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February 24, 2016

Mid-Atlantic CIO Forum
C/O Mr. David Powell
7400 York Road, Suite 407
Towson, MD 21204

Dear Mr. Powell,

Thank you for your long history of providing financial assistance and scholarships for many of our brightest and most worthy students. Just as importantly thank you for the support you give to the overall university, Dave Vanko, the Fisher College of Science & Math and the Computer Information Sciences Department in particular.

In accordance with your Grant Policy outlined on your website, I hereby humbly submit for your review and perusal the attached detailed grant request in the amount of $10,000 for the spring of 2016.

Below is the grant request summary:

Contact Information:
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150 years

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Project Description – Objectives / Goals
The immediate objectives / goals of the project are to help children with severe disabilities more easily communicate, control their environment and navigate while sitting in a wheelchair.

Project Costs – We anticipate total year one (2016) cost of $30,000. $10,000 of which will occur in the spring, 2016.

Projected Outcomes: The projected long term outcomes are that children with severe disabilities will be able to more easily communicate, change and control their environment, ultimately significantly improving their quality of life.

Project Schedule: The project is underway and we expect to conduct the first stage of a user study in 2016, begin to deliver results in 2017, and disseminate findings to the community and apply results to other health conditions in 2018.

We trust that the attached detailed grant request defines and points out the need and makes a worthy case for funding. More importantly we are confident that it supports the Mid Atlantic CIO Forum's mission and purpose of fostering information technology, innovation, and STEM in an academic environment.

Thank you in advance for your consideration and for your contributions of knowledge and experience to the overall community and continued financial generosity.

Most Appreciatively,

Ron Brown
Director, Corporate Relations

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A Multi-modal Communication/Support System For Young Children with SMA

Prepared by:
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Heidi Jinjuan Feng[1]

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[2] Department of Occupational Therapy and Occupational Science

I. Overview

What is SMA?

Spinal Muscular Atrophy (SMA) [8] is a rare genetic disease affecting approximately 1 in 10,000 babies (750,000 worldwide), yet it is the #1 genetic killer of infants and toddlers [1]. SMA affects an individual's motor neurons in a range of ways depending on the particular type; people with SMA are often unable to walk, many cannot sit up unassisted, and (in the most severe forms) are unable to eat and breathe. Although researchers have identified the gene that causes SMA, and potential parents can be screened to find out if they are a carrier, there is currently no known treatment or cure [1].

Who is Max?

Max is a two and a half year old child with SMA Type I, the most severe form. He and his parents (Yahnatan and Kristen) live in Derwood, Montgomery County, Maryland. While he is fully intact cognitively, Max is unable to function independently in many domains. He uses a tracheostomy tube and ventilator to breathe, and requires assistance to sit and to hold his head up. Max wears an exoskeleton and other assistive/mobility devices to help him utilize his minimal movements (due to extreme muscle weakness), and must have 24-hour supervision to monitor his vital signs. Despite these challenges, Max and his family, together with a large and dedicated team of physicians and therapists, have made incredible strides toward making Max's life as "typical" as possible. Max enjoys looking at books, listening and dancing to music, watching his pet fish, playing with playdough and puzzles, and going outside to the park and the zoo.
This video shows the daily life of Max: https://www.youtube.com/watch?v=dUAbRXkWeuo
This video shows Max playing with toys through an ultralight switch:
https://youtu.be/fVeojGWhmyc

Why this project?

