



Designing Human-Centered Services for Visually Impaired Seniors

Naz Mirzaie, David Morgan

Essential, Future In Sight

naz@essentialdesign.com, dmorgan@futureinsight.org

Abstract

This human-centered, ethnographic research discloses the foundational knowledge on behaviors, attitudes, and unmet needs of visually impaired seniors gained throughout a pilot project.

Keywords

Blind and visually impaired seniors, service design, ethnographic research, mobility, assistive technology, independence

Introduction

Seniors comprise an increasing percentage of individuals who have no or low vision in the United States. According to the 2015 disability statistics by Cornell University, in New Hampshire more than 26,000 individuals live with vision loss, with some estimates that two-thirds are seniors over 65. This trend is accelerating as baby boomers age and seniors live longer. ‘Future In Sight’ is a New Hampshire-based non-profit that provides a range of education, rehabilitation, and training services to children and adults living with profound vision loss. Recently, ‘Future In Sight’ decided to expand its services to include a larger portion of this population, particularly seniors who live in rural areas at or below the poverty line and have limited access to rehabilitation and medical services.

In an effort to better understand the emerging needs of this target group, ‘Future In Sight’ reached out to Essential to craft a pilot research project. The study employed Design Thinking principles to provide foundational knowledge on senior clients’ behaviors, attitudes, and unmet needs, and to learn about future design and innovation opportunities.

In this pilot project, five individuals in different stages of their vision-loss journey were given a chance to be an advocate for more tailored and informed services. The results of this pilot project will be used as evidence to support future grants, enabling ‘Future In Sight’ to serve a larger population with improved and expanded service offerings.

Founded on systems thinking, Service Design identifies goals and outcomes that a customer must achieve to feel satisfied in all phases of their journey with an organization. Through this systematic approach, service designers align organizations’ capabilities and business opportunities with customer needs and experiences, exploring front-stage and back-stage activities from all stakeholders’ perspectives (Reason, and et al. 2016).

This paper reviews the process and the results of the aforementioned qualitative study, which used the service design approach to offer insights and opportunities for improving ‘Future In Sight’ services.

Methodology

Service Design and Design Thinking often rely on ethnographic research that has roots in sociology and anthropology. With direct involvement of research target groups, Design Thinking provides contextual and in-depth knowledge about people’s thoughts, feelings and actions. Direct involvement of visually impaired people in research validates their experiences and empowers them to have a voice in designing services that can meet their needs (Bühler, 2001). The team conducted five 120-minute sessions in the form of an exploratory, co-creative, and semi-structured interviews at the participants’ homes using a combination of qualitative methods inspired by Hanington and Martin: in-depth interviews, home walk-throughs, a “day in the life” and journey mapping (Hanington and Martin, 2011).

The process of protocol and activity development was challenging due to lack of previously conducted research projects and the prevalence of visual-driven methodologies and activities in Design Thinking. Considering the sensitivity of the subject, the goal was to create a rapport and to provide comfort and ease where participants would be inspired to openly share their experiences and emotions. The team was looking for an approach that allowed for a deeper connection as well as access to tacit knowledge of visually-impaired seniors. Studies by J. Berbrier in 2002, U. Herrmann in 1995, J. Michael in 1981, and E. Inman in 2016 shed light on the power of the art therapy practice in eliciting these emotions and building empathy. Using the the art therapy strategies put forth by aforementioned studies as inspiration, the created research stimuli were tactile-driven with the goal to trigger memories and emotions, to offer a space

where visually impaired seniors could describe their dreams and to better communicate and to engage with the sighted world. The methodology and stimuli, shown in Figure 1, were also adjusted to accommodate an individual's sensory abilities and comfort level (Michael, 1981, Berbrier, 2002, Herman, 1995, and E. Inman, 2016).

