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RESEARCH ARTICLE

A 55 QUESTION SURVEY AND FOCUS GROUP TO DEFINE TECHNOLOGY, HEALTHCARE AND NAVIGATION NEEDS FOR THE BLIND AND LOW VISION.

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Abstract:

Through the introduction of a variety of innovative technological devices, the independent travel experience for people who are blind or have low vision can be exponentially enhanced. To address this dearth of information, an online survey was developed with the assistance of the National Federation of the Blind to assess specific issues in the healthcare and navigation spaces for the Blind Low Vision [BLV], which has not been adequately addressed in existing surveys. The Survey included fifty-five questions in total, which included topics such as navigating obstacles, indoor and outdoor injuries, and access to healthcare. The results of the [herein referred to as the Survey] results are detailed within this paper. Following the Survey, three moderator-facilitated telephonic Focus groups were held with NFB to further validate and drill down on the Survey details, which will be used to design, develop, and test prototype concepts for the BLV.

Key Words:- Blind and or Low Vison [BLV], general healthcare and navigational needs survey, cane technology, collaborative research, ableism.

Introduction:-

Technology creates opportunities for people to travel and access information in dynamic ways that significantly increase their productivity and quality of life. This is especially true for people who are Blind or have Low Vision [BLV]. The implementations of strategies that allow greater independent access to information make it possible for blind people to live, work, and play as active members of their communities. For centuries, blind people have used the white cane effectively as an orientation and mobility tool, and it continues to be a fundamental independent travel tool of the blind today. There is a critical need for the research and development of navigation and orientation aids to ensure that BLV individuals maintain a level of independence in this evolving world of rapid technological development. However, it is important to first query the BLV on what their needs are before enhancement of current tools and technology can be developed. Unfortunately, this approach has been underused and therefore the recent technology that is being developed often does not address the very needs of the population it was intended for. Moreover, existing surveys soliciting BLV's input on their general, navigational and healthcare needs are lacking and therefore TRF's reached out to National Federation of the Blind Jernigan Institute [herein referred to as NFB] to develop such a tool. The Therapeutic Research Foundation [herein referred to as TRF] is a 501c3, non-profit company that was founded to bridge the gap between industry and academia to meet unmet healthcare needs. Currently, they are exploring novel approaches to meeting the unmet navigational and healthcare needs of the BLV.

According to the World Health Organization [WHO] (2014), there are 285 million people who have low vision and 39 million who are blind worldwide. In the United States [US] alone, according to the American Academy of Ophthalmology [AAO] (2011), more than 3.6 million people over 40 years of age have low vision, and more than one million people are identified as being legally blind. The global cost of vision loss is nearly 3 trillion dollars in direct and indirect costs. Direct costs equal $2.3 trillion which include medical costs for diagnosed disorders, medical costs attributable to low vision, medical vision aids, vision assistive devices and adaptations, and

direct services including special education and assistance programs (Gordois et al., 2012). Indirect costs include productivity losses, long-term care, informal care, and the costs of transfer and entitlement programs (Gordois et al., 2012). Those who are blind or who have low vision that cannot be corrected with current technology are likely to face different limitations than individuals with functional vision and are likely to have more limited opportunities to earn an income which will further limit their choices in life (Frick, 2012). For this reason, TRF is committed developing safer and more efficient means of navigating, via new and promising innovative solutions, hoping to decrease the US annual health expenditures of the BLV while increasing choices that create opportunities for their improved quality of life.

Note: The term "blind" is used in its broadest, sense to mean persons who are blind, deaf-blind, or have low vision. In some instances, Blind and Low Vision [BLV] is used as a concession to replace the use of Blind and Visually Impaired [BVI].