Dr. Amanda Jozkowski (Towson University Department of Occupational Therapy) began treating Max when he was approximately 6 months old. In talking with his parents, Amanda found that one area they are struggling with is helping Max to communicate and control his environment as desired. Max's parents spoke about his intelligence and obvious desire to interact and engage with the world, but they felt that he was completely dependent on others for all aspects of his care and participation. They envision Max as being able to independently participate – for example he might wake up, call for his mother, turn on the lights in his bedroom, and then select and start playing a computer game while he was waiting to be fed. Currently, to perform these tasks, Max would need someone to notice he was up, turn on the lights for him, ask him what he wanted, set up a communication device or attempt to interpret his vocalizations (he is unable to form words due to low facial muscle tone), bring over a switch-adapted toy or computer tablet, hook up his hands and position everything correctly, and then stay with Max to make sure everything is in place and usable. Max is not capable of repositioning devices by himself if they are moved. In addition, many of the products currently available require too much force for Max and other children with SMA Type I to actuate, or they are not as sensitive and accurate as needed for the desired applications. Max's family and his care team feel very strongly that he has the potential and the underlying capacities to be able to operate devices such as an eye-gaze communication system, a power wheelchair, a personal environmental control system, etc. yet have not been able to identify appropriate devices to fit his unique constellation of needs at this time. While Max's family is incredibly talented and devoted to trying new ideas, adopting emerging technologies, and even programming their own equipment, they feel extremely inadequate when it comes to advanced or new technology.

The challenge in communicating with other people and controlling the environment is faced by most children with SMA Type I. Many parents of those children are eagerly looking for solutions. Max's father, Yahnatan, is one of the leaders in the SMA community for technology adaptation and adoption. He is actively involved in two Facebook groups: the SMA Adaptability and SMA Support System groups. The solutions developed and the lessons learned through this project will be readily disseminated to the SMA community through the Facebook groups and other connections of Max's parents.

II. Project objectives:

Dr. Jozkowski contacted Drs. Feng and Tang in the Department of Computer and Information Science at Towson University forming a team to address the problems outlined above. Together with two graduate research assistants (in Computer Science and Speech/Language Pathology), this group has committed to working with Max's family to help them develop solutions to make Max more independent in his daily life. The following is a brief outline of the goals of this project, which were developed in collaboration with Max's family, as well as input from other families in the global SMA community.

The team hopes to develop and test a wearable system/device that would allow Max to:

(1) more easily communicate
(2) control his environment including light, temperature, and entertainment/play options
(3) navigate while sitting and control his power wheelchair

The most important and unique characteristics of this device are that it is:

A. Customizable (i.e., can be modified/adapted for others with SMA Type I and similar disorders)
B. Affordable/accessible to people in the SMA community
C. Usable (does not take more than 5 minutes to set up and can easily be understood and modified by families who are not technically trained)
D. Durable
E. Responsive/sensitive
F. Accurate
G. Allows for maximal functional movement patterns (i.e., palms of hands are not obstructed so they can still be used for play)
H. Improves quality of life and meets the needs of very young children (approximately 18 months-5 years), for whom very few therapeutic products currently exist

III. Related work

Existing research on young children with SMA Type I is quite limited. No directly related work was found from the assistive technology and accessible computing field that examines how to use information technology to help these children communicate with other people or control their environment. A limited number of studies examined customized systems for teenagers with Duchenne Muscular Dystrophy [8, 10]. However, the target users in those studies possessed significantly higher physical capabilities than young children with SMA Type I. Similarly, there are studies that investigated more accessible wheelchair control systems for people with disabilities [4]. But the target users are all adults with much stronger muscle power, larger range of motion, and more accurate control of their movement as compared to children with SMA Type I. From the occupational therapy perspective, studies have been conducted to investigate the factors that affect the adoption of general assistive technologies [5]. However, no directly related assistive communication and support system for children with SMA Type I has been reported. Although advanced technologies have been utilized to sustain the life of these children and, in many cases, improved their quality of life, the fundamental need of independence and active participation in their everyday activities have not been addressed.

