Well actually I was first diagnosed in the days where they thought it was post-polio when I was about 6. When I was ten they did a muscle biopsy and determined that it was muscular dystrophy, but at the time they only knew about Duchenne. All of us at that point were thought to have Duchenne. SO it wasn't until I was actually twenty nine and in a wheelchair full time that they had a way to determine that it was limb-girdle.

C: IT doesn't make the treatment any different though does it, I mean them misdiagnosing it as one thing as opposed to another?

T: Well I kept living longer than they thought I should (smiles). When they gave the diagnosis of Duchenne, they said, "Take her home and make her happy." When I was ten, they said I'd only live for a couple more years.

C: They were slightly wrong on that one.

T: Yeah, (laughs) they were slight wrong on that. That was 52 years ago.

C: And it is a debilitating, degenerative condition?

T: Yes it is.

C: Do you notice the degeneration as time goes on? Well I'm sure it's an extremely slow process but can you tell that something is slowing down a little bit or your losing functionality a little more than you use to have?

T: Well I stated to realize after a while that it's not something you really notice because you adjust. I noticed I've had more and more complicated wheelchairs. My trays have had to be raised higher and higher so I can eat, things like that.

C: And what is the extent of your functionality, especially in the limbs, as in what can you move and what can you not move?

T: My ankles still have a little strength in them, and my toes. I can move my legs up and down a little with the ankle. How Limb girdle works is from the central trunk body out. For instance I used to be able to move my fingers and bend them. Now you can see I can only move them a little bit. These ones are getting worse, but the first one is straight I can't bend it at all.

C: So even with your fingers it starts and kind of works its way out?

T: It kind of spreads out mm hmm. It's called limb girdle because it started in the hips and the shoulders and moves out from there.

C: So you still can move your wrists and your fingers to do your daily tasks?

T: Yeah I can get things done, but it's not what I suppose you would call normal. I've learned to keep typing even though I can't bend them right.

C: You can probably type faster than me I type like this.... (Simulated one finger key strokes)

C: What tasks do you have trouble performing on a daily basis?

T: about everything. Let's see. I have help getting me up out of bed. I have a Hoyer lift, not because I'm heavy but what tissues left will tear very easily if I'm lifted manually. I'm moved from the bed to the chair to the toilet, and all that. And I have attendants that come in and get me up, and help me with bathing and bathroooming and dressing and hair. I can brush m teeth with an electric toothbrush though! (Smiles) they have to put the tray on, not without the tray I can't. They do my hair, my makeup. I get lipsticks that are real long so I can put it on myself. My caregiver hands it to me... that's not one thing I'm willing to give up! I finally did give up doing my eye makeup. First preparation of food has to be done for me I can't do that. It has to be cut up.

C: Cut up into sizes that you can stab through?

T: I got a whole crew of girls that work for me. I got about 4 or 5 girls at a time, not all the same time. They take morning shifts or evening shifts or they'll come in during the day for bathroooming and to set my lunch up and that sort of thing. They help me fix dinner when mom's not there so I can feed myself and my Dad.

C: How about when you're with office stuff like when you're here. I notice your keyboard is not the standard looking keyboard, and you have a trackball instead of a mouse. How exactly does that keyboard work?

T: It's concave. Before I couldn't lift my hands up to reach the keys in the back row. I saw this keyboard I think on the internet. I was searching for something. Because I couldn't reach the middle of the keyboard. And I found this one just by going to websites where they have ergonomic keyboards and this one came up. It's concave so it brings all the keys closer together under each hand.

C: So you don't have to move your hands up and down?

T: That's right, I don't move them at all they are right there. It's great I got the same kind of keyboard at home that I got here.

And you can just pull right up to that and your chair slides under that thing and you can get your hands on the keyboard and mouse?

T: The chair slides in and out, then I can get one hand up and use the other one ... (loss of sound on video).

C: Are there tasks that take a while to perform?

T: Eating!

C: I'm guessing yes that there are a lot of tasks. This is kind of what we are trying to solve here, a little bit easier and a little bit faster.

So you do have a care giver, do you have any other assistive devices aside from the Hoyer lift?

T: Breathing...

C: Breathing and your wheelchair is pretty assistive. IS there any specific task that you would like or need a device for? You've seen what we've done so far is there anything else that we can possibly help you out with that we haven't really thought of yet, maybe aside from just lifting your arm straight up? Like a task such as I don't know, like paint?

T: Oh yeah I'd love to be able to use at least one arm to do a lot of things. Shaking hands is another one. People are kind of uncomfortable when they come to meet me, and I can't lift my arm up to them so I usually slide it out. I kind of put it like this and they don't know what to do. It would be kind of neat to be able to throw my hand right out there and be able to shake hands when I meet people. I always have a big smile on my face so it's not a critical thing but eating and reaching things. I'd like to be able to get my own cup of water instead of asking someone to fill it up and put it over where I can reach it.

