Knowledge Co-Creation and Assistive Technology[1]

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Abstract
This article presents reflections from the perspective of two computer science researchers who have used knowledge mobilization services (as opposed to technology transfer services) in service of research goals that arose from an evolving critical praxis. We situate co-created knowledge outputs, as produced from engaged modes of scholarship, in the ecosystem of assistive technology production and consumption.

Keywords
Knowledge output; Knowledge mobilization; Assistive technology

Introduction

A subset of science and engineering researchers, including us, is focused on the development and application of novel and innovative computer-based *assistive technologies* (e.g., computational speech and language analysis, computer vision, automated reasoning, software frameworks and/or components) and/or their human usability. The term *assistive technology* (AT) is the umbrella term[2] used to describe the hardware, software, and peripherals that assist people with disabilities in accessing computers or other information technologies (The National Center on Accessible Information Technology in Education, 2013). Our research lab, located within an electrical engineering and computer science academic unit, has been dually focused on the development of new scientific knowledge and on the development of novel computer-based assistive technologies.

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In this article, we address the following questions: What are the possible non-academic impacts of work such as ours? How does (or can) the (co-)creation of knowledge take place in this scholarly domain?

We feel these questions are relevant, since our application domain is connected to core societal issues (e.g., equity for individuals with disabilities). We feel that it is important to engage in a meta-level discourse about our scholarly activities and also, for the scholarly field as a whole, to find ways to better leverage academic outputs into a sector that has a demand for them. We must reflect on the serendipitous convergence that is at hand: a paradigm shift toward a broader understanding of the nature and purposes of academic scholarship, and a paradigm shift in the field of assistive technology, which has begun to espouse participatory design, hacker/maker approaches, micro-fabrication, open source, and other technology deployment modes.

Non-academic impacts of assistive technology scholarship

In Canada, as well as many other countries, the ecosystem of assistive technology (AT) production and consumption is tied both to the landscape of social, health, and educational policy and to the consumer software/hardware marketplace, the result of which is a complex complement of actors, with myriad flows of knowledge, expertise, and influences among them. We, as scholars and researchers in the area of computer-based AT, have begun to critically interrogate our role(s) within these "flows of knowledge." Researchers in the natural and physical sciences and engineering are thought to have relatively straightforward ways to point to non-academic impacts, such as intellectual property generated and/or the economic contributions of spinout companies. And yet this is not the case for scholarly work that concerns computer-based AT. To understand why, we must first discuss the nature of the marketplace for AT software and devices, and the nature of the main actors.

Diseconomies of scale

The market size for AT software and devices is quite fragmented because of the large number of different types of impairments (motor, sensory-perceptual, speech, and cognitive) and disabling effects in the environment (referring both to the built and societal environment), occurring in myriad permutations and combinations (Tobias, 2013). AT interventions most often must be tailored to their contexts of use; the one-size-fits-all approach is simply not effective (Phillips & Zhao, 1993). This results in many different and relatively small AT markets. Other commercial markets (e.g., for personal devices and software applications) are sizeable enough to justify relatively large up-front research and development (R&D) efforts. When the expense of these efforts is amortized over a large-enough number of deployed units, the per-unit R&D cost sinks low enough that market appetite can bear the per-unit price. Commercial enterprises are generally not enticed to invest resources in small markets.

Another difficulty is the disconnect between the consumer and the payer. In Canada and the US, access to AT is mandated by governmental policy (often at several levels of government) and supported by public funds (though not exclusively so), giving rise to a fairly sizeable bureaucratic apparatus. For instance, in Ontario, for the cost of a piece of AT to be borne (or partially subsidized) by public funds via the provincial Assistive Devices Program (ADP), that piece must be "prescribed" by a duly-recognized speech-

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language pathologist (SLP) – with whom the requisite assessment appointment may be preceded by a months- or years-long waiting time. It must be drawn from a list of products that have been pre-approved, and be purchased from a reseller who is authorized under the ADP (Strong & Plotkin, 2010). Several categories of non-academic "actors" in the AT ecosystem can be identified.[3] First, there are the governmental actors, who oversee and determine the direction of the ADP and other related governmental policies and programs. They can be identified as "large-scale" decision-makers. Second, there are the AT *practitioners* (e.g., speech-language pathologists, occupational therapists, special education teachers), whose scopes of practice will involve various aspects of prescribing, recommending, and devising AT solutions for their clients/students, and who may also perhaps have a role in policy development (e.g., provision of service within a caseload). These actors can be identified as "small-scale" decision-makers (the scope of their decisions extends to his or her caseload). Third, and most importantly, there are the end-users, who are decision-makers in a very fundamental way (the scope of the decision concerns only him- or herself), since they are the ones upon whom decision-making about technology uptake/abandonment ultimately rests (this includes both children and adults).