IV. Proposed solution

Due to severe muscle weakness, most children with SMA Type I have minimal movements in their limbs or heads and cannot speak. Therefore, they are not able to communicate with other people or the environment through the typical approaches (e.g., speaking, traditional switches or remote controls, traditional input devices such as the mouse, keyboard, touchscreen, etc.). However, most children with SMA Type I have normal voluntary eye movements that allow them to interact with eye-gazed based applications. Most of them also have limited but voluntary finger and arm movements that may allow them to use special ultra-sensitive switches. In addition, many children with SMA Type I, including Max, use medical devices that continuously track their vital health data such as heart rate, blood pressure, and blood oxygen level. Those key vital health data may be used to examine the user's current state and help make more informed decisions. Thus, we propose a multi-modal support system that integrates data from different sources and provides a user-friendly communication solution designed to fit the unique challenges for children with severe SMA Type I.

System architecture

The architecture of our proposed system is described in Figure 1. The system input data can be divided into passive and active categories and the output is used for providing three services, namely environment control, mobility control and communication.

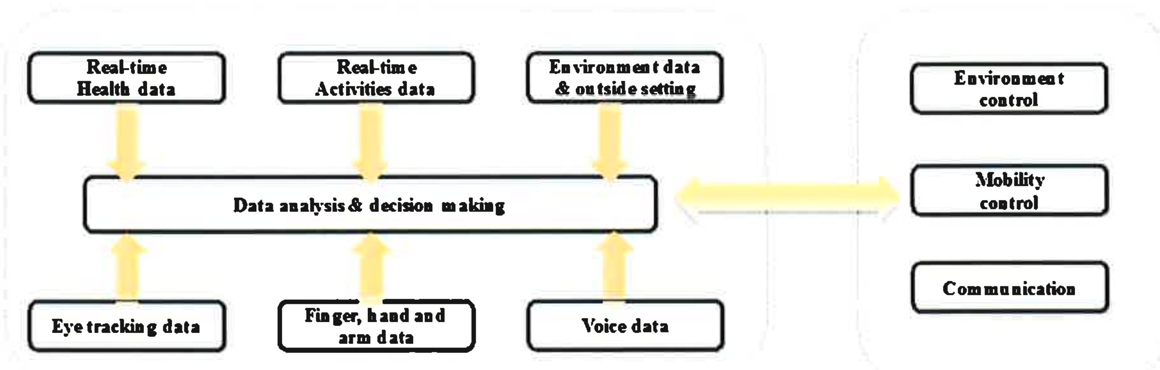

Figure 1. System architecture of the proposed solution

Passive data input

Passive data, including health and activities information, can be used to decide users' current status. That can be acquired from various devices such as traditional heart rate monitor or wearable devices. Due to the special physical conditions, the vital health data of children like Max are monitored continuously. In our system, we would like to explore commonly monitored health data such as blood pressure and heart rate.

Moreover, environmental data and external settings will be included as passive data input too. For example, the current room/location (e.g. bedroom, playroom, or gym), current time and pre-defined personal schedule will be recorded automatically in the background to help analyzing users' needs. In addition, we will also track wheelchair moving speed, obstacles around users and other similar data to better understand user status.

Active data input
Even though children with SMA Type I have very limited physical capabilities, their voluntary movements are the most important and valuable interaction channel. Considering the physical conditions of the children, we will focus on collecting three types of user data, namely eye movements, finger/arm movements, and vocalization.

Data output
Given the passive and the active data inputs, data analysis and decision making module' will use machine learning technology to determine the user status and provide services from the following three aspects.

Environment control
The proposed system will allow users to have some control over their environment. In the current stage, we would like to focus on the basic controls such as turning on or off the lights or TV. Some automatic controls will be considered. For example, when the current time has passed the typical wake-up time of the child and the system detects that the child is awake, the display screen can be turned on automatically and ask the child whether he would like to turn on the light or pull up the curtain. Environmental control will also allow users to change their location. For example, the child can choose to go to the gym room after staying in the living room for some time.

Mobility control
With limited physical capability, people with SMA largely depend on their wheelchairs to achieve mobility. Therefore, mobility control is a very important service we would like to support through the system. Even though there are many advanced wheelchairs available, it is still very challenging for children with SMA Type I to use them because of safety concerns and the precise positioning required to operate the wheelchairs. In this project, we will explore the possibilities of using data from multiple sources (e.g., EEG, voice, eye and finger movements) to improve the accuracy of the control. Similar to environmental control, we will consider some automatic control in this service as well. For example, if the system detects the wheelchair speed is too fast, it will automatically slow it down.

