Empowering Assistive Technology Communities to Make Strategic Use of Intellectual Property: Three Case Studies from the CoCreate Program

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Abstract. This paper explores good practices as exemplified by emerging strategies for co-design of assistive technology (AT) for persons with disabilities (PWDs). Designed not as a thorough study, but as a small set of grassroots exemplars that can inspire and instruct designers, developers, caregivers, service providers, and policy makers, the study examines three co-design projects. The three projects utilize the Humanistic Co-Design approach to designing assistive devices tailored to the needs of those with visual, mobility, and speech and language impairments. Implications for the design of AT in open innovation models are discussed, as well as potential real-world implementations.

Keywords: Persons with disabilities (PWDs) · Intellectual property (IP) · Assistive technology (AT) · Co-design · Accessibility

1 Introduction

Persons with disabilities (PWDs) are often viewed as helpless, dependent, and passive [1, 2]. Assistive Technologies (ATs) have made a great impact on the disabled community through empowering individuals by enabling independence. Unfortunately, 35% or more AT devices that are purchased become unused or abandoned [3–5], as they are not aligned with their needs. The main reason for this is not engaging PWDs in the design of AT, which not only results in poor acceptance rates but also encourages continued dependence. These issues mainly arise due to the fact that PWDs are often on the receiving end of help and they are not viewed as contributors of help and support [2].

There is a need for culturally sensitive, user-centered design models for assistive devices and services that empower PWDs, thus transitioning them from victims and

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receivers of help to drivers and subjects of rights. In order to fulfil this need, it is first necessary to understand what users, caregivers and stakeholders conceptualize as the goal for the person with a disability. Caregivers often cite dignity, independence and purpose. When the questions related to AT design and service provision are addressed and ideas are more definitively understood, service providers and policy makers are better able to translate these concepts into the sustainable provision of AT devices, products and services for people with disabilities.

2 Background and Motivation

In this section, we summarize how co-design models have been applied in HCI research and practice. We then describe the Design Innovation (DI) approach. This is followed by prior work in Humanistic Co-Design and its alignment with open innovation and policy regulating the ownership and use of intellectual property (IP) rights for the different stakeholders in the CoCreate program (e.g. researchers, technicians, students, co-designers) and commercialization partners such as industrial sponsors, consultants, non-profit organizations, and SMEs. Finally, we describe the gap in knowledge that Humanistic Co-Design can begin to fill in HCI, open innovation and IP utilization.

2.1 Studies of Co-design

Assistive technology companies are often composed of teams with either clinical or engineering backgrounds [6]. The main goals of those teams are problem-solving, and cost-cutting. They follow a linear, top-down approach, starting from the problem towards the solution. Although these linear processes work for problems that are well defined [7], they do not apply well to problems built around assistive technology for PWDs. Problems concerning disabled people are complex. It would be inadvisable to rely on traditional data gathering and analysis techniques. These problems require iterative trial and error in order to better understand the social, emotional, physical, and cognitive needs of PWDs. Co-design builds on the methods and underlying principles of User Centered Design (UCD), which assumes PWDs to be experts in their own domain, and that they should, therefore, be actively involved in the design of assistive and accessible technologies [8]. Therefore, co-design aims at collaboratively validating solutions with users, putting the user at the center of the iterative process and working on understanding their perspective, and engaging latent perceptions and emotional response. The iterative approach aims at better understanding ‘what is needed?’ and ‘what can be built?’ [6]. During every cycle, more insight is gained. Co-design has been used as a methodology to design ATs for PWDs, such as serious gaming technologies for children with hearing impairments [9] and the technologies described in [10].

2.2 IDC Design Process

The Design Innovation (DI) process is a human-centred and interdisciplinary approach for innovation that was developed by the International Design Centre (IDC) in Singapore [11]. The process integrates creative, technical, and analytical methods from

well-established schools of thought: Design Thinking, Business Design, Design Engineering and Systems Engineering. The DI process begins with the execution of design methods that advocate for user-centredness. The choice of methods and the transitions between them is governed by a series of processes known as the 4D process. The DI process aims to promote the culture of design with ubiquitous best practices, mindsets, and principles that guide the execution of design methods throughout the design process.