C: I think that's about it for the questions, oh yeah demographics we just wanted to know your age, and your job.

T: I'm sixty two, and the Assistant Dean of Student Life.

## APPENDIX B

### USER EVALUATION OF PAL DEVICE

FOLLOW-UP EVALUATION  
 Christopher Grasso's Arm-raiser Thesis Project  
 Arizona State University  
 September 10, 2008

The arm-raiser project has terrific potential to help thousands of individuals with severe arm weakness and immobility with activities of daily living such as eating, putting on make-up, shaking hands, reaching, adjusting glasses and something as simple as wiping one's nose! I am an active (retired from ASU in 2005; now own a small bookstore in Tubac, AZ) sixty-five year old female with progressive limb-girdle muscular dystrophy and respiratory insufficiency (ventilator dependent 24/7). I use a motorized wheelchair (Permobil Chairman 2K) for mobility and an adapted tray attached to my wheelchair for eating and working with paperwork (e.g., paying bills, etc).

Although I am unable to move without assistance (personal care givers, family, friends), I still have some use of my fingers. I can type once my hands are placed on my special keyboard. I can feed myself, but it has become increasingly difficult because I must lean against a raised tray with my right arm propped against the edge. A caregiver must lean me forward so that I can use leverage and an adapted, lightweight fork to feed myself. Unfortunately, leaning forward cuts off air from the ventilator so that eating is very tiring. I am unable to wipe my nose. I struggle to answer the house phone, but can more easily answer a cell phone if it is on my lower tray. The house phone is better for communication because my voice is very soft due to respiratory insufficiency and hard-wired phones seem to have better speakerphones! I cannot adjust my glasses; I would like to be able to switch between reading bifocals and computer glasses. I have trouble reaching things on my desk and tray unless they are right near the front edge. Shaking hands is difficult because people are afraid to reach over and pick up my hand. I can't swat flies or mosquitoes away from my face!

Since 2005, Christopher Grasso, with Don Herring's guidance and encouragement, has worked on making the arm-raiser project a reality. In early September of 2008 Chris drove to Tubac, AZ where I now reside, and attached the arm-raiser to my wheelchair, made several adjustments, and trained my mother and two care-givers in the assembly. I have used the arm-raiser all weekend and will continue to use it until Chris comes to pick it up!

### PROS OF THE ARM-RAISER:

1. Able to raise and lower my hand/arm up to my face.
2. Able to feed self in upright position without cutting off my air supply.
3. Able to wipe my own nose!
4. Able to adjust my glasses.
5. Able to answer the phone more quickly and with ease.
6. Able to reach things on my desk.
7. Able to shake hands and wave.

### PROBLEMS WITH THE ARM-RAISER:

1. Unable to type on my special computer keyboard due to angle of arm in the sling; unable to move arm laterally.
2. Assembly is not difficult, but needs to be disassembled and reassembled every time I have to use bathroom or when going to bed (about 4 times a day). (Note: we use a sling and patient lift to take me in and out of the wheelchair; the arm-raiser impedes this process.)
3. Sling is uncomfortable after long use and trying to move my arm more laterally.

### SUGGESTED SOLUTIONS TO PROBLEMS

1. Drill a second hole for positioning the arm-raiser out to the side for easy access to a computer keyboard. It would have to be repositioned by a care-giver, but would be very simple to do.
2. Cut and hinge the lateral pipe in front of the vertical rod that holds the assembly so that it can be folded up and out of the way for egress to and from the wheelchair. This would require temporary release of the spring and artificial muscle which is much easier than complete disassembly of the whole apparatus.
3. To reduce stress on the wrist, hand and arm (trying to move laterally), design a sling that has more stability (e.g., metal or rigid plastic bars) across the top of the forearm with a durable nylon sling under and around the arm, closed at the elbow, so that the arm is supported but not tightly bound.

## SUMMARY

This is a great project that works very well. It is still rough, but it is a well thought-out project that has real potential for thousands of people with muscular dystrophy and other debilitating disabilities. I can hardly wait to demonstrate it for the Muscular Dystrophy Association.

Respectfully submitted by,

Tedde Scharf  
PO Box 4752  
Tubac, AZ 85646  
520-398-9309 (home)  
520-981-7098 (cell)

## APPENDIX C

### SURVEY OF AT AND ADLS FOR WHEELCHAIR USERS

## Assistive Technology and Activities of Daily Living for Wheelchair Users

1.01.08

Dear Participant:

I am a graduate student under the direction of Professor Donald Herring in the Department of Industrial Design at Arizona State University.