The bureaucratic apparatus for the ADP becomes, in effect, a "gatekeeper" for the technology (the issue of innovation-uptake in this climate, unfortunately, must be left for another discussion). Certainly, an individual may pay out of pocket to circumvent this process, but the AT product costs are relatively high (possibly running to many thousands of dollars) and the community is already subjected to marginalized financial circumstances (Stapleton & Burkhauser, 2003). Alternatively, enterprising and resourceful practitioners (small-scale decision-makers) may draw from the (relatively limited) pool of open source software systems and other free resources for AT (e.g., nonprofits such as the Tetra Society of North America), but there are fairly large obstacles in place, notably in terms of perquisite technical skills and knowledge, which are not typically part of formal training.

Uptake of academic knowledge outputs

There are several scholarly communities relevant to AT, such as those that concern health policy analysis and innovation, internationalization, social justice, critical analyses in the fields of critical disability studies, empirical efficacy studies, and analyses conducted by researchers in speech-language pathology and/or education. Academic outputs from these communities may find uptake on the policy side of the AT ecosystem.

The academic outputs of scholarly communities, with a focus on the development of novel computer technologies for AT, may find uptake on the supply side of the AT ecosystem (i.e., which pieces of AT software and devices are available). This could happen, in principle, through commercialization via one of the main companies (such as Ablenet, Mayer Johnson, Assistive Technology, Dynavox, or Prentke Romich; see Websites) or via a spinoff research company (though this rarely, if ever, happens given the aforementioned market dynamics). Alternatively, technology transfer may happen through non-commercial vehicles, such as open source repositories (or very low-stakes commercial vehicles, like 99-cent Apple or Android apps). We focus on the latter mode of technology transfer, as we feel that it represents a viable alternative route for the transfer/uptake of AT. This mode has the potential to circumvent the dual barriers of ADP bureaucracy and of the commercial inhospitality of the marketplace. Moreover, we feel that a community of peer production has the potential to provide alternative modes of other aspects of AT delivery, although it is clear that there will be many challenges and difficulties. The aspects include information dissemination of new technology developments to stakeholders groups, which is now accomplished via various modes, such as through the sales forces of commercial AT entities and via professional development programming offered by relevant professional bodies (e.g., the College of Audiologists and Speech-Language Pathologists; the Ontario Teachers' Federation Special Education Gateway). The aspects of training and follow-on support are particularly important for AT delivery, and thus must be a component of any technology that is actually instantiated via open source. The inclusion of the necessary emphasis on training and support for end-users is likely to be among the biggest challenges facing the community of open source AT practice.

Academic research projects that seek to impart tangible impacts via open source dissemination represent, or as Ernest L. Boyer (1996) terms it, a *scholarship of integration*. In such efforts, academic research projects seek to place their resultant information and communications technology (ICT) innovations in a broader context, which, in our case, is the ecosystem of AT uptake and usage. The open source approach refers to a constellation of characteristics, such as copyright licenses aimed at ensuring availability, free (re)distribution of the source code, and giving end-users the ability to input into the software development process (e.g., to suggest new features or to report faults). The open source philosophy is based on the ideals of the hacker culture, which is premised upon breaking down barriers (e.g., the freedom to use, create, and tinker with software) (Kollock, 1999). Two such repositories are currently active.[4] Analyses have already shown that the best approaches for AT include open source software that runs on mainstream hardware (rather than proprietary and commercial hardware and software components) (DeRuyter, McNaughton, Caves, Bryen, & Williams, 2007), and modularized, component-based approaches (Pino & Kouroupetroglou, 2010).

(Co-)creation of knowledge about assistive technology systems and devices

In the science- and engineering-oriented AT academic research, a wide range of scholarship approaches can be seen. For this discussion, we make the assumption that such projects share a common set of characteristics: (i) development of a novel mathematical algorithm and/or analysis (computer science knowledge), (ii) application and computational instantiation of underlying computer science knowledge, (iii) embedding of a computational module within a software application (an application with a user interface and some sort of task-oriented domain of use), (iv) evaluation/analysis. In some modes of AT science scholarship, the user community becomes involved only at the very final phases (i.e., the point after the novel technology has been developed when evaluation studies are conducted and it is time to start recruiting subjects for testing). For quantitative empirical evaluation studies, researchers will oftentimes already have determined the outcome measures in accordance with established academic practices (but in the absence of input from the user community). Critiques and analyses of the ecological validity of these approaches can be found in the research literature. Sometimes, and disappointingly, there is no engagement with the target user community at all. Even worse, sometimes the users are

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not actually drawn from communities of individuals with disabilities and, rather, are drawn from a community of more easily accessible undergraduate students, who are then subjected to constraints and/or obstacles to "emulate" impairment (such as blindfolding to emulate vision loss or restraining the hands to emulate motor impairment).