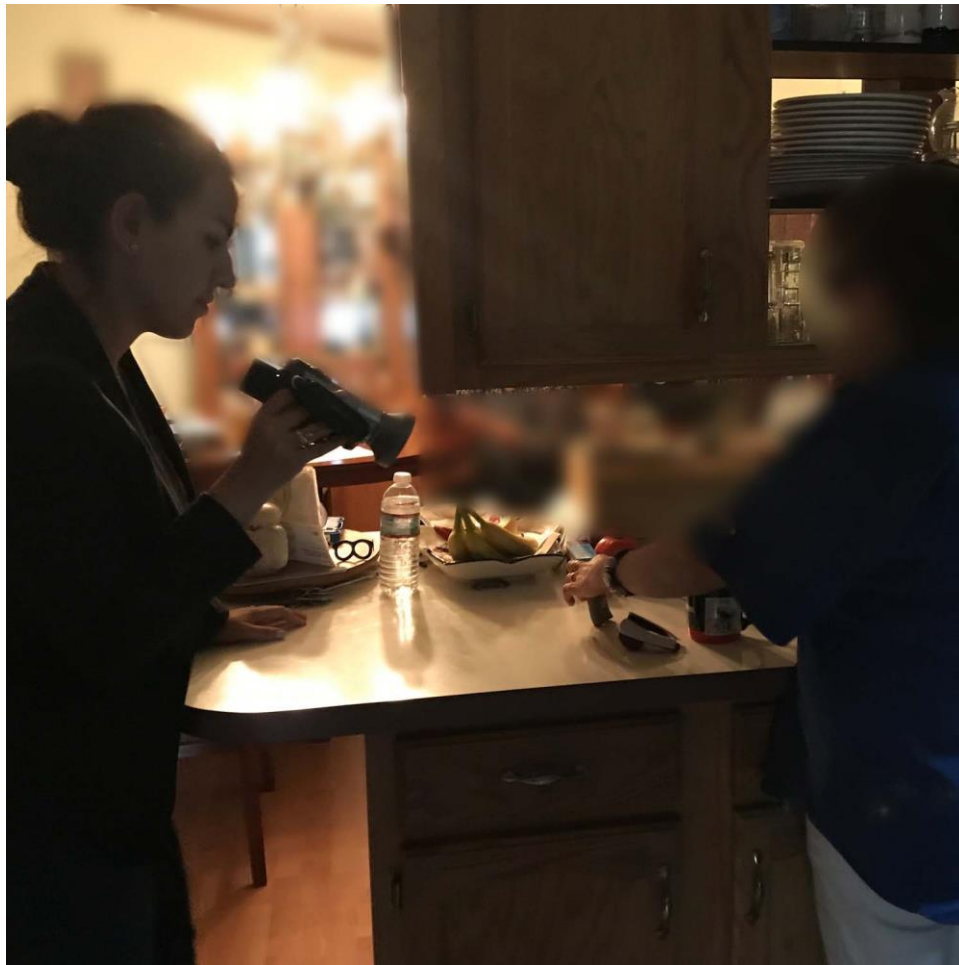


Fig. 1. The sample of the methodology and stimuli that were adjusted to accommodate individual's sensory abilities and comfort level – from the left to right journey mapping, home tour, and helpers and hurdles.

The topics were arranged in a sequence to cover three areas: warm-up and building a foundation, dive into life with low vision and its consequences from different perspectives, and reflecting on the past to design a better future:

- The warm-up introductory questions were followed by mapping each participant's journey after being diagnosed with low vision
- The deep conversation part started with identity and life with low vision, followed by daily life experiences both indoor and outdoor, helpers and hurdles and their relevant influence, and feedback about 'Future In Sight'
- The opportunity section covered the role of technology, positive moments, and aspirations.

In the journey mapping activity, participants shared their experiences from the time they began noticing a loss of vision until now, with prompts, such as *"Let's start with when you first noticed your vision loss. Could you share your experience with me? How was the situation? Where were you? How did you feel?"* As a way for participants to better indicate their emotional state and how these emotions changed throughout their journeys, an abacus was designed with a bead attached to each column, Figure 1, Right Image, which stood for a stage of a journey. Participants used the location of the bead to communicate their emotional state at that time; top for positive, bottom for negative, and neutral if in the middle.