I am conducting a research study on assistive devices that aid in the day to day activities of people with living with disabilities. I am inviting your participation, which will involve a ten to fifteen minute survey. Your participation in this study is voluntary. You can skip questions if you wish. If you choose not to participate or to withdraw from the study at any time, there will be no penalty.

My goal is to find similarities in individual limitations and functionality. I want to see which activities are the most troublesome and also which activities people have the desire to do but physically cannot. I am also interested in knowing which devices are being currently used and of those how many are being used for a different purpose than what they were designed to do. Based on this research, I will make design recommendations toward actionable insights for assistive technology. If a product comes into fruition and a prototype is built, you will be the first ones to test it if you would like to. Also, if a device is eventually made (this is not very likely at this stage of research), you will receive it free of charge. There are no foreseeable risks or discomforts to your participation.

I will be storing all paper information under lock and key and all electronic information on a password protected hard drive. Your responses will be kept confidential. The results of this study may be used in reports, presentations, or publications but your name will not be used.

If you have any questions concerning the research study, please contact the research team at: [Christopher.Grasso@asu.edu](mailto:Christopher.Grasso@asu.edu), [Donald.Herring@asu.edu](mailto:Donald.Herring@asu.edu) or (716)909-1429. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Research Compliance Office, at (480) 965-6788.

Return of the questionnaire to [Christopher.Grasso@asu.edu](mailto:Christopher.Grasso@asu.edu) will be considered your consent to participate.

Sincerely,

Christopher Grasso  
MSD candidate, Industrial Design  
Arizona State University

1. What disability(ies) are you currently living with, and how long have you had this condition?
2. How does this condition affect your functionality (limb and body movement)?
3. Do you require special assistance, and if so, for what tasks?
4. How does your limited functionality affect your daily tasks? Are there certain tasks you perform each day that are particularly troublesome?

5. Think of the top 5 daily tasks that are the hardest for you to perform on your own. (Rank them from 1 to 5, with 1 being the hardest).
6. Do you own any sort of assistive devices (no matter how simple or complex) that allow you to complete your activities of daily living (ADLs) faster or easier?
7. Are these devices being used for their intended purpose or have you adapted them to fit your specific needs in any way?
8. Of the devices you own, do any seldom or never get used (if yes, which ones)
9. Have you ever created your own assistive device, or modified a device you purchased? (if yes, to help you with what specific activities)

10. Is there any particular activity that is personal and important to specifically you that you find yourself unable to do?

11. If you were to go out tomorrow and purchase a new assistive device, what would it be and what task would it help you with?

Demographics:

1. What style of chair do you use?
2. What is your age?
3. What is your current occupation (or field of study)?

## APPENDIX D

### MDA CHAT ROOM REFERENCE GUIDE

List of chat room topics:

1. Current physical condition, what disability they are living with, range of motion and how it affects their activities of daily living.
2. What kind of assistive devices or help from others do they use or require daily? Do they own devices they don't use, or create or modify devices to better fit their needs?
3. What are the most troublesome tasks to complete with their condition?
4. Specific tasks that are personal or important to them they can't do but would like to.
5. Are there similarities in difficult task completion that they've noticed they share with other disabled persons?

## APPENDIX E

### YAHOO!® MESSENGER INTERVIEW WITH SUNNY

sunnysunil1960: i try 2 use short forms

Christopher Grasso: sorry my computer just froze

Christopher Grasso: after my last thing i wrote about my 6th email address

Christopher Grasso: i tried to get on as quick as possible

sunil arora: i type slowly

sunil arora: i use onscreen kbd

Christopher Grasso: thats understandable...

Christopher Grasso: mouse pointed?

sunil arora: ya

Christopher Grasso: what time is it in new dehli right now?

Christopher Grasso: its 9:49 pm here

sunil arora: i've been usng patient lifter fr abt 7 yrs

sunil arora: 10.19 am

Christopher Grasso: a lift for transferring between bed and chair?

sunil arora: ya

Christopher Grasso: is your chair power or manual

sunil arora: manual, powerd r 2 expensive 2 affd

sunil arora: \$200 v \$2000

Christopher Grasso: yes they are really expensive. do you require someone to push you or can you use your arms and shoulders enough to power it

Christopher Grasso: even upwards of 10000 here

Christopher Grasso: the ibot chair is 25000

sunil arora: i need 2 b pushd

sunil arora: wow

sunil arora: i cant lift my hands

Christopher Grasso: i believe they make add on powering devices to put onto a manual chair to convert it for cheaper than a powerchair would cost

sunil arora: tht's what is fr \$2000 here

Christopher Grasso: wow

Christopher Grasso: do you have a caregiver 24/7 or a family member help you?