Material and Methods:-

Review of the current technologies/devices revealed a lack of information on specific needs of the BLV persons as some experts failed to gather evaluations and feedback from the intended users. Therefore, TRF's designed a comprehensive fifty-five question survey in collaboration with NFB to identify and address the gaps in current technology (Lewis, 2015). The Survey tool consisted of three sections: general (including demographics), navigation, and healthcare. The State of Connecticut Department of Rehabilitation Services Bureau of Education and Services for the Blind [BESB] provided additional feedback. Then, NFB distributed the Survey to its nationwide network of 50,000 blind members (2015). Following completion of the survey, a brainstorming session was held with NFB to further drill down on the Survey details. Following preliminary analysis of the online Survey findings TRF's, and NFB moderator-facilitated telephonic focus groups were conducted with fifteen NFB volunteers.

It is important to note that BLV individuals participated as collaborators in the development and execution of the research, not just as research subjects. This proved helpful in the development of the survey questions, as well as, interpreting the responses to the survey questions and the feedback from the focus groups. Insightful aspects of everyday challenges of the BLV were discovered, which would aid in design, development, and testing prototype concepts.

Results:-

Three hundred seventy-seven NFB members [herein referred to as respondents] completed the Survey over a one-month period. Note that respondents participated in survey without any incentive or remuneration offerings. The results of The Survey are described in detail below. The total number of respondents varied from question to question as they had the choice of opting out of any question they did not want to answer but still complete The Survey.

Demographics

In the Survey, 97% of the respondents answered the question regarding their fluency with reading and understanding English of which the clear majority, 99% answered 'Yes,' indicating that they knew enough English to complete the survey.

Specific to age, 94% of respondents answered the question, and of these, 3% were less than eighteen, 9% were between the ages of eighteen to twenty-four, 32% were between the ages of twenty-five to forty-four years old, 44% were between the ages of forty-five and sixty-four and 12% were above the age of sixty-five. In summary, the majority (76%) of our respondents were between the ages of twenty-five and sixty-four. Gender was similar in distribution to the general population; across the 92% of respondents who answered this question, 45% were male and 55% were female.

Additionally, regarding ethnicity, of the 88% of respondents, 81% were Caucasian, while the remaining 19% included African American, Hispanic, Asian, Mixed, and 'Other'.

General:-

Together, of the 92% of respondents, 98% were BLV. Of the 90% of respondents, 66% noted that they had been blind since birth. Respectively, 31% of respondents noted at what age they lost their vision, 12% were younger than three, 40% were between four and seventeen, 13% were between eighteen to twenty-four, 20% were between twenty-five and forty-four, 14% were between forty-five and sixty-four and 1% were above the age of 65.
It was noted that of the 89% of respondents, 47% made acknowledgement to having some form of visual capacity (i.e. light, color, perception). These functional limitations are often used to support misguided assertions of incapacity and the need for medical interventions. We recognize them as instances where alternative blindness skills and/or access technology would be beneficial toward assisting the BLV to maintain or increase their independence and quality of life., working with the NFB, is seeking to identify and develop innovative tools to meet the unmet navigational and healthcare needs of the BLV.

Magnifying Aids/Computer/Tablet/Phone

30%-40% of the survey respondents used magnification tools. Regarding use of a computer or tablet, of the 84% of respondents a resounding 97% answered 'Yes'. In particular, of the 81% of respondents, 99% indicated that they had access and utilized the internet. This information, coupled with 75% of the respondents who replied that they use tools and/or special software regularly, speaks to the importance of this type of medium for the BLV, perhaps more than any other medium that precedes it. Although thirty-nine distinct types of tools/software were cited, the three most common included JAWS, VoiceOver and Braille displays, which matches the survey results from Web Accessibility in Mind [WebAIM] (2014). Moreover, this highlights that the BLV are using computers, as well as mobile devices, and reinforces the need for non-visual access, including Braille, to digital information.

With the proliferation of access technology, it can be difficult to discern what technology is being used and how it is being used. The Survey questions relied on the respondent to be knowledgeable of their specific technology to respond to the question appropriately. Because the survey was an online survey that required some degree of experience with access technology to complete it, many of the answers are likely correct. The caveat is that access technology nomenclature will occasionally use product names as generic. As a result, it can be difficult to determine whether the user is using JAWS as their screenreader, or is using "JAWS" as a generic term while referring to a different product. JAWS has long been the most prevalent screen reader, and screen reader users have on occasion referred to their screen reader as JAWS much like the average person would state that they use Kleenex regardless of what tissue they use. With the assistance of NFB access tech specialists, TRF was able to gain greater clarity in how to interpret this data while preparing this report. Yet, in retrospect, it would have been helpful to ask additional questions to determine the level of access technology training the respondents had received to better evaluate the answers to the survey questions related to use of computers and screen reader technology.