In the home tour exercise, participants shared areas of their homes where they perform their daily activities while pointing out their favorite areas, tasks and objects as well as the ones they struggle with and frustrate them.

In the helpers and hurdles activity, participants were offered two groups of models: circles on the right for helpers and squares on the left for hurdles. They were prompted that these helpers or hurdles could be anything: people, places, things/objects, behaviors, needs, inside their home or outside and were asked to describe how they were affecting their lives. After making a

pile of helpers and hurdles, they were given a bar, Figure 1, Left Image, and asked to show how the scale tilts– weighing their helpers and hurdles.

In the opportunity section, participants were presented with a list of potential opportunities, such as personal grooming, support for families, peer advice, awareness services from healthcare providers about existing services and organizations, and public education and volunteer services. They were asked to pick the items they may want ‘Future In Sight’ to pursue or cover more strongly.

In the second part, the discussion focused on the role of technology in meeting each individual main needs and desires. To enhance the engagement and support from less vocal participants, a list of potential solutions/benefit statements was presented, covering daily needs such as:

- A VoiceOver technology that gives you auditory descriptions of what is on the screen of your device, reads text aloud and provides suggestions.
- A smartphone app that uses vibration to guide you through routes in your home, which are marked by colored tape on the ground.
- A smart cane that vibrates at different levels depending on how close you are to objects and hazards.
- A scanning device that reads and announces the color of anything around you.

Results

Analysis Process

The gathered data were analyzed through an iterative, sense-making process with the aim of framing the problem from different perspectives and understanding the hidden connections – as L. Kimbel put it “what goes on in a context from inside it.” The analysis process requires

creativity and openness to what surfaces from the data including unexpected findings and surprises (Kimbel, 2014). Accordingly, the team drew relationships among many data points, such as what people do, say, feel and know, in meaningful ways both from a bird's-eye and detailed views – using sticky notes and large excel sheet posters. As a result of this rigorous process, more than 40 insights emerged and clustered into topics comprising of: participants' needs, goals, attitudes, thoughts, emotions, and actions during four stages which include 1) Pre-Diagnosis, 2) Diagnosis and Progression, 3) Engagement, and 4) Future. These topics yielded nine core themes: disconnection from surroundings; many mobility barriers; power of small changes; independence is a rare golden feeling; irreplaceable role of family, friends, and peers as key supporters; awareness and preparation; fear of unknown; aspirations; and the pivotal role of technology.

One of the first realities of vision loss is the disconnection with the physical world and loss of control over surroundings. Consequently, people slow down, create ad-hoc solutions, and adopt new skills and behaviors. From the mobility perspective, replacing abandoned activities with new achievable activities increases hope and redirects energy. Low/no vision is just one of many obstacles individuals face when trying to remain or become mobile: these can include a negative self-image, fear of strangers' inappropriate behaviors, and the protective impulses of family members. Mobility (or lack thereof) is also a self-reinforcing process. People with low/no vision often become homebound and isolated due to a lack of mobility services. If they do go outside, they don't encounter many limited-vision peers, which further discourages them from going outside and also makes the need for improved mobility services more visible. As a result, opportunities and solutions that enhance mobility and provide independence were widely appreciated.

Independence is a rare, golden feeling, where as losing one's driver's license and the ability to help others or asking for help are felt to be signs of dependency and are the lowest moments of an individual's journey. Family, friends, and peers are key supporters in individuals' journeys; lack of support from any of these groups extensively impacts individuals' lives. Interactions with peers, both one-on-one and in a group, assists individuals and their families in coping with their condition, inspiring them to take action and build community.

Looking at each participant's journey, awareness of where one is on their journey and preparation for what is to come can benefit individuals in coping with their condition. However, people don't know about available resources and are hesitant to ask unless they are innately extremely proactive. Confronting this new reality and its limitations is a hard but necessary step for adopting a positive attitude toward their present and future life with vision loss. Fear of the unknown can be so overwhelming that people opt to remain in denial as long as they can.