Communication
As the most important service component, assisting communication of children with SMA Type I is the key module of the proposed system. We will utilize both passive and active data from multiple sources to understand user intentions. In the first stage of the study, we will focus on three main categories, namely self-care, play, and environmental control. For example, if Max wants to play with a puzzle with his father, the system should be able to allow Max to easily specify 'puzzle' from the 'play' category. Alternatively, Max may need to be repositioned or wish to request suctioning of his airway, so he can select these options from the 'self-care' menu. We will use a Visual Scene Display (VSD) to embed the language concepts within the Augmentative and Alternative Communication (AAC) system. A VSD is a visual scene such as a photograph or picture that depicts or represents a situation, place, or experience for a child. For young children, grid layouts impose more metalinguistic demands that are beyond their skill levels [6]. When language concepts are represented within a context, it allows the child to generalize new vocabulary and find target vocabulary faster and easier, while also reducing metalinguistic

demands on the child [7]. Literature supports the fact that VSDs are beneficial for young children and can be modified to fit the child's specific needs. Hot spots and specific vocabulary concepts can be easily adapted and are simple to learn in relation to a photograph or picture that the child is familiar with. We propose to first address the areas of self-care, environmental control, and play for Max's system, and will then expand to other functional areas as he learns and his needs change.

Technological challenges and system functionalities

In order to develop a low-cost, customizable, user friendly and effective support system, we will explore various possibilities focusing on the following three aspects.

1. Real-time data tracking and integration: Health and activities data are tracked and recorded automatically and continuously for children with SMA Type I. Those data need to be exported to a central system and integrated with other data for further analysis. In addition, active user data such as eye, hands and finger movements need to be tracked and recorded. We will use image based computer vision technologies to build a non-intrusive tracking system. Moreover, infrared and sensor based tracking technologies will also be explored. Considering the physical conditions of our target users, we will also study how to use body sensor network to acquire accurate and detailed motion data. To make our system easily accessible, we will explore some existing tracking systems such as Wii, Tobii, and Makey Makey.

2. Data analysis and decision making: When data are collected and recorded in a central server, we will analyze them and make real-time decisions on user intention and the desired response. We will investigate various decision making algorithms to identify the most accurate and efficient algorithm for the proposed solution. Specifically, we will consider adopting mathematical models and methods widely used in recommendation systems to build our data analysis and decision making module. In addition, data related to how users with SMA Type I interact with the proposed system will be recorded and analyzed to improve the accuracy of the decision module.

3. User friendly application and interface design: The mobility of children with SMA Type I is already limited due to them being tethered to medical devices. Therefore, in order to make a convenient and user friendly system, we will examine how to make the proposed system less intrusive while maintaining high computational power to process the data constantly. We will follow the client server architecture and evaluate tablets, mobile devices and various sensors that can communicate with a local server. Communication through wireless or Bluetooth will be explored.

V. Development and evaluation plan

The entire project cycle is listed in Figure 2 below and the 1st year tentative plan for system development is described in Figure 3. The preliminary project timeline is listed below. Note that user participation and design evaluation is closely integrated in every development stage.