Lack of consideration to the development of accessible websites and mobile apps continues to limit the ability of the BLV to take advantage of these emerging interfaces. Of the 77% of respondents, 57% reported that they avoid websites that they would otherwise access because of their inaccessible design. To that end, 35% of the respondents reported Amazon, Facebook, and Google as the most difficult sites to access. Importantly, the aforementioned sites align with most commonly used sites illustrated by the Alexa Poll (2016). In the same respect, of the 60% of respondents, 93% downloaded apps. Unfortunately, it was reported that these apps generally functioned as expected less than 50% of the time. Problems arise when design and development are done without BLV accessibility in mind, which further speaks to the need for improving the existing design barriers of current technologies. As depicted in Abeele, de Cock, & Roe (2012), albeit the internet and mobile apps are useful tools at times for the BLV, the original design was for individuals with functional vision and therefore, satisfaction gained from the internet was limited as different barriers hindered nonvisual use.

With respect to phones, of the 82% of respondents 95% used a mobile phone. Hence, of the 77% of respondents, 80% used a smartphone and of the 62% of respondents, 83% named iOS (iPhone, iPad) as the most popular operating systems utilized.

Home/Living Arrangements

Of the 85% that responded, 65% lived with someone such as their spouse or family member. This statistic would be interpreted by many to mean that these individuals choose to live at home in order to get the needed support, and that they are incapable of living independently on their own. This is an inappropriate conclusion to draw from this data, and reflects what could be referred to as an Ableism Bias. Ableism, discrimination in favor of

the able bodied, leads to a predisposition to believe that a person with a disability is incapable of performing various tasks. An ableism bias usually results from an able-bodied person making inferences by assuming that they could not perform certain tasks if they were disabled (Eichler & Burke, 2006; McLean, 2011). However, it could also exist in instances where a person with a disability has not been educated or trained in the alternative techniques that make it possible for them to perform various tasks. The benefit of this collaborative research between TRF and the NFB is that the ableism bias is identified and can be appropriately addressed in future research so that we can obtain the desired information to properly direct our research and development (Burke & Wolbring, 2010).

Perhaps the survey respondents choose to live at home because they feel that they could not live independently. However, it is not reasonable to simply assume this is true. In order to eliminate this bias, we should seek to truly determine whether these BLV individuals choose to live at home because they feel they cannot live independently. An additional follow up question should be added asking, "Do you choose to live at home because you feel you cannot live independently?" Moreover, for those that answer this follow up question in the affirmative, we should seek to parse out some specific concerns they may have. Are their concerns related to cooking/cleaning, personal finance, transportation, safety, etc.? Gaining a better understanding of these concerns would help direct the development of new training, products or services.

Employment/ School

According to Erickson, Lee, & von Schrader (2013), individuals who are legally BLV in the US, suffer high rates of unemployment. In 2013, the employment rate in the US of working-aged people, between ages twenty-one and sixty-four with disabilities was 35% as compared to 77% for those people without disabilities (Erickson et al, 2013). However, Bell, & Mino (2015), mentioned that many adults who are BLV have obtained competitive employment and good wages. Furthermore, completion of higher education along with mastery of the alternative skills of blindness taught by qualified rehabilitation professionals are directly linked to influencing better employment outcomes (Bell & Mino, 2015; Leonard, D'Allura & Horowitz, 1999).