Finally considering the role of technology, losing vision does not negatively impact tech-savvy individuals' interest in supportive technologies. They are actively looking for new resources and mastering new skills. However, losing vision could have negative impacts on the technological interest and skills of less tech-savvy people. They may avoid technology because they feel unable to understand it, feel overwhelmed with the other adjustments vision loss requires, or aren't interested in utilizing their resources.

Experience Frameworks

To share the process that yielded these insights and bring them to life for the audience, various frameworks were used, such as User Profiles, Experience Maps, Maslow Hierarchy of Needs, and Five Human Factors.

A User Profile framework depicts a thorough picture of each participant using various data points, such as needs, goals, attitude toward condition and technology, feedback on ‘Future In Sight’, and aspirations. For example, Figure 2 shows PL’s Profile— one of the female participants. She started her journey with ‘Future In Sight’ a year ago. She had to quit her job a couple of months after being diagnosed with Retinitis Pigmentosa.

Her main hobby was writing, but she does not write that often anymore: *“I don’t write as much as I used to because it’s harder for me to do it...sometimes it’s just so hard to see. It wasn’t like I was a typer. It wasn’t like I was on the computer.”* She finds her hurdles, such as lack of support from her family and not being comfortable to go out, a little bit heavier than helpers since they do not change. She is relatively happy with her services and found her visitors from ‘Future In Sight’ very encouraging, but believes there is a need for more tailored services, where individuals get more time with staff. *“They need more time with people...if there were a little more time and stuff...when you come into this you don’t know what to expect.”*

An Experience Map captured end-to-end participants’ experiences with a holistic view of individual’s daily life or life chapters, providing a foundational knowledge that illuminates how ‘Future In Sight’ fits into a broader context. The experience maps uncovered actions, expectations, emotional goals and triggers, and contextual pain points. PL’s lowest journey moments, shown in Figure 3, are being diagnosed with Retinitis Pigmentosa and giving up driving: *“When the doctor told me I shouldn’t have been driving for four years and shouldn’t be driving anymore I became unglued. I cried and wanted to rip everything in the place. It took away my ability to be myself. It feels like you’re losing your identity. Because I used to travel for my job and was always driving.”*

The second circle on the map depicts her current situation, where she feels despair and loneliness that are being balanced by ‘seeking online resources to learn new adjusting skills’ and ‘continuing emotional and physical support by ‘Future In Sight’s’ peer group and volunteers.’ The experience map also shows her emotions, as well as experience with ‘Future In Sight,’ e.g., her primary pain point, was ‘the on-boarding process from different services’ and her positive moment ‘meeting with peers.’

The Maslow’s Hierarchy of Needs framework, illustrated in Figure 4, was used to showcase different levels of participants’ needs and to start a conversation around opportunities with the ‘Future In Sight’ team members. Firstly, people would like to maintain their routine and health; then, they aspire to be more active and social, and finally, want to adopt new solutions and skills to improve their lives. The latter two proposed a new line of opportunities for ‘Future In Sight.’ Looking at PA’s goals and aspirations, she would like to gain the support of her family and friends, be more mobile, attend a writing class and finish her book, and finally, perform public speaking – advocating for people with low or no sight.