Year 1	Year 2	Year 3
• Understand user population • Review literatures • Explore new research approaches • 1st stage system development • 1st stage user study	• 2nd stage system development • Web-based service development • 2nd stage user study • Deliver results to SMA community	• System finalization and evaluation • Refine and generalize results to other health conditions

Figure 2. Project cycle

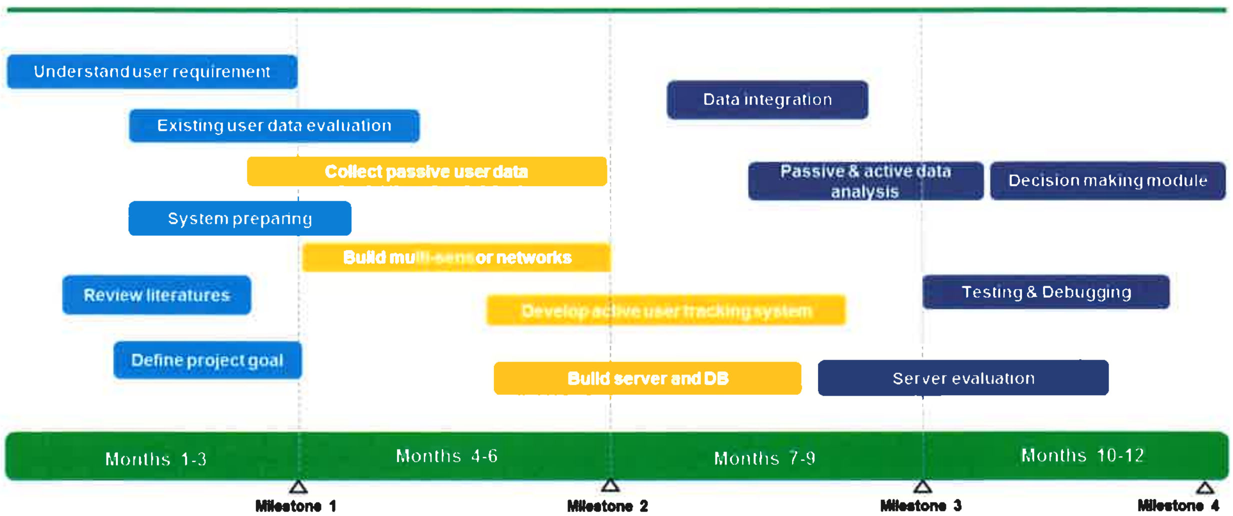

Figure 3. 1st year tentative project plan

VI. Significance of work

The proposed research will advance our understanding of how to help children with severe disabilities (SMA Type I) in particular) gain more independence through information technologies. The proposed system will provide a better match between the demands of the tasks and the abilities of the user, and accordingly, can lead to increased accessibility and more effective solutions. The main benefits of the proposed solution include:

- The system will allow Max and other children with similar conditions to communicate with people and control their own environment, which is crucial for independent living;
- This system bears much lower cost compared to existing commercial solutions that only support one fragment of the proposed activities (e.g., commercial eye-gaze applications cost several thousand dollars);
- This system will be available to assist the user 24 hours a day, 7 days a week;
- This system is highly flexible and customizable. Caregivers and therapists could update related data such as schedule or specific settings whenever needed.

The proposed research is particularly innovative and compelling because:

- Although children with SMA Type I are fully functional cognitively and have the ability to engage in various activities when appropriate support is available, the needs and abilities of this group of individuals have received little attention in the assistive technology field.

- The idea to use contextual information and a multimodal solution to support children with SMA Type I is an innovative solution with great potential. Our approach will take into consideration comprehensive contextual and task related information to enhance decision making and improve accuracy.
- Our results may lead to new context-aware, multimodal assistive solutions for other user population such as patients with ALS (Amyotrophic Lateral Sclerosis), cerebral palsy, spinal cord injuries, myasthenia gravis, and muscular dystrophies.

From the occupational therapy perspective, in the joint statement on the occupational therapy research agenda, the American Occupational Therapy Association (AOTA) and American Occupational Therapy Foundation (AOTF) emphasize the need for applied and translational research to develop and disseminate therapeutic interventions that: (a) Are client centered (i.e., personalized); (b) use the environment as the method of change; (c) are theory-driven; (d) are structured and replicable; and (e) involve a "priority population" of concern to society and the field of occupational therapy [1]. The proposed project addresses each of these aims, in that:

(a) The multi-modal communication/support system will be developed in response to a need articulated by the client/community, and will be designed so that components are modifiable to the individual user. For example, the wearable apparatus may be adapted to fit the unique size, skin integrity, and positioning needs of each child. Additionally, the visual feedback screens can be adapted to each user's personal environment and interests.