Participatory Design (PD)

Other technology-oriented scholarship involves the stakeholders (the user community, families, friends, and relevant practitioners) throughout the entire trajectory of the research project (rather than just the final evaluation stages). The mode of scholarship for such engaged software development initiatives is very well captured by the design methodology of participatory design (PD), which has, at its core, the principle of engaging actual users of technology in the design of the technology (Muller & Kuhn, 1993). PD emphasizes a deep understanding of the needs of specific users. The methodology recognizes and affirms the validity of the user perspective, and values the expertise that comes from experience (Kensing & Blomberg, 1998). This mirrors the principle that practitioners and academic researchers each possess different forms of knowledge and can learn from each other (van de Ven & Johnson, 2006). The term *engaged scholarship* is used to describe a wide range of collaborative, community-based, participatory, and partnered research and associated knowledge mobilization and knowledge transfer activities. Thus, PD *requires* engaged scholarship. The methodology of PD and the methodology of engaged scholarship are two sides of the same coin, each methodology evolving within and emerging from its own domains, analogous to Darwinian convergent evolution.

The methodology of PD can be differentiated from the body of design practices that is concerned with the creation of inherently accessible environments and technologies. The broad-spectrum ideals of Universal Design (Inclusive Design, Design for All) advocate a design approach that emphasizes inherent accessibility, thereby obviating the need for population-specific adaption. Successful Universal Design is predicated on a broad and sophisticated understanding of a very diverse user population, whereas PD is predicated on engagement with specific users; thus, the approaches accomplish different objectives, and each has its respective merits and challenges.

Over the last decade, PD is increasingly used for the development of AT. For instance, Mike Wu, Brian Richards, and Ron Baecker (2004) used PD with a group of six individuals with memory loss (amnesia) to develop a computational tool to help with the problem of disorientation. In another research project, PD was used with people with aphasia in the development of an Enhanced with Sound and Images (ESI) planner for the personal digital assistant (PDA) (Moffatt, McGrenere, Purves, & Klawe, 2004). Julia Galliers, Stephanie Wilson, Abi Roper, Naomi Cocks, Jane Marshall, Sam Muscroft, and Tim Pring (2012) also engaged potential users with aphasia, and conducted a series of workshops in which five participants used gestures (rather than spoken or written language) to express ideas about software and paper game prototypes and to provide evaluations of them. In a study aiming to develop a communication application for individuals with cognitive disabilities, Melissa Dawe (2007) used a "technology probe" (an early prototype). Lisa Anthony, Sapna Prasad, Amy Hurst, and Ravi Kuber (2012) conducted a one-day PD workshop with 12 postsecondary students with various learning disabilities. In a study with eighteen older adult participants, Jennifer Davidson and Carlos Jensen (2013) involved potential users in the design of a smartphone app to monitor health. Isabel Gómez, Rafael Cabrera, Juan Ojeda, Pablo García, Alberto Molina, Octavio Rivera, and A. Mariano Esteban (2012) have developed a research praxis that combines PD with overt engaged scholarship. Below, we describe our lab's experiences in converging the methodology of PD and engaged scholarship.

Pre-exposure to KMb unit

The initial research activities in our lab, which were launched in 2002 when the first author of this article was hired as a new faculty member, centred on the design and quantitative evaluation of software interfaces of assistive technology software applications, with a focus on the application of computer compression and other algorithms. This was mostly curiosity-driven research, in a "science-based" mode typical of computer science research – rooted in the field's logico-mathematical intellectual foundations and then fused with empiricism and the scientific method (Gorn, 1983). Our initial work was positioned toward the theoretical side of the various techniques and methodologies in the domain of Human-Computer Interaction (HCI) scholarship. The primary publication venues were "traditional" (peer-reviewed workshops, conferences, and journals).

The objective in undertaking this program of research was to improve the design practice of assistive technology (to develop and validate optimal design principles), which in turn, would lead to more effective and efficient computer-based AT software and devices. We wanted to generate knowledge to be used for *de novo* designs (designing AT solutions from first principles), and also for the analysis of extant AT systems, such that design inefficiencies could be identified and remedied. Examples of work in this vein include various algorithms (e.g., for the analysis of a modified keyboard that can be operated with as little as a single push-button, for users with severe motor impairment) (Baljko 2005a; Baljko 2005b, Baljko & Tam 2006; Hamidi, 2007), which subsequently allowed us to derive optimized AT software applications (Hamidi & Baljko, 2012; Hamidi, Baljko, & Livingston, n.d.; Hamidi, Baljko, Livingston, & Spalteholz, 2010).