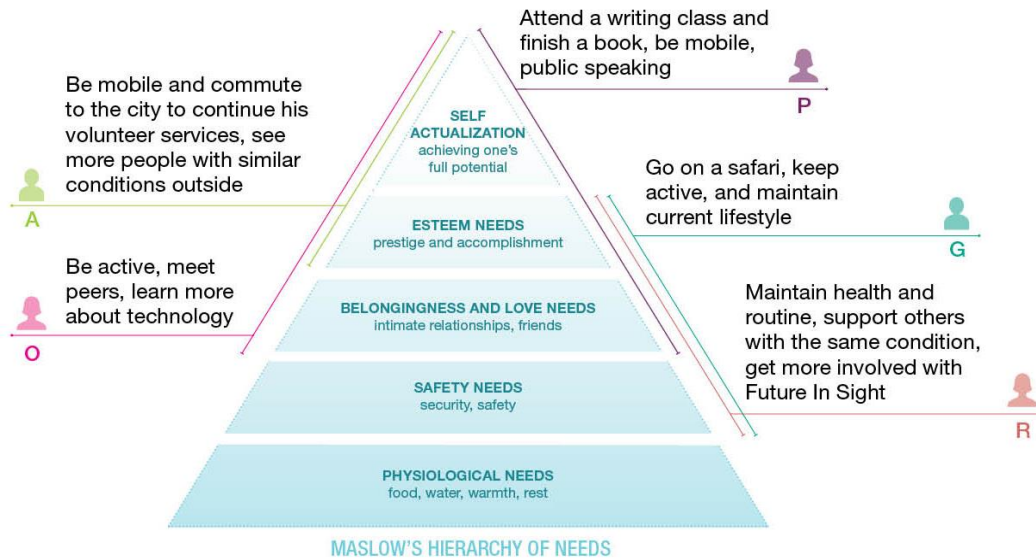


Fig. 2. Maslow Hierarchy of Needs was among the various frameworks that captured the study's process and insights.

The Five Human Factors, captured in Figure 5, was among the frameworks used to structure data gathering and analysis, illuminating participants' needs and desires. Besides people being the chief entity, each factor also includes content referring to activities, environments, interactions, and objects. Kumar introduced social and emotional needs as two aspects of the Five Human Factor framework (Kumar, 2012), where some of the fundamental insights correlated closely to these two aspects. Physical, cognitive, cultural are the other three aspects.

From the emotional needs perspective, feeling insecure is a source of fear and frustration for no/low vision individuals and their families. Some participants had built coping mechanisms around self-talks and meditations. A study by Marquès-Brocksopp (2014) showed that promoting this positive behavior and mindfulness enhances individuals' spiritual well-being, as well as their emotional, social, and physical health. Another emotional need insight echoes the fact that

confronting the new reality and its limitations is a difficult but necessary step to adopt a positive and proactive attitude towards vision loss. From the social needs’ perspective, mobility and social integration are connected and symbiotic: the lack of one can result in isolation, which is the most common negative emotion among the participants. The helpers and hurdles model, illustrated in Figure 5, confirms these needs. In order of significance, family and friends, being mobile and independent, and support from ‘Future In Sight’ play positive roles in an individual’s journey.

HELPERS	FAMILY & FRIENDS	FUTURE IN SIGHT + PEERS	OBJECTS/TECH	CURRENT JOYS	PETS
	Spouse Grandchildren Living close by all the family Friends & Family Family having adjusted to her and not asking too many questions Neighbors	Future In Sight Volunteers from Future In Sight Interactions with peers	Magnifiers Computers Audiobooks Personal hacks: the order and shape of his medication Coffee Mug	Looking forward to getting to know NH Spending time in the garden Being stable Being able to live here independently	Her dog Spending time with her neighbor’s cat
HURDLES	FAMILY & FRIENDS	DRIVING & BEING MOBILE	DAILY TASKS	LOSING TEMPER	
	Lack of support from her family Decision not to live with his children, did not want to be a burden A friend, who makes her aware of what it is like to start losing her mind	The thought of not being able to drive Not being able to drive Uncomfortable to go out, goes only once a week usually with the help a volunteer Cannot exercise Cannot exercise Not being mobile & not being able to go outside Not knowing where he is at any given moment in his home	Makeup and doing her hair Cannot read magazines Not being able to write that often Cannot see the food on his plate House chore, e.g., cleaning and cooking Identifying his clothes and putting them on, on the correct side	Losing her temper Loss of her patience	

Fig. 3. The Helpers and Hurdles Model illuminates the significant role of family, friends, and ‘Future In Sight’ services.