In the Survey, of the 86% of respondents, 48% were employed and the three top careers included assistive technology, teacher and computer (i.e. programmer, web accessibility, internet technology, support, training, analyst and design). Regarding workplace accommodations, of the 42% of respondents, 87% required accommodations at work. With this in mind, 35% of the respondents, listed sighted assistance (i.e. tasks/driving), assistive access technology to computers in addition to accessibility and formatting technology to documents, and hardware (Braille, markers) as the adaptations most frequently required. In like manner, of the 84% of respondents, 48% acknowledged that they utilized human sighted assistance at school, work, or home. Nevertheless, 37% of the respondents further described the most common needs from sighted included drivers, readers, and housekeeping.

Healthcare:-

Concerning healthcare, 58% of the respondents experienced challenges while visiting a pharmacy or doctor's office, and the most common cited included completing paperwork, violations of privacy, lack of sensitivity/knowledge of staff, communicating needs and orientation/mobility. It was noted that of the 78% of respondents, 60% visit go to doctor's office or pharmacy alone, which is indicative that the BLV consumer would benefit from further independent access to healthcare related information. On another note, of the 44% of respondents, 72% utilized the internet for searching health care information. Importantly, of the 77% of respondents, 69% take prescription medications. Besides this, of the 52% of respondents, 88% reported difficulties reading labels such as, inability to read printed information on bottles, dosing and side effect instructions, warnings and refill information. As an illustration, 47% of respondents used assistance from a sighted person (spouse, parent, other), strategic placement and memorization of medication(s), and Script Talk as the top solutions to help overcome aforementioned challenges. Other tools used to take medications included a click pen and an eye drop dispenser. Whereas, 34% of respondents had other healthcare barriers and the most common cited included reading pertinent medical information (including lab/exam result), insurance information and long distances required to reach providers/specialists. The obstacles to healthcare mentioned above were consistent with the O'Day, Killeen & Iezzoni, 2004; Iezzoni, Davis, Soukup & O'Day studies. Future efforts must continue to influence healthcare policies that meet patient needs so utilization of high quality care can be achieved for the BLV. Moreover, this high-quality care must include independent access rather than reliance on sighted assistance, for privacy and convenience.

Navigation

Regarding abilities to navigate around a familiar building, of the 75% of the respondents, 97% were able to do so effectively. With reference to the most utilized tools/techniques to do so, 47% of the respondents cited cane, Orientation & Mobility [O & M] /memorization and guide dog as the most popular. However, with the implementation of navigation technologies like GPS, along with indoor navigation applications, that offer sighted individuals more information about their travel environments, nonvisual access to these technologies are of growing concern for the BLV.

Injuries

Jafri, Ali, Arabnia & Fatima (2013) noted that loss of vision hinders an individual's ability to perform daily activities such as navigation, obstacle avoidance, information access, synthesis, and recognition of nonverbal signals along with living and non-living environmental surroundings. Moreover, several studies have confirmed that vision loss increases the risk of unintended injuries such as falls, occupation-related injuries, and traffic related injuries (Legwood, Scuffham & Cryer, 2002; Manduchi & Kurniawan, 2011).

It was promising to note that of the 74% of respondents, 72% did not sustain injuries while traveling indoors. Of the 28% of respondents that reported indoor injuries, the most common included bruising, scrapes, sprains, and fractures. The main causes for reported injuries included falls, tripping and bumping into unexpected objects or simply not paying attention or being present in the moment. According to the National Safety Council [NSC] (2016), falls are one of the top leading causes of non-intentional injuries sustained in the home, which almost always could have been prevented.

Unfortunately, by comparison, of the 73% of respondents, 62% sustained injuries while traveling outdoors. In this way, 44% of the respondents cited the most common injuries sustained included bruising, scrapes, sprains, and fractures from falls, slipping on ice and collision with unanticipated objects caused by above the head and/or significant changes in grade or pitch (i.e. platforms that drop off, construction sites, hills, and rural terrain, etc.). Therefore, it is fair to assert that the development of additional tools would prove helpful for the BLV. Four questions were asked on types of transportation used regularly: of the 68% of respondents, 71% used public transportation; of the 62% of respondents, 48% used Paratransit or Dial-a-Ride; of the 69% of respondents, 95% utilized family or friends; and finally, of the 62% of respondents, 73% used cabs, shared ride services, or hired drivers. Crudden, McDonnall & Hierholzer (2015) regarded public transportation as particularly difficult for BLV as environmental signals were designed for those individuals with functional vision. However, note that with proper navigational training the BLV can navigate public transportation systems independently. Moreover, improvements in technology design will prove promising in allowing greater accessibility to public places while ensuring safety and practicality of the experience.