However, as we engaged in our scholarly field, we increasingly began to interact with actual users of our software. We further refined our critical praxis. For instance, we noted that the definition of AT is a *functional* definition, since it defines technology in terms of its capacity for empowerment, as opposed to the technology's intrinsic properties: i.e., any technology that can be used by individuals with disabilities in order to perform functions that might otherwise be difficult or impossible. Thus, the definition of AT can be fraught, since it is predicated on the definition of disability, which has been the focus of much critical analysis and critique (Goggin & Newell, 2003). We refined our conception of the *target user population* to include not only individuals who have motor, language, and/or sensory-perceptual impairment, but also their communication partners (parents, friends, peers, work colleagues, caregivers, educators, and so on). We are deliberate in this characterization of the target user population, since we now reject medicalist conceptions of disability that place the locus solely on the individual (Oliver, 1998). Since disability emerges from a nexus of societal factors, so too should assistive technology interventions be concerned with meta-individual contexts of use. We became convinced of the necessity of using a design methodology such as participatory design.

We became progressively more interested in the deployment of assistive technology in the field. We reflected upon the fact that there seemed to be relatively little uptake of knowledge outputs from the research literature in the AT user community. We saw very little evidence that the algorithms and computational systems that were so carefully disseminated in the research literature were ever taken up by other researchers or taken up by the user community (either as commercial or even non-commercial products). Success in the arena of peer-review publication began to ring hollow.

Exposure to KMb unit

We reached out to our institution's knowledge mobilization unit in order to explore options for building relationships with user communities. We were motivated by a desire to apply the methodology of participatory design in our scholarly research work. The knowledge mobilization unit (KMb) at York University is a fully integrated, institutional research infrastructure developed at York that seeks to connect academic research and expertise to non-academic individuals and organizations so that research can inform decisions about public policy and professional practice. It was developed as part of a university outreach strategy to engage diverse non-academic communities (including businesses and government agencies) in research activities (Phipps & Shapson, 2009).

On a conceptual level, we struggled with whether we were a fit with the KMb services. For instance (emphasis added): "knowledge brokers support an interactive process between researchers and *decision-makers* so that they can co-produce new knowledge to inform *policy and/or practise decisions*" (Phipps, 2011). We felt hesitant because we felt that KMb services surely were intended for partnerships with the "large-scale" decision-makers of the AT landscape (as identified in the Section "Non-Academic Impacts of Assistive Technology Scholarship"). Our desire was to connect with the "small-scale" decision-makers or end-users in the AT landscape (also identified in Section "Non-Academic Impacts of Assistive Technology Scholarship"). Also, the form of the new knowledge was expected to be pieces of technology and practices around their use. This seemed to diverge from expectations, which were slanted toward generating non-academic impacts from social science research, as opposed to science- and technology-oriented research.

Despite what appeared to be a conceptual misalignment, we were encouraged for two reasons. First, the inclusive and open attitude of the KMb unit was very encouraging. Second, we came to recognize that a piece of software could be viewed simply as knowledge instantiated in computer code (just as a scholarly analysis is knowledge instantiated in the form of written prose). Over 200 faculty members have become involved with KMb since 2011 (Phipps, 2011), and we are two of a very small number[5] of researchers who are funded by the Natural Sciences and Engineering Council of Canada (NSERC).

KMb Services Employed

We were asked by KMb to develop a plain language summary (PLS) that would serve as our "calling card" to introduce non-academics and decision-makers to our research expertise (Phipps, 2013). Even the "plain language" description that was developed as part of an NSERC Discovery Grant (which was the funding source for this thread of research) was inappropriate, as it was too technical. As noted by many others, "clear language" for a science/engineering audience is not the same as clear language for a non-academic audience. The PLS proved to be a challenging exercise and it took several iterations. As documented by Phipps (2013), dedicated and trained KMb staff worked with us to complete it.

Another KMb service we experimented with during the period from 2012 to 2013 was the online social networking and collaboration suite called O3, which was provided by the Ontario Research and Innovation Optical Network. It is an integrated suite of social media tools specifically designed to foster research and educational collaborations. We developed and deployed a first-generation website for our research lab, but eventually abandoned the effort due to O3's inflexible cookie policy (specifically, the Web platform cannot make any content available to browsers with cookies turned off, which is problematic for many computing professionals and practitioners).

On the basis of our PLS, a KMb staff member facilitated an introduction to the Markham-area Participation House, which is the site of an adult basic literacy program[6] led by Madelene Levy, an adult basic literacy teacher with over 18 years experience. Technology is a key component of her teaching philosophy, both to support learning concepts like budgeting and literacy, and also for communication and social skills. For us, she represented the ideal collaborator, given her role in running an educational program that specifically focuses on individuals with special needs, and her enthusiastic and open-minded approach to novel forms of technology. Students in the program are drawn from the residents of Participation House and from the community. Our relationship with them began in 2008 and continues to this day.