The IDC's DI Process progresses iteratively through four phases, i.e. the 4D process: Discover, Define, Develop, and deliver. In the discovery phase, designers utilise research methods, such as interviews and journey maps, to identify and understand the needs of their users by collaborating and co-creating with stakeholders. During the discovery phases, designers are encouraged to adopt an empathetic lens to encourage the understanding of others and their feelings free of judgement, as well as support divergent thinking within the opportunity space. The define phase follows next to converge and narrows downs the ideas into an 'opportunity statement' by mapping user needs into activities, functions, and representations mindfully and without judgement. Several research methods are used in the 'define' phases, including personas, activity diagrams, hierarchy of purpose, and affinity diagrams. In the next phase, develop phase, designers divergently ideate and model concepts that are based on the identified opportunity statement. Designers are encouraged to adopt a joyful mindset when applying research methods (e.g. collaborative sketching, mind-mapping, or design by analogy) for the 'develop' phase of the DI process. Concepts developed in the develop phase are iteratively delivered to the stakeholder in the 'deliver' phase as prototypes for the purpose of evaluating and refining them. While the 4D process sequence is archetypal, in practice the design projects will grow iteratively between the phases.

2.3 The Humanistic Co-design Program

The Humanistic Co-Design Program, CoCreate, adopts the DI process in its co-design practices by focusing on what the user and the organisation really need and want to support strategic impact and digital transformation. The program started in January of 2020, when MIT's Humanistic Co-Design team introduced the program to Saudi Arabia with a three-day workshop ending with the formation of teams, focused on designing and developing AT. What makes the Humanistic Co-Design approach different from the traditional co-design approach is its focus on human values of PWDs, such as dignity, independence, and purpose, that can only be understood through various empathy exercises. According to Dr. Kyle Keane, head of the Humanistic Co-Design Initiative, "Humanistic Co-Design is an extension of contemporary design approaches, such as design thinking and human-centered design, that emphasizes the emergent inspiration that comes from the dissolution of the designer-client relationship in favor of a mutual engagement of peers with complementary experiences and expertise" [12].

The program aims at helping designers, makers, and engineers apply their skills in collaboration with PWDs, placing PWDs in the driver's seat as contributors to design solutions. In addition, the program worked in collaboration with individuals, organizations, and institutions to increase awareness about how to empower PWDs, allowing them to become subjects of rights by enabling advocacy and ownership through the potential publications and commercialization of assistive technologies through entrepreneurship

or licensing agreements. The central goal of the program is to develop solutions to real-world problems in this community, empower PWDs, bring awareness of disability, and promote cooperation within this field.

CoCreate Roadmap. MIT's Humanistic Co-Design team used the DI process and Humanistic Co-Design approach to design the CoCreate roadmap (Fig. 1 below). The main participants involved in the program were the designers and co-designers. MIT's Humanistic Co-Design mentors served as supporting figures for the design process, while the Saudi Arabian IP Authority and the Saudi Health Council's National Health Lab for Emerging Technology served as local supporting figures. There are six main steps in the roadmap: empathize, identify opportunity, gather information, ideate, prototype, and test and refine.

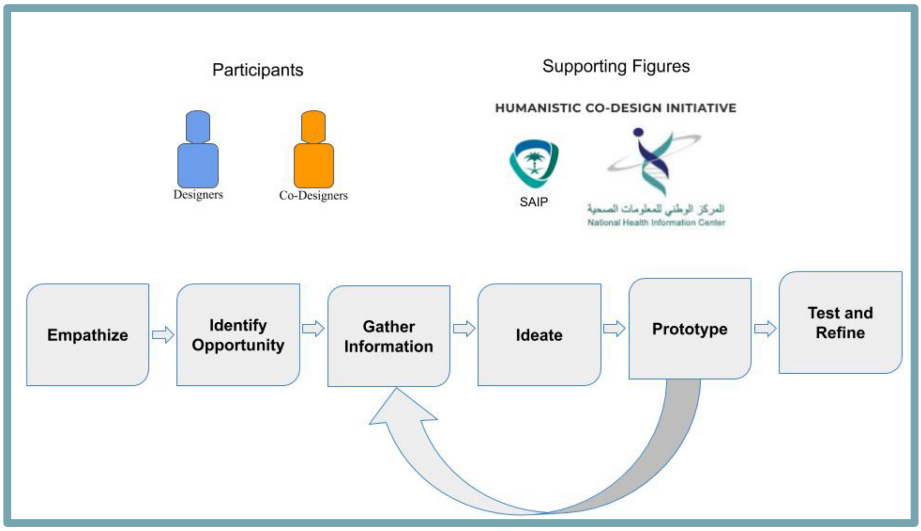

Fig. 1. CoCreate roadmap

Roles of Designers and Co-designers. The designers are the engineers and clinical specialists who act as supporters of PWDs in finding an opportunity space and solution. Their role is to first better understand the disability community, then engage PWDs in order to answer the question of 'what is needed' and 'what can be built'. After this, they must go through iterative trial and error with the help of the PWDs, in order to better define the problem and better design the solution.

In this program, the label Co-Designer was given to the PWDs, as they are empowered to make design decisions. The co-designer is involved from the inception of the project, in identifying a design opportunity, and throughout the iterative design process. As the development of the project continues, more co-designers are recruited to gain more feedback.