(b) By allowing the client better access to control of his or her environment, and by lessening the burden on caregivers for direct support, independence and functional communication will be enhanced.

(c) We have drawn on constructs from computer science, occupational science [9], developmental/learning theories [2], and ecological/systems approaches [3] to focus and justify the project considerations.

(d) Our dissemination plan, which includes not only scholarly presentation and publication, but implementation of open-source sharing of the technology with the community through a user-friendly website, will promote translation (i.e., taking up of the ideas in practice) and generalization of the product to other relevant populations.

(e) Priority populations, as outlined by the AOTA, include individuals with physical impairments, such as Spinal Muscular Atrophy, the target of this project. We anticipate that in the future, the proposed system will be effective for other populations who experience severe limitations in communication and mobility such those 47.5 million people worldwide who are living with ALS, cerebral palsy, spinal cord injuries, myasthenia gravis, and muscular dystrophies.

VII. Project personnel

The proposed research is highly interdisciplinary and requires knowledge and expertise in occupational therapy, computer hardware and software development, human computer interaction, assistive technology, and multimedia interface. The research will be completed by a collaborative team consisting of two faculty members from the Department of Computer and Information Sciences (CIS) and one faculty member from the Department of Occupational Therapy and Occupational Science. The team has extensive experience in all related areas and has strong potential to attract external funding. In addition, a doctoral student from the CIS Department and a graduate student from Audiology - Speech-Language Pathology and Deaf Studies program of Towson University will be fully engaged in the project. A brief summary is provided below regarding the qualifications and responsibilities of the team members.

Dr. Katherine Ziying Tang is an Assistant Professor of Computer and Information Sciences at Towson University. She received her Ph.D. in Computer Sciences from University of Texas at Dallas. Her research interests include multimedia systems, computer graphics and computer version, human computer interactions, and mobile health. Her previous experiences in multimedia, rehabilitation game and autism assistant study will be very helpful for building the proposed system to the target population. She will be actively participating in all aspects of the project, especially in system building and testing.

Dr. Amanda Jozkowski is an Assistant Professor of Occupational Therapy and Occupational Science at Towson University. She received her Ph.D. in Occupational Science from the University of Southern California. Her research interests include the use of novel and emerging technologies to enhance health and well-being for individuals with Autism Spectrum Disorders, developmental disabilities, and physical limitations. Her dissertation work focused on the use of active motion-capture video game systems ("exergaming") with young adults on the Autism Spectrum, and relationships between video game play and sociality and physical activity. Her primary roles in the project are to coordinate communication with the family, and contribute to the design of a wearable and usable device from a functional perspective. Additionally, Dr. Jozkowski will provide input on the theoretical approach for the project using an occupational justice and health framework.

Dr. Heidi Jinjuan Feng is an Associate Professor of Computer and Information Sciences at Towson University. She has a Ph.D. in Information Sciences from UMBC in 2005. Her research focuses on human-centered computing and has been studying the use of IT by individuals with disabilities for a decade. She has extensive experience conducting user studies and working with people with disabilities. She initiated and is actively working on a number of projects that use information technology to help people with cognitive disabilities in learning, independent living, and career development. Her research has been supported by grants from the National Science Foundation, the National Institute on Disability and Rehabilitation Research, and other institutions (total amount of more than one million). She will contribute to designing the system and application functions and interface, conducting evaluation studies, as well as data collection and analysis.

Sheng Miao is a doctoral student in the Department of Computer and Information Science. He has a bachelors' degree in Electrical Engineering and his doctoral dissertation topic focuses on applying machine learning technology to make more informed decisions in computing applications. Sheng's experience in both hardware and software development will be very valuable to the project.