Journey with Future In Sight

The participants' experiences with 'Future In Sight' were mapped using the five-stage Customer Journey model (Entice, Enter, Engage, Exist, and Extend). A Customer Journey communicates a rich understanding of customers' behaviors and how they interact with a company— covering their end-to-end experiences. It offers a strategic direction for an ideal journey by supporting a team to generate ideas for the before, during and after interactions. This model, illustrated in Figure 6, highlights the critical moments that can make or break the service experience in green and orange. The figure on the left displays channels that individuals encounter on their journey with 'Future In Sight'.

Often, doctors recommend 'Future In Sight, ' and alternatively and rarely if people are proactive, they find out about the organization through research. After this first encounter, there is usually a period of denial since people still have some vision, which ranges between a couple of months to years. Then, a social worker visits individuals who will assess the situation and introduce 'Future In Sight' services for further engagements.

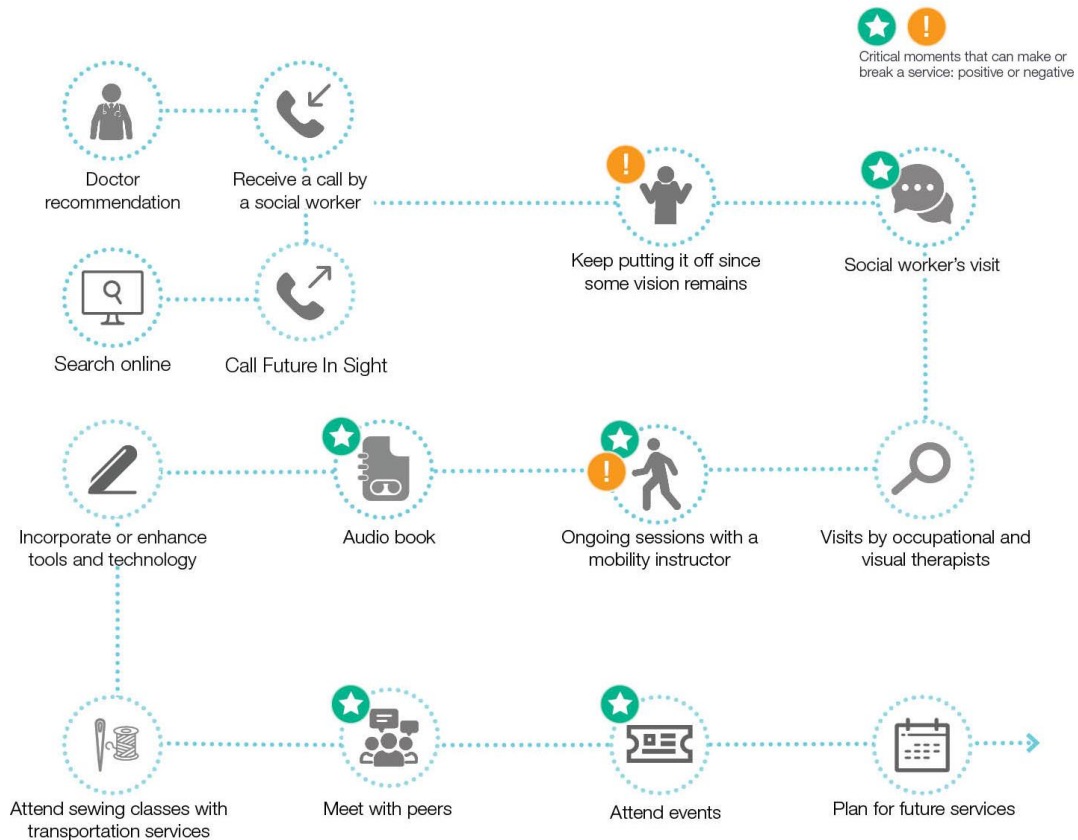


Fig. 4. The participants’ experiences with ‘Future In Sight’ were mapped using the customer journey model.