Roles of MIT's Humanistic Co-design Mentors, SAIP, and NHLET. Humanistic Co-Design Initiative team actively coached the designers and co-designers throughout their design process and provided resources. Meanwhile, the role of the Saudi Authority for Intellectual Property (SAIP) comes into play to empower innovators through the process of creation and utilization of IP, as Intellectual property (IP) is a key factor in fostering innovation and value-creation. SAIP offers on-site consultations and other related services through IP Clinics on Intellectual Property Rights (IPR), which include patents, copyright, industrial design, and trademarks. SAIP also provides IP and business advice, resulting in turning strong innovative ideas into businesses and directing creativity while generally contributing to raising the awareness of intellectual property. The Saudi Health Council's National Health Lab for Emerging Technologies (NHLET) also offered to mentor by connecting teams to local organizations, advocate groups, institutions, and policymakers. These supporting figures were vital in creating awareness about how to empower PWDs by allowing them to become subjects of rights by enabling advocacy and ownership through the potential publications and commercialization of assistive technologies through entrepreneurship or licensing agreements.

Three Day Workshop. The inception of the program started with a three-day workshop. The aim of the workshop was to kickstart the program by going through the first phases of the CoCreate roadmap: empathize, identify opportunity, gather information, ideate, and prototype.

The first day of the workshop was structured to help designers empathize by introducing the concept of disability and accessibility to local designers prior to meeting co-designers (i.e. PWDs), as well as priming the designers for empathy development. The designers attended a short lecture series about disabilities, assistive technology, building co-designer relationships, and product design. The designers were then brought through a series of disability simulation activities where they try to accomplish a series of tasks while using props to induce artificial impairments and limitations.

The second day of the workshop was centered around identifying an opportunity. Co-designers were invited and given time to introduce themselves, as well as pitch any idea they presently have. After which, designers were broken up into arbitrary groups in order to circulate among co-designers to learn more about their daily lives, interests, strengths, and challenges. After all groups have met each co-designers, designers were allowed to organically form into project teams centered around a particular co-designer. Teams were encouraged to develop an interview protocol to identify an activity the co-designer could use a piece of technology to engage in more independently. Throughout the day, designers are given mini-lectures to introduce them to research methods popularly adopted within the DI process, such as scenarios and journey mapping. These techniques often followed interviews with co-designers to uncover users' intentions, motivations, and emotions.

On the last day of the workshop, teams worked on gathering information, ideating, and prototyping. They completed a template to specify the project plan with an initial idea that will serve as their first prototype. This report included a visual mockup of the idea, market research, potential production materials/technologies, and a detailed description of the device and what problem it solves. The team then pitched their completed project plan to a panel composed of professionals with expertise within the field of assistive

technology. The panel provided constructive feedback to each team, and a select number of teams were invited to join the year-long fellowship (Fig. 2).

Fig. 2. Sessions with co-designers, ideation and mentoring, and showcasing creations

Continuous Iteration through a Year-Long Fellowship. After the three day workshop, more co-designers were recruited to gather feedback on the initial prototype. After going through the loop of gathering information, ideating, and prototyping several times, the final step is to test and refine the final prototype. Throughout the process, designers and co-designers are involved in all steps, and supporting figures helped mentor the teams. Opportunities for publishing and filing for IP became clearer as the solution space became more well defined. The ultimate goal of the program was to develop solutions to real-world problems, empower PWDs, bring awareness of disability, and promote cooperation within this field.

3 Methods

This study focuses on three case studies that utilize the Humanistic Co-design approach during the CoCreate program. The three case studies were among the 2020 Fellowship cohort in Saudi Arabia. The case studies analyze and identify the opportunities for advancing ideas from concepts to products and the major barriers facing each team in the co-creation process; document the theory of change for each AT product cycle; and assess the implications for the future Humanistic Co-Design programs in the local socio-technical context. The sample is small and highly selective and so the findings are advanced here as a set of rich insights into a range of co-design frameworks with an HCI focus.

Our analysis documents the vision, challenges, hurdles, knowledge, and good practices undertaken to develop each AT product. As families, caregivers, designers and communities - regardless of where they are geographically - ultimately shoulder the responsibility of identifying and appropriating AT for this population, these case studies also highlight ways in which those with this responsibility can be supported, taking into account existing policy, local conditions, sociocultural norms, and resources.