Molly Lichtenwalner is a graduate student in the Speech Language Pathology and Audiology. Molly completed an honors thesis at the Pennsylvania State University on the effects of AAC stimulation on the dorsolateral prefrontal cortex and conducted independent bilingualism research abroad. Molly's experience working with Augmentative and Alternative Communication devices and studies related to understanding speech patterns at the neurological level will greatly inform the project.

References

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Appendix 1. Budget for CIO Forum grant (Spring March, 2016 to May, 2016)

<u>Salaries and Wages</u>	
Doctoral student support 20 hours / week,@ $15/ hour for 9 weeks (20 X $15 X 9 = $2700)	$2,700
Graduate student support 10 hrs. / week, @ $15 / hour for 8 weeks (10 x $15 x 8 = $1200)	$1,200
FICA at 8% ($3900 x 8% = $312)	$312
Total Salaries, Wages and FICA	**$4,212**
<u>Student Training and Travel</u>	
Training	$1,200
Travel: 11 roundtrip visits to patients' home at $ .54 / mile x 101 miles (11 x .54 x 101 = ($599.94)	$600
Total Training and Travel	**$1,800**
<u>Materials and Supplies</u>	
Eye tracking system	$3,000
Multiple sensors system	$1,000
Total equipment and supplies	**$4,000**
Total Cost	**$10,012**

Appendix 2. Budget for potential CIO Forum grant (Fall / September, 2016 to January, 2017)

Salaries and Wages	
Doctoral student support 20 hours / week,@ $15/ hour for 19 weeks (20 X $15 X 19 = $5,700)	$5,700
FICA at 8% ($5700 x 8% = $456)	$456
Total Salaries, Wages and FICA	**$6,156**
Travel Travel: 14 roundtrip visits to patients' home at $ .54 / mile x 101 miles (14 x .54 x 101 = ($)	$764
Total Travel	**$764**
Materials and Supplies	
User end interaction system	$2,200
Materials and others	$1,000
Total equipment and supplies	**$3,200**
Total Cost	**$10,120**

Appendix 3. Budget from TU Fisher College Endowment Fund (January, 2016 through August, 2016)

Salaries and Wages	
Doctoral student support 20 hours / week,@ $15/ hour for 18 weeks (18 X $15 X 20 = $5400)	$5,400
FICA at 8% ($6,000 x 8% = $456)	$432
Total Salaries and Wages	**$5,832**
Equipment and Supplies	
Hand finger tracking sensors	$1,500
Environmental sensors and software	$1,500
Materials and others	$1,000
Total equipment and supplies	**$4,000**
Total Cost	**$9,832**

Appendix 4. Possible hardware and software candidates:

1. Eye tracking system:
    a. Tobii eye gaze developer's software and hardware,
    b. Surface Pro (or similar) tablet, etc.
2. Hand finger tracking system:
    a. iPhone,
    b. XBox Kinect sensor,
    c. MiMu gloves setup (http://dev-blog.mimugloves.com/materials/ $500)
3. Multiple sensor system:
    a. Sensel Morph + developer pack ($300),
    b. Fabric stretch sensors (http://www.kobakant.at/DIY/?p=210 $50)
    c. Light touch pressure sensors ($25 http://www.kobakant.at/DIY/?p=5210),
    d. Capacitative touch sensors ($25 https://www.adafruit.com/products/1374),
    e. Long and short bend sensors ($50 https://www.adafruit.com/products/182),
    f. Ultra Light switches ($100 https://www.enablemart.com/atec-ultra-light-1-hd)
4. user end interaction system:
    a. Makey Makey ($50),
    b. Arduino ($50),
    c. 50" flat screen TV ($400),
    d. Ultra sensitive joystick/mouse system ($750, for example: http://sensoryguru.com/product/wheelchair-joystick-mouse/)
5. other materials:
    a. Stands/clamps/holders $150,
    b. Wearable hand-mounting materials (includes strapping, padding, outriggers, tools, and splint-making material $500).