sunil arora: thr's no state-help

sunil arora: i need care-gvr 24/7

sunil arora: parennts can no longr hlp physcly

Christopher Grasso: i see

sunil arora: 68 n 73 yrs old

Christopher Grasso: is BMD a progressive kind, as in is your functionality worsening

sunil arora: yes

Christopher Grasso: do you use a trackball instead of a mouse?

sunil arora: ths yr it's mor difficlt 4 me 2 brsh my teeth thn it ws last yr

sunil arora: i use mouse

Christopher Grasso: thats kind of what my research is on... activities of daily living

Christopher Grasso: things such as teeth brushing, eating, grooming, or any other daily things that you find difficult

sunil arora: and 4 ppl w/prog. disab needs keep chngng

Christopher Grasso: what would you describe your functionality as, like what can you move still?

Christopher Grasso: yes this is true...so a device may not be able to be used in a year or two

sunil arora: i've some hand novmnt like i cn write 2 a4 sheets

Christopher Grasso: take your time i know i type fast sorry

Christopher Grasso:

sunil arora: np

sunil arora: but i cant tk a glass up my mouth

Christopher Grasso: how do you brush teeth or eat if you cannot lift your arms?

sunil arora: i cn use mouse

Christopher Grasso: drink i bet you have long straws

Christopher Grasso: +

sunil arora: i tk supp of wash-basin n i bend my neck a bit

sunil arora: for eating i use a small on bed table

sunil arora: long straws n long spoons

Christopher Grasso: do you have any assistive devices now such as grabbers or things of that nature

sunil arora: whn i'm on w/c i put a round pillow on my legs

sunil arora: no dvices lik tht. all home solutins

Christopher Grasso: those are the kind im interested in.. home made stuff that you cant buy in a store... things you may have made out of a broomstick and a rubber ball or something like that

Christopher Grasso: just hypothetical

sunil arora: my yngr bro also hs md n his condtn is wors thn mine

Christopher Grasso: also BMD?

sunil arora: ppl in devlpng counris mosly usthose thgs

sunil arora: ya

Christopher Grasso: i actually got a book on assistive tech for developing countries while doing this research... using local supplies and low tech stuff to accomplish tasks

sunil arora: earlier we used thn walkng stck for usng elect. sitches

sunil arora: switches

sunil arora: my hnd is gvg way now

Christopher Grasso: i like the shorthand youve adapted... i can understand it well

sunil arora: i'll b bk aftr 2 hrs. may b u r awake till thn

Christopher Grasso: i should be or maybe tomorrow... thank you so much for your help.

sunil arora: yw

sunil arora: bye 4 now, tc

Christopher Grasso: i like meeting new people.. especially so far away... bye!!!

## APPENDIX F

IRB LETTER OF EXEMPTION; IRB LETTER OF REVIEW NOT REQUIRED



Research Compliance Office  
Office for Research & Sponsored Projects Administration  
P.O. Box 873503  
Tempe, AZ 85287-3503

**Phone**  
**(480) 965-6788**  
**Facsimile**  
**(480) 965-7772**

**To:** Donald Herring  
AED

**From:** Mark Roosa, Chair  
Institutional Review Board

**Date:** 10/11/2007

**Committee Action:** **Exemption Granted**

**IRB Action Date:** 10/11/2007

**IRB Protocol #:** 0706001956

**Study Title:** Assistive Technology and Activities of Daily Living for Wheelchair Users

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2) .

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.




Research Compliance Office  
Office for Research & Sponsored Projects Administration  
P.O. Box 873503  
Tempe, AZ 85287-3503

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(480) 965-6788  
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**To:** Donald Herring  
AED

**From:**  Debra Murphy, Director  
Research Compliance Office

**Date:** 12/21/2007

**Committee Action:** **IRB Review Not Required**

**IRB Action Date:** 12/21/2007

**IRB Protocol #:** 0712002427

**Study Title:** PAL: the Pneumatic Arm Lift

The above-referenced protocol has been reviewed and it has been determined that IRB oversight is not required because the study does not meet the criteria under Federal Regulations, 45 CFR Part 46 for research involving human subject participation..

You should retain a copy of this letter for your records.

## APPENDIX G

### Letter of Consent for Participation in Class Project

I, Tedde (Edna M.) Scharf, give Donald Herring, Associate Professor of Industrial Design, and Christopher Grasso, MSD student in Industrial Design, permission to work with me on the design and testing of an assistive device to raise my arm to perform simple daily living tasks such as eating.

Signature: Tedde (Edna M.) Scharf  
Date: January 21, 2005