4 Case Studies

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4.1 AT for People with Visual Impairments

The co-creation of assistive and accessible technology empowers people of all abilities and creates the right environment to collaborate, communicate, and produce. The project involved the co-designer, a person with visual impairments, with the team of developers in the requirements elicitation phase of the project and maintained engagement in the multiple iterations for the product development process as a partner in the creation of intellectual property being filed for indoor navigation aids. The co-designer was interviewed and discussed how she walks every day from her home to her office, with the help of her assistant. The individual wanted to be more independent but felt hesitant to walk alone, as there were many objects along the way. The same thing happens in new indoor environments for her. She needs a solution that can help navigate indoor areas without a cane, so she can feel better about doing tasks on her own. Based on this the team focused on a solution with glasses with a camera attachment that can be worn and be able to "see" objects through a software program. The goal is that this product will warn the user of where objects are and allow them to walk freely in a new environment.

4.2 Co-design of Wheelchair Tray Table for People with Physical Disabilities

The Humanistic Co-Design program set the tone for facilitating the partnership between the designers and a wheelchair-bound PWD through the ideation, planning and design of a bespoke wheelchair tray table. The co-ownership of intellectual property that is filed, ranging from the industrial designs of the tray tables and patents to the co-authorship of publications related to the design process, have linked a sense of empowerment for the PWD to better outcomes in the scope of product design and portfolios of the designers and co-designers in this project. The co-design for this project uses a table often and wants something easier to set up and put away. Many problems exist with current solutions, such as a table being too high or too low, or if it doesn't extend over the front portion of the wheelchair. These issues are compounded by the presence of the control elements, such as the joystick, above the armrests, which may require tables to be placed higher than is comfortable for the user. The potential product is an automated table that can be attached to an existing wheelchair model. The current evaluation shows that this can use a stepper motor to rotate a lead screw which lifts the up and over the armrest of the wheelchair where it will then rotate downwards in front of the user. The main design consideration is that the area beside the armrest, and by extension the armrest itself,

should remain unconstrained so it can be moved up and down as not to impede the normal function of the wheelchair.

4.3 Augmentative and Alternative Communication (AAC) Co-design for Autism

The Humanistic Co-Design program facilitated the commercialization of augmentative and alternative communication applications that were designed in partnership with speech and language pathologists (SLPs) in local disability service centers. Being cross-institutional in the composition of its team of contributors, the project emphasized shared ownership of the licensing of the software that was developed in partnership with practitioners and co-designers. Moreover, the project facilitated shared IP filing for the copyright of designs in picture-based communication content that was designed and developed with co-designers.

5 Discussion

A number of themes emerge from these three case studies. And while any theme can be advanced only as an informed observation – given the methods used to identify these projects from within the Humanistic Co-Design community projects – it can inform the AT development of new and replicative co-design processes for PWDs.

The Humanistic Co-Design program, CoCreate, served as an important structure between individual causes and proposals and social impact. The program offered a turning point in which PWDs are pushed towards increasing involvement in movements for social change. This turning point includes interacting with familiar individuals expressing challenges, and discussing painful experiences (medical errors or discrimination) with the community of PWDs and designers, makers, and developers, and inspiring design solutions.

The Humanistic Co-Design model followed in this paper demonstrated ways in which empowerment can be achieved by encouraging advocacy and ownership through publications, licensing agreements, and entrepreneurial roles. Socialization of PWDs into empowered co-designer roles occurred through three main avenues, first, engaging them in intensive interactions with new PWDs who have already internalized struggles, goals, and design solutions, to encourage commitment to advocate. Second, providing them with resources, surrounding them with designers, makers, and developers, and connecting them to policy makers in order to empower them and make a direct impact in the community. Finally, giving them ownership through publication rights and entrepeneurialship and licensing agreements, thus creating a future business model, allowing them to participate in the financial remuneration benefits.

This work has formidable implications for the co-design of assistive technology through the future Humanistic Co-Design programs in the local socio-technical context. designers, makers and developers must examine their work practices with PWDs and strive to treat them as drivers and rights bearers rather than victims and receivers of help. The designers, makers, and developers must act as consultants and helpers rather than dictators of decisions. It may be difficult for designers, makers, and developers to take a back seat in the decision making, as they often expect to be in control. Thus,

they need to educate themselves to prepare for their new role. They may need to redefine disability for themselves by becoming involved with local disability rights groups and developing friendships with PWDs. Finally, they may contribute to redefining disability by facilitating interaction between PWDs, the general public, and public policy makers through avenues such as publications and licensing agreements. Through this new paradigm, PWDs not only become self-advocates, but they are given ownership of their ideas through publications and IP and thus move to systems advocacy, potentially affecting public policy decisions.

6 Conclusion

This work aims to raise awareness of disability and promote cooperation within this field. The outcomes show potential into the future implementation in AT development of novel and reproducible co-design processes for PWDs. The solutions presented are representative of the products and services that can be utilized by these persons in order to improve their overall quality of life. This paper also addresses the current deficit in evidence-based knowledge on designing technology solutions for PWDs, and significance as a component of the increasingly pressing global sustainable development and health challenges for well being and inclusion.

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