According to Guiding Eyes for the Blind [GEB] (2016), only about 2% of the BLV work with guide dogs in the US, which was related to accessibility and costs. As for aids used for mobility, of the 72% of respondents, 76% utilized the Long White Cane; of the 76% of respondents, 63% use a sighted guide; and of the 56% of respondents, 31% use a guide dog. Just as, of the 53% of respondents, 33% used an electronic device to navigate, and the most popular included iPhone and smart phone with GPS and other navigational apps.

Regarding the navigation challenges faced by respondents, 64% of the respondents described the types of environments that they completely avoid because they seem impractical or impossible to navigate. The most common areas included large/noisy intersections, transit terminals, nature/wilderness trails, hiking, camping, beach, and large/crowded venues (i.e. movie theatres, concerts, etc.). 71% of the respondents included cane, tactile navigation such as feet, a guide dog, Echolation, Shoreline Technique, Kenneth Jernigan's "Structured Discovery" method, and Open Palm and Pencil Grip Technique to navigate changes in grade/elevation. 72% of the respondents who identified the most typical techniques used to navigate unfamiliar places included, asking a sighted person for assistance/directions, use of canes and guide dog. Finally, of the 46% of respondents, the most usual challenges not previously addressed included traffic lights without audible signals, silent cars, ambiguous directions, and finding correct bus/taxi. Furthermore, as with the access technology questions, it would have been helpful to ask additional questions to determine the level of orientation and mobility training the respondents had received to better evaluate the answers to the survey questions related to mobility and travel. Moreover, it would be interesting to evaluate the differences in the responses from those who have received traditional O&M training to those that have received structured discovery based O&M training.

Telephonic Focus Group Interviews

After a preliminary analysis of the online The Survey findings, three moderator-facilitated telephonic focus groups were held which included fifteen NFB volunteers in total. The main purpose of the Focus groups was to synthesize the qualitative data obtained from the Survey to validate and glean further details around the BLV target population. All participants were provided with pre-interview literature for review of pertinent information highlighted from questionnaire results. The interviewees were extremely interested in collaborating on the development of user-friendly technologies in the healthcare and navigation spaces.

Navigation concerns that arose from the focus groups revealed that the BLV had little to no previous exposure to distance measurements (i.e. feet, yards, miles, etc.). However, in getting around familiar places the most popular technique cited included O & M Techniques, counting steps, Braille/tactile markers, use of landmarks such as length of hall, counting doors, change of flooring (tile to carpet), light/dark space, sound, air flow, cane, memorization, mapping and guide dog. At the same time, O&M training does not assist with preventing hitting/bumping into low hanging objects or identifying space under stairs. Most importantly, it was favorably noted that for mobility, the cane was the most trustworthy and it was used as both a 'bumper and probe'. Additionally, it was emphasized that cars (i.e. electric) that do not make any noise were hazardous, as there is no audio alert and therefore viewed as life threatening. Similarly, daily the BLV are endangered by busy intersections without audio signals, vehicle drivers who make right turns on red, snow, and ice-covered sidewalks and other natural sporadic obstructions. Also of note, were challenges identifying bus stops, street signs, detour signs, taxis, and address/house numbers. It was also revealed that when GPS, alerted the user that 'you have arrived at your destination' it was perplexing to determine which direction to head or even which side of the street to be on. Furthermore, GPS is dependent on good satellite signal reception and therefore not appropriate in rural areas, or indoors, etc.