The goal of the Entice stage is creating awareness and curiosity. In this stage, ophthalmologists have a fundamental role in engaging and re-engaging individuals with ‘Future In Sight’. As one of the shared resources for seniors, they should actively provide information about available resources and services. Coping with vision loss and its consequences is overwhelming, authorities and other resources should reach out to individuals instead of the other way around. One of the hypothesis formed in this stage was around stigma: people treat vision loss like Alzheimer’s, and unlike cancer they avoid talking about it. This results in there not being enough familiarity and awareness about different phases, emotions and strategies of vision loss.

In the Enter stage, with the goal of designing the first experiences, awareness of where individuals are in the journey, and preparation for what is coming next, can help them to cope more easily with their condition. The challenge is that people are usually unaware of their available resources and are hesitant to inquire. The only exceptions are the extreme, proactive participants. In response, one of the principal strategies is offering a reassuring, positive outlook to raise awareness and influence an individual's acceptance of their condition, and its present and future consequences. A model by S. Hugo and et al. in 2011 also found self-awareness, associated with individual's first contact with their loss, and self-identification as two chief milestones of the adaptation process.

The findings of the Engage stage stem mainly from onboarding and personalized services. Onboarding needs time and attention and is substantial in incorporating solutions into an individual's lifestyle. The other key strategy is designing customized services based on triggers, personality, and journey of an individual. This strategy highlights the value of the service design's co-creative approach in developing, delivering, and augmenting the clients' experiences. The emphasis of service design on this participatory, individualistic approach is a part of a broader philosophy of the inclusion and empowerment of people with impairment in more aspects of their lives – in consultative positions and decision-making processes (Luck, 2003).

Finally, in the Exit & Extend stages, the goals are to design remarkable end-of-journey experiences and to enrich connections with customers. The study revealed that people strongly value the opportunity of volunteering for 'Future In Sight'; playing an ambassador role brings joy and purpose, and helps them accept assistance from 'Future In Sight'. Furthermore, successful experiences with one organization motivate and encourage individuals to reach out to

similar services and organizations in new places. As a result, efforts from one organization like 'Future In Sight' has direct influences on perception around similar organizations and attitude of individuals and their network in reaching out for help.

Findings on the role of technology were focused on the level of interest, attachment to current solutions, and the desire for being mobile. Overall, people expressed interest in technology support and enhancement. Younger participants were more open to technology and more eager to adopt new solutions for coping strategies, being independent and setting life goals. They have currently incorporated technology into their lives and expressed the highest level of enthusiasm toward the provided list of opportunities.

Access to technology has major effects in increasing the role of technology in people's lives. For example, online research will lead to learning about and seeking new resources while not being able to use a basic house phone with voice recorder can disconnect individuals and decrease their interest in adopting new resources. Playing "phone tag" can also make people give up on reaching out. Similarly, as mentioned in one of the core themes, losing vision can negatively impact the interest and skill-development of less tech-savvy people. Moreover, mobility is one of the major concerns among the participants; opportunities offered by technology to enhance mobility and provide independence are strongly valued.

From adopting a new solution perspective, besides low vision, an individual's attitude toward technology is another important factor influencing whether or not someone will use technology for support. People also in any stage would like to stick to their current solutions and may resist change, even though that change could make their life easier. They will adopt new resources and technologies that work best with their existing ones. For example, WA, our oldest participant, has access to many resources, such as a laptop, smart TV, Kindle and Alexa, but he

is not interested in using them to their full potential. He already embraced reading on a Kindle and did not want to try an audio player, but he is open to trying better magnifiers as his current ones are not working well.

Raw Data Workshop and Opportunities

After the analysis process, Essential organized a raw data workshop with the ‘Future In Sight’ team members to share the results and discuss the next steps. At the end of the workshop, a list of opportunities using the “How might we” expressions were introduced to facilitate conversations identifying future services. For instance, how might we:

- show seniors they need services even though they still have some eyesight?
- encourage a proactive attitude without making people feel negative about their future?
- use technology to help people with way finding and with meditation?
- fight societal stigmas, catalyzing a change in perceptions of living with low/no vision?

