Design and Use of Assistive Technology

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Editors

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Social, Technical, Ethical, and Economic Challenges

Foreword by Maja J. Matarić

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Foreword

The not too distant future will feature assistive technology as an integral part of people's lives. This future is ensured by the disquieting speed at which the need for that technology is growing. With the aging population trends in developed countries and the growing rates of developmental and other disorders and conditions in children, large sectors of the population are in need of one-on-one, dedicated, and individualized care. At the same time, our species' ever-increasing lifespan means such care is needed for increasingly longer periods, beyond convalescence and into long-term rehabilitation and life-long support. Given population demographics, there simply will not be enough human labor available to provide this needed care. The resulting "care gap" presents a niche for human-centered technology. What does it take to create such technology?

The challenges of safe, ethical, culturally-appropriate, engaging, accessible, and affordable assistive technology are many, and constitute the motivating forces of the growing interdisciplinary research trend reflected in this book. If we are to make progress toward addressing these challenges, we must create a culture that sustains an active interaction between the technology developers and the intended user communities, by bringing them much closer together than they have been or have needed to be so far. The two communities must inform each other; the collaboration must be bidirectional. In an effective collaboration, users direct research to make it relevant to real-world needs, and researchers disseminate technologies and training through service models. To succeed, we must also address the complex ethical issues of technology acceptance, dependence, access, and safety throughout the process, not after the technology is developed. Finally, the foundation for making all this possible must rest on a funding structure that provides support for the full cycle of collaborative, interdisciplinary, and community-centered development, testing, evaluation, and iterative improvement.

The future is in sight but we are not yet there. This book and related work aid in outlining the steps that will bring us closer to what will be a true

paradigm shift in technology-aided medicine and health. In the words of a participant in one of our assistive technology studies, "The sooner we can do this, the better!"

University of Southern California *Maja J. Matarić*
May 2010

Preface

Assistive technologies have the potential to significantly improve the lives of people with disabilities, by enabling independence and facilitating social connections. However, these same technologies can be a barrier to independence and social connectedness if they are poorly designed, do not effectively incorporate user requirements, or are inappropriate for the task at hand. Effective assistive technologies depend not only on "good" engineering design (sometimes a challenge in and of itself), but also on the extent to which the technology has been integrated with clinical needs, user requirements, ethical concerns, and the social context of the technology's use. In fact, poor, ineffective, or inappropriate design is a key cause of device abandonment. The gaps between engineering design, clinical evaluation, and actual use represent an inherently multidisciplinary challenge that must be forcefully and creatively addressed if assistive technologies are to better succeed in enhancing people's lives. In a workshop held July 22–24, 2009 at the University of British Columbia, "Removing barriers and enabling individuals: Ethics, design, and use of assistive technology" (http://www.removingbarriers.pwias.ubc.ca), clinicians and researchers from computer science, engineering, ethics, medicine, and rehabilitation sciences gathered specifically to address this increasingly expensive issue.

This book is a result of presentations and discussions that took place over the course of the 3-day joint Peter Wall Institute for Advanced Studies (PWIAS)/Institute for Computing, Information, and Cognitive Systems (ICICS) Exploratory Workshop. The workshop was unique in its interdisciplinary focus and opportunities for multidisciplinary, small-group discussion. The workshop focused on four different *topics*: evaluation, sensing, networking, and mobility, and four different cross-cutting *themes*: novelty, customization, privacy, and user perspective. Workshop participants were encouraged to go beyond mere anecdote to identification of current problems and potential improvements in the entire cycle of design, evaluation, knowledge transfer, and actual use of assistive technologies. Three key recommendations were identified: (1) The user's experience must be fully – not just partially,

anecdotally or vicariously – integrated into both engineering design and clinical evaluation. (2) Academic outreach via service models should be widely adopted to create customized assistive technology solutions for clients as the experience simultaneously educates the embedded researcher and students in real-world situations. (3) Knowledge transfer should be enabled through the creation and enforcement of regulations and standards to increase quality and reduce cost, the implementation of mechanisms to pool risk and limit liability, and the financial support to small businesses to capitalize on the inherent advantages of agile, niche companies.

The purpose of this book is to assess some of the major hurdles in bringing assistive technologies out of the lab and into everyday use and to provide guidelines and recommendations to improve their design and use. Some of the most difficult problems in creating effective assistive technology are (a) the inherent heterogeneity of the user population, (b) privacy concerns in data gathering and analysis, (c) knowledge transfer of novel technologies, and (d) incorporation of user perspective into the design process. It is our belief that true solutions to these issues can only arise through a multidisciplinary approach.