Healthcare challenges were also uncovered that interfered with BLVs access, self-respect and self-care management. To that end, increased awareness from the medical community as it pertains to completion of paperwork was discussed as office iPads and online portals can pose problems. Online portals are often not designed with accessibility in mind, resulting in difficult access, and office kiosks, even those such as the iPad which have accessibility built in, often do not have any accessibility features enabled, forcing a blind person to seek sighted assistance. In addition, staff often shows a significant lack of understanding of the resulting privacy violations regarding personal and health information. Many sighted individuals do not realize that being blind does not imply ineptness or general lack of functionality. Equally important hurdles included limited public access to doctor's offices, reading, and opening medicine containers and other pertinent medical information that would be easier to use if accessibility were incorporated in tools available to patients and if pharmacies adopted accessible tools (i.e. Script Talk). Likewise, O'Day et al. (2004) cited similar if not identical barriers and hurdles as aforementioned.

Overall, the Survey results were consistent with the feedback revealed by the focus groups. The main difference was the live focus group interaction, which allowed for a deeper and more complete understanding of results. Challenges and Recommendations were gleaned which will be further synthesized and shared with academia for prototyping and/or proofs of concept.

Discussion:-

The key to ensuring that the devices and strategies have significant impact is for researchers to actively include the BLV in the research and development process. TRF's collaborated with the NFB, throughout the development, execution, and evaluation of the research. Through our collaboration, we recognized that it would be extremely helpful to determine the level of access technology training that a BLV has received to properly evaluate the usefulness and usability of various access technologies. We also determined that it would be helpful to determine the extent of orientation and mobility training a BLV has received to better understand their response to questions related to their travel safety and their level of comfort traveling independently in various environments. These will be key considerations as we and others conduct future research. Moreover, rejecting the ableism bias that could occur in the evaluation of the Survey and focus group discussions will allow us to continue to determine what true access barriers exist in an effort to develop appropriate strategies and/or devices to eliminate or overcome these barriers.

Blind and Low Vision individuals seek to be fully participating members of their communities. Obviously, those who are BLV are likely to face different challenges than individuals with functional vision. The continued use of ineffective medical vision aids, vision assistive devices, and direct services including special education, rehabilitation, and assistance programs to attempt to overcome these challenges result in an increased indirect cost from productivity losses, long-term care, informal care, and the costs of transfer and entitlement programs (Gordois et al., 2012). We developed a survey tool and conducted subsequent focus group interviews concentrating on the general, navigation, and healthcare needs to better understand the access barriers experienced by the BLV and to identify and design innovative, cost effective solutions. The use and performance of current support devices such as visual aids, mobility devices, and computers were evaluated through the use of an online Survey.

Magnifying aids, computer access and phone access with speech and large print, albeit positive, were not sufficient to resolve barriers to employment, education, financial security, and health and self-care management. Novel solutions being developed were stated to have limitations such as poor interface design, clunky hardware, and unappealing and embarrassing wearability. Moreover, much of the evolving technology is dependent on signal strength, battery life, support services and other interesting challenges that present limitations for the user. Identified barriers to healthcare access in the BLV community include lack of affordable dependable transportation, absence of sufficient accessible tools or strategies to independently measure and administer medication. Other major barriers noted were inaccessible technology resulting in an inability for the BLV to independently read and fill out forms, lack of well-trained healthcare staff, along with an overwhelming lack of privacy due to the inaccessibility of healthcare tools and the resulting need for human sighted assistance.

There is a clear need for more enhanced accessible technology, innovative navigation tools/strategies, and accessible healthcare interventions that assist the BLV to improve their quality of life and to gain additional opportunities to achieve greater independence. is committed to empowering the BLV by developing innovative navigation prototypes that are mindful of meaningful purpose and cost efficiency. TRF is working to develop a comprehensive informatics-based navigational system for the BLV, leveraging expertise in engineering, perception and awareness, personal mobility and human system interaction. Moreover, TRF is committed to ensuring the active engagement of the BLV throughout every phase of research and development. The active development of far-reaching but user-friendly prototypes would prove helpful in addressing the navigation and healthcare needs described in this paper, while decreasing the US annual health expenditures. TRF equates, "Doing Science for the Right Reasons™."

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