In 2009 – in part inspired by the exposure to the ideas of knowledge co-creation acquired from our initial KMb contact – both authors spent an academic year[7] at CanAssist, an organization (non-academic unit) at the University of Victoria.[8] Employing a diverse group comprised of individuals with disabilities, co-op and graduate students, and volunteers (consisting of retired engineers and other professionals), CanAssist develops technological solutions for community-identified problems, oftentimes by customizing and modifying existing technologies.

Post-exposure to KMb Services

The KMb services we received have afforded us the means to undertake several research projects with significant community engagement (see next section). Although the KMb services were most explicitly put to use in the CanSpeak project, there were significant carry-over effects for other projects, even when KMb services were not explicitly employed.

Evolved practices

CanSpeak

CanSpeak is a software system that allows individuals who have difficulty using the keyboard, mouse, and speech input to operate computer software (e.g., Web browsers and word processors). Typically, such users have motor disabilities and dysarthria of speech (poor motor speech articulation). CanSpeak's underlying idea is the combination of a user-tailored specialized input protocol – something akin to phonetic alphabet of the North Atlantic Treaty Organization (NATO) – and a user-tailored speech recognition engine.

In the research literature, many academics disseminate knowledge about the computational instantiation and evaluation of a design conjecture for a piece of AT. However, the CanSpeak research project is novel because it employs engaged scholarship. From the outset, we were engaged with community stakeholders, and this sparked the insight that an individual's immediate circle of communicators possesses great amounts of knowledge that could be cleverly leveraged into the software tool (Spalteholz, Lin, Livingston & Hamidi, 2008).

At every stage of the development, the design methodology of participatory design (PD) was employed, so the system was, in effect, co-designed with individuals with disabilities. We have combined PD with elements of reflective design (Sengers, Boehner, David, & Kaye, 2005) and thoughtful design (Lowgren & Stolterman, 2004), both of which promote paying close attention to design choices and allowing users to view the technology as a dynamic open-ended entity rather than a final solution. This attitude encourages creativity and allows for co-designers to come up with ideas that might, at first, seem undoable, but upon further reflection might contribute significantly to the design. On a technical level, we used modular design for this project, meaning that the system is sub-divided so that particular modules can be replaced to change functionality. Modular design allows for easy customization and modification, and it allowed us to do research using different modules, given that we engaged with different community groups (described below).

During initial system development (2008), we engaged users and stakeholders at CanAssist in Victoria, BC. Subsequently (2009 to the present), we engaged with Madelene Levy and a group of her students at Participation House (Markham/York Region District School Board). This collaboration was directly enabled by KMb services. Also, we collaborated (2012 to the present) with a second York-region community partner, the Friedreich's Ataxia Made Easier (FAME) organization[9]. We undertook this collaboration on our own initiative, but using knowledge and experience from the prior community engagement.

Our collaboration with Participation House included many face-to-face meetings, on-site meetings, and design sessions with collaborator/users and a collaborator/practitioner (Madelene Levy). The participatory design methodology proved to be fruitful as the insights that we gathered from input by users and their community (e.g., parents, caregivers, teachers) helped us tweak the system in novel and effective ways. Directly arising from our collaboration, for instance, we identified a process allowing parents to spearhead the speech recognition engine customization.

For our FAME collaboration, we engaged in requirement-analysis discussions with two collaborator/users[10] and undertook a participatory design process with one of them. The project, conducted over a ten-month period, resulted in a software system that is usable and, most importantly, has been adopted by our target users (Hamidi & Baljko, 2013). As an outcome of these collaborations, we have a relatively mature software system that we plan to deploy through an open source repository. The knowledge outputs of this phase of the project were disseminated at the 13th annual International Conference on Computers Helping People with Special Needs (Hamidi & Baljko, 2012).

Key lessons from this series of three community engagements include the importance of incorporating specific design features suggested by users (as opposed to having user involvement solely for evaluation purposes); the importance of establishing a trusting and ongoing relationship with community partners; and the importance of coming from a place of collaboration and respect. When communicating with individuals with disabilities, it is paramount to understand that additional time and energy may be required and to be prepared to invest accordingly.

Switch-Activated Writing System (SAWS)

Another community engagement project involved a small group of stakeholders in Agassiz, BC. The group consisted of a single end-user, MD, her communication facilitator (CF),[11] her special education teacher, practitioners from the BC Chapter of the Canadian Deafblind Assocation, and CanAssist. At the time, MD was a high school student in a regular academic program with aspirations to attend a college-level program after graduation. MD has severe motor impairment, severe speech impairment (she is intelligible only to her most frequent communication partners), and severe vision and hearing loss. She completed her schoolwork with the assistance of her CF. The PD process was employed in order to develop a system that could be operated by MD through the use of her existing motor capabilities (she could operate a single hand- or foot-mounted push-button, but not more complex input devices). The PD process resulted in the Switch-Activated Writing System (SAWS), a system that MD began to use on a daily basis to complete written components of her course work (prior to SAWS, MD used dictation via her CF to complete written components). SAWS entailed the development of several novel technologies and algorithms, but these scientific innovations needed the initial "spark" of insights gained through a collaborative team of academics and non-academics. The knowledge outputs of this research project are pending dissemination in the scientific literature, as is distribution of the software to other potential users.

Tangible computing

Rafigh is an ongoing project in which we are designing a tangible game for children with speech disorders. For this project, we are again using a mode of engaged scholarship, this time building collaborations with speech-language pathologists who work with children and other stakeholders. We have (informally) engaged with practitioners from the Toronto District School Board, as well as private specialized daycare providers. The project, at this early stage, motivates children to practice speech by interacting with living media (plants and mushrooms). We have been able to engage in productive discussions and have incorporated community feedback into the design.

We are now evaluating the tangible game as played by children drawn from the target client population (Hamidi & Baljko, 2013).

Democratization of design

One aspect of engaged scholarship is providing a more accessible pathway for non-academics into academic research. This parallels the maker movement, which loosely refers to the proliferation of amateur and professional designers who use both novel (e.g., 3-D printing) and traditional (e.g., metalworking) fabrication methods to subvert the mass production factory model and engage directly with every stage of the creation of their customized small-batch designs. It is greatly empowered, if not made entirely possible, by a democratization of manufacturing brought about by recent technological advances (Anderson, 2012). We see evidence of this particularly in the emerging movements concerned with the development of inexpensive prosthetics and orthotics (Dombroski, Balsdon, & Froats, 2014; Koutny, Palousek, Koutecky, Zatocilova, Rosicky, & Janda, 2012; Record, Ratto, Ratelle, Ieraci, & Czegledy, 2013). Also evident of this movement is a recent project concerned with the low-cost printing of tactile books to support emerging literacy for children with low vision (Stangl, Kim, & Yeh, 2014). Academics in the fields of computer science and engineering are well positioned to take advantage of these technological advances and serve as bridges to community members (since the technologies are not entirely mainstream at this point).

Our lab employs such maker techniques and by virtue of our mode of engaged scholarship, provides broader access to maker techniques that would not otherwise be possible. For instance, Rafigh and others projects involved the use of rapid prototyping (3-D printing) and embedded digital design tools. In recent years, access to these fabrication techniques has lowered barriers to the design and production of digital artifacts. This has allowed a greater number of amateur designers to actualize their ideas and turn them into physical working objects. The hacking subculture refers to a unique approach to the design and implementation of technology, and especially computer hardware and software that emphasizes sharing, challenging authority, playful cleverness, and the decentralization of technological resources (Levy, 2001). An important part of the hacker approach is the belief that technology should be used to improve life conditions, particularly through the democratization of access to information. The design philosophy behind this movement promotes both sharing design and involving users of a design in every stage of its fabrication, thus enabling a democratization of design.

Forms of research output and research capacity building

As an adjunct to traditional forms of research dissemination (peer-reviewed publication), we have undertaken novel forms of research output for non-academic audiences, including popular science articles, radio interviews, and workshops for non-technical audiences. We have become convinced about the value of so-called "grey literature," since it is through these communication methods that we have been able to inform the public about our work. In return, our audiences have given us constructive feedback and ideas for possible future directions.

As a result of our engaged scholarship projects, we have developed a vibrant and diverse community of lab "volunteers" (consisting mostly of undergraduate students and community members) and have collaborated with research groups and labs that have similar visions. Our lab atmosphere has grown to be very multidisciplinary, with students drawn from both computer science and science and technology studies graduate programs. A novel lab initiative has involved conducting tutorials and workshops on digital design and prototyping methods in Bhutan. This has provided an opportunity not only to exchange information about technologies and methods but also to engage in a multicultural dialogue that widened our perspective and motivated us to explore the views of different cultures and communities on design and assistive technology. Through this work, we have become exposed to the Bhutanese concept of Gross National Happiness (GNH), a socioeconomic indicator proposed as a more holistic alternative to the Gross Domestic Product (GDP) indicator that is commonly used to assess the economic health of a nation (Ura, Alkire, Zangmo, & Wangdi, 2012). GNH entails the identification of factors that lead to happiness and a better quality of life, and attempts to quantitatively examine the existence and prevalence of these factors within society. We found GNH highly relevant since it seems to better capture the "quality of life" goal that is often associated with AT.

Discussion and reflection

Rigour and quality of scholarship

In general, the rigour, quality, and independence of work that is explicitly welcoming of outside participation and influence may be questioned, but the contrary holds true in the particular domain of assistive technology. In fact, the absence or low degree of stakeholder engagement and low ecological validity has been critiqued in previous work. We have proactively circumvented potential criticism about the rigour of evaluation methodologies by following best practices in usability assessment (e.g., the adoption of appropriate empirical and experimental methodologies, careful collection of data, and careful statistical analyses to substantiate assertions of significance).

Outcomes and impact

In our domain, research impact – in terms of number, calibre, and citability of publications in peer-reviewed venues – remains a key indicator of outcome. In terms of stakeholder benefit, this measure remains qualitative rather than quantitative. Our intensive participatory design research and evaluation methodology precludes a large number of engaged collaborators, though our goal is to disseminate knowledge about our process in addition to the process outputs. Our goal is to foster awareness of open source resources and to supply the community with open source systems, so eventually we will be able to report statistics (in terms of numbers of downloads and ongoing system usage).

We note with interest that NSERC, a key funding source in our research area, has recalibrated their assessment process for Discovery Grant funding applications in the last few years, with an increased emphasis on the training of "high-quality personnel" (i.e., the applicant-researcher's previous/planned impact in terms of positively influencing the training of graduate and undergraduate students). It is through this mechanism that we see one of the most promising outcomes of our mode of engaged scholarship – providing new opportunities for student involvement at both the graduate and undergraduate levels – converge with an outcome measure that is valued by a funding body.

Effectiveness of the KMb approach

Our experience demonstrates the positive impact of KMb services in perhaps unexpected ways. There is a great serendipity in the confluence of the goals of KMb services, the particular characteristics of our technology-oriented program of research, and the methodology of participatory design. We came to view developing the KMb plain language summary as an exercise that had great value to us as researchers (to clarify and focus our thinking about community engagement). Our approach was to simplify even further the NSERC plain language summary.[12] Our research trajectory demonstrates the value of KMb facilitation and support in setting up even one community partnership – it gave us the knowledge and experience necessary for establishing many other community partnerships.

Politicization

We would be remiss if we did not acknowledge the political dimensions of engagement with disability communities. Since these communities are generally marginalized and underfunded, and since the academic engagement provides benefit (albeit limited in scope), engaged community partnerships will be inequitable if not equitably distributed. If the supply of willing academic partners cannot meet the demand for collaboration from community partners, then this tension will be fundamentally unresolvable. We seek to mitigate this potential inequity by maintaining transparency about our work and objectives, and by maintaining an open disposition to any potential collaborators. And for the present, the producer-push side appears to be stronger than the consumer-pull side of the equation (Tobias, 2013). Our long-term goal is to undermine the extant power structures by bolstering accessibility to AT technologies via open source (software and hardware). This may serve to subvert the efforts of the commercial actors in the AT landscape (albeit only over the long term).

Evolution, current and future

The practice and status of engaged scholarship is evolving for academic researchers concerned with AT technology. The field generally understands that success is achieved when effective AT components are developed and taken up by actual stakeholders (as opposed to a large number of highly cited publications). In addition to this, however, we feel that we are on the cusp of a sea change in how AT research is done (i.e., participatory design, open source dissemination, hacker/maker ethos). KMb services have served as a key driver for us, and could do so for many other similar application-oriented computer science and engineering research labs.

Conclusion

In this article, we have described how, over time and as supported by KMb services, the focus of our research activities has shifted from an emphasis on the abstract and theoretical aspects of assistive technology (AT) software components toward an emphasis on the deployment and usage of AT software by stakeholders. This emphasis is enabled by our engagement and interactions with the stakeholder community. We have evolved to see the intellectual and social value in collaborating with non-academic partners, specifically individuals with disabilities and their communities, in the production of new knowledge as it concerns AT. Our exposure to KMb services and its conceptual framework has given us the tools and capacity to undertake new and better modes of AT scholarship. We have located the value of this new knowledge within the extant ecosystem, identifying opportunities for researchers who undertake engaged modes of scholarship.

We believe that the inclination for engaged scholarship does not necessarily evolve naturally or even intuitively in our sub-discipline within computer science. We recognize, in retrospect, that our adoption of engaged scholarship was influenced by several factors, including the development of our research lab's critical praxis and the ready availability of institutional knowledge mobilization services. Also important was the lack of appropriate technology transfer services for our particular type of applied scholarship. There is a special confluence in the domain of assistive technology research among the philosophical underpinnings of engaged scholarship, participatory design, hacker/maker approaches, and open source software.

Notes

1. See the appendix for a research snapshot of this project.
2. The term can also be used to refer to non-ICT related technologies – including mobility devices such as walkers and wheelchairs – but does not in this article.
3. This characterization simplifies the landscape for the sake of brevity, but the essential information is preserved.
4. Two open source software repositories and forges (where software is developed) dedicated to assistive technology (AT) have been developed, OATSoft (Judge & Lysley, 2005) and Project: Possibility, which have formed active developer and user communities (Pino & Kouroupetroglou, 2010).
5. It would be ideal if we could quantify this further, but we do not have the data (yet).
6. This day program is run by the York Region District School Board (YRDSB). It is a separate entity from Participation House, which provides residential, respite, and supportive housing for adults with developmental disabilities
7. In the form of a sabbatical and academic internship, respectively.
8. Interestingly, York University and the University of Victoria are both early institutional partners in KMb strategy development, but this connection was coincidental to us.
9. Friedreich's Ataxia is a progressive degenerative neurological condition, often with muscle weakness and loss of coordination, making the operation of a standard keyboard/mouse difficult, especially after any sustained period of time. An individual's speech may be impacted by dysarthria, but is recognizable for specialized speech recognition programs (such as CanSpeak).
10. FAME is a grassroots organization that does not have an attached practitioner.

11. A CF is a skilled signer who mediates two-way communication (e.g., through translation of speech to sign to a deaf-blind person, close vision, or tactile sign language).

12. Coordination between the preparation of a PLS for NSERC and a PLS for institutional KMb units could be seen as a "low-hanging fruit" (since the extant NSERC PLS could be leveraged into a large number of them for KMb).

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Assistive Technology, Inc., Dedham, MA, http://www.assistivetech.com
CanAssist, University of Victoria, BC, http://www.canassist.ca
Dynavox Technologies, Pittsburgh, PA, http://www.dynavoxsys.com
Mayer Johnson, LLC, Solana Beach, CA, http://www.mayerjohnson.com
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The Benefits of Co-Creation for Assistive Technology

What is this research about?

Assistive technology (AT) is technology designed to assist people with disabilities, and involves many phases: design, creation, testing, and publishing. AT stakeholders consist of people with disabilities and their community, including peers, parents, teachers and caregivers. AT stakeholders are often brought into research during the testing phase. But how would AT change if stakeholders had a say in the design phase?

Knowledge mobilization (KMb) is about bringing together stakeholders and researchers to move towards a solution for a community need, and KMb tools help to include stakeholders in research projects. The researchers overcame logistical, research culture, and outreach issues to use KMb tools with stakeholders.

Working with stakeholders during the AT design phase has clear benefits. When AT is created for stakeholder needs, it improves their sense of having a say in the design. Thus, stakeholders gain more influence in the world and a stronger impact on KMb and KMb projects.

What you need to know:

Knowledge mobilization tools let researchers engage stakeholders earlier in a project. Making stakeholder concerns become the basis for a research question. Thus, research goals can change from being theoretical to practical, which develops assistive technology that is better suited to the needs of project stakeholders.

What did the researchers do?

The researchers worked with York University's Knowledge Mobilization (KMb) Unit to learn how to bring stakeholder input into AT design. They also worked with CanAssist, an AT research entity at the University of Victoria. The program involves academics, stakeholders and professionals who work together to create AT for community concerns.

The researchers used Participatory Design (PD) methods as a means to include stakeholders at each stage of the research process. Together they developed AT for stakeholder needs. Reflective and thoughtful design methods allowed for theoretical context and sound design, while including stakeholder suggestions.

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The researchers connected with four community stakeholders. These relationships have lasted from one to five years. Two ATs were developed through co-creation. A third AT is being developed. Information about AT was shared through non-academic sources for all stakeholders to use. This included the use of Open Source resources, radio interviews, workshops and articles in non-academic journals.

What did the researchers find?

The researchers learned to:

- Find a way to make sure stakeholder suggestions are integrated into AT design.
- Maintain relationships and clear goals to build trust with stakeholders.
- Be patient when more time and energy is needed to co-create with stakeholders.
- Meld together the methodology of Participatory Design (PD) and KMb practices.

AT became more useful because the project stakeholders were engaged with each research phase. Open source resources also helped to engage stakeholders. It personalized AT to a person's needs. It also serves as an important tool to measure the impact and benefit of research for stakeholders.

KMb services had positive effects for this process. Researchers learned how to engage with stakeholders by presenting research in plain language. The KMb Unit also helped form connections with stakeholders.

How can you use this research?

Researchers who have not used KMb tools will learn about the positive impacts stakeholders can have when they are included at each stage of research. The importance of maintaining positive relationships with stakeholders is outlined. Discussion of ways to keep good relationships with stakeholders will be a good starting point for researchers wanting to use KMb tools in their research. Researchers who employ the methodology of PD will understand the goals of PD and KMb are intertwined.

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Knowledge Mobilization at York

York's Knowledge Mobilization Unit provides services for faculty, graduate students, community and government seeking to maximize the impact of academic research and expertise on public policy, social programming, and professional practice. This summary has been supported by the Office of the Vice-President Research and Innovation at York and project funding from SSHRC.

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