We have gathered in this book a set of papers that demonstrate how process improvements in assistive technology deployment have the potential to empower businesses, researchers, and nonprofit organizations to create and bring to market new devices, such that they incorporate ethical, social, and clinical concerns by design. Contributors to the book are leading researchers in their fields, and their contributions are inherently broad in scope and accessible to researchers from a wide range of disciplines. We provide a critical assessment of hurdles in assistive technology that are relevant for researchers in engineering, computer science, rehabilitation sciences, and ethics. The book is organized according to the main outcomes of the workshop: regarding the user's experience, research and academic outreach, and development and commercialization.

We begin with a discussion of the issues that inherently frame how assistive technology is conceived of, designed, used, and perceived. In Chap. 1, Silvers identifies key ways in which ethics of assistive technology differ from seemingly similar issues in engineering ethics and medical ethics. Miller Polgar provides an alternative framework in Chap. 2 in which to consider the role and assumed neutrality of assistive technology, both as a barrier and as an enabler. Even the words commonly used to describe "assistive" technology have implicit assumptions about perception of and identification as an individual with a disability. Ladner makes a case for "accessible" technology in Chap. 3. In Chap. 4, Cook and Adams focus on how technology can enable play for children with disabilities. In Chap. 5, Cook, Miller Polgar, and Livingston discuss need-based and task-based assistive technology design and evaluation as a means to prevent device abandonment. They employ the human activity assistive technology (HAAT) model to evaluate both successful and failed technologies.

The second part of the book focuses on models of the research pipeline and the role of academic outreach in improving how assistive technology is designed, evaluated, and used. Simpson discusses in Chap. 6 common barriers in the typical research pipeline. Livingston discusses in Chap. 7 how community service in academia can not only enable improved technology design and use, but is also a means to create a new workforce of engineers and technologists cognizant of accessibility issues, irrespective of whether the technology they design is truly "assistive." Matsuoka and Lewis provide a case study in Chap. 8 of the creation of a non-profit organization, spun off from work done originally in academia, to create highly-customized assistive technologies. Lastly, Danielson, Longstaff, Ahmad, Van der Loos, Mitchell, and Oishi discuss in Chap. 9 the results of a recent survey in the ethics of assistive technology that highlights some of the unique challenges in the research, development, evaluation, implementation, and use of assistive technologies.

The last section of the book discusses some of the most difficult aspects of improving assistive technologies – the broader legal and economic context that influences the development and commercialization of assistive technologies. In Chap. 10, Birch evaluates the current regulations and standards (as well as those in process but not yet implemented) and argues that enforcement of regulations and standards is required to provide truly universal access. Borisoff draws upon his personal experience as an entrepreneur, to discuss in Chap. 11 some of the unique challenges and opportunities in assistive technologies due to the small market for AT products.

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Acronyms and Abbreviations

AAC	Augmentative and Alternative Communication
ACM	Association for Computing Machinery
ADA	Americans with Disabilities Act
ANSI	American National Standards Institute
ASL	American Sign Language
ASSETS	ACM SIGACCESS Conference on Computers and Accessibility
AT	Assistive Technology
CAE	Centre for Applied Ethics
CAOT	Canadian Association of Occupational Therapists
CAPTCHA	Completely Automated Public Turing test to tell Computers and Humans Apart
CHI	International Conference on Human Factors in Computing Systems
CRTC	Canadian Radio–television and Telecommunications Commission
DHRN	British Columbia Disabilities Health Research Network
DSS	DriveSafe System
EADL	Electronic Aid to Daily Living
EATS	Efficiency of Assistive Technology and Services
EMG	Electromyography
E&J	Everest and Jennings, Inc.
FCAOT	Fellow of the Canadian Association of Occupational Therapists
FCC	US Federal Communications Commission
FDA	US Food and Drug Administration
G3ict	Global Initiative for Inclusive Information and Communication Technologies
GPS	Global Positioning System
HAAT	Human Activity Assistive Technology
HAC	Hearing Aid Compatibility

HCI	Human–Computer Interaction
ICICS	UBC Institute for Computing, Information, & Cognitive Systems
ICRA	IEEE International Conference on Robotics and Automation
ICT	Information and Communication Technologies
IDEA	US Individuals with Disabilities Education Act
IEEE	Institute for Electrical and Electronics Engineers
IEP	Individualized Education Plan
IRD	Interactive Robotic Device
IROMEC	Interactive Robotic social Mediators as Companions
ISAAC	International Society for Augmentative and Alternative Communication
MBA	Master of Business Administration
MPT	Matching Person and Technology Assessment
NASA	US National Association for Space and Aeronautics