Following the workshop, Essential created a graph, Figure 7, illustrating future approaches and opportunities to design more inclusive services, including topics such as: ‘enriching initial contacts and curiosity’, ‘improving socializing and mobility services’, ‘fostering emotional support and peer communities’, and ‘reducing stigma in the society’.

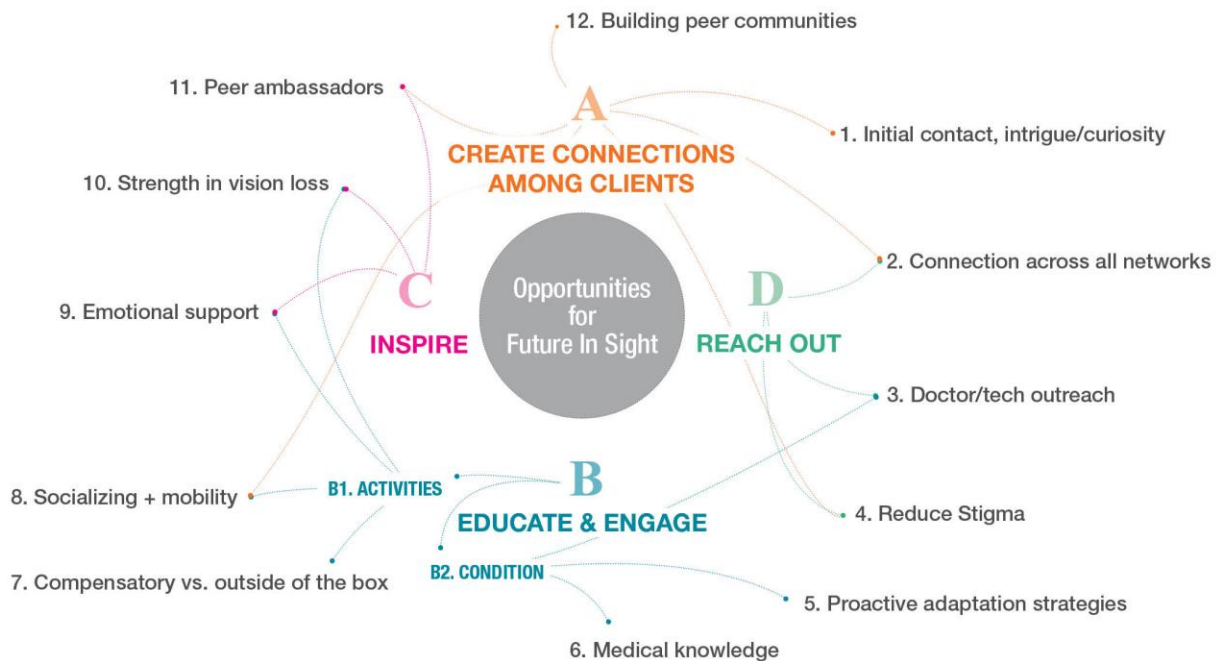


Fig. 5. Future approaches and opportunities for 'Future In Sight'

Conclusion and Future Studies

This exploratory study was a pilot project with the goal of introducing the value of Design Thinking and the Service Design approach to the 'Future In Sight' team. That value was recognized by identifying core themes like the pivotal roles of independence, awareness, and technology when creating services for visually impaired seniors. Accordingly, the findings of this study call for further research into these core themes and their emergent hypotheses. For example, stigma about vision loss often leads to lack of awareness and isolation which causes seniors in early stages of the vision loss journey to feel less secure and/or confident.

Vision loss is not the end of a journey but the beginning of a new chapter in an individual's life. In other words, new challenges create opportunities for self-actualization. Negligence has wide-reaching consequences where vision loss becomes the cause for many other losses such as reading, driving (mobility), careers/livelihoods, socialization, and ultimately,

independence. However, coping with vision loss and its consequences is so overwhelming, that it is up to society at large and advocates like 'Future In Sight' to reach out to individuals (instead of the other way around), supporting their need to overcome fears and frustrations to meet their full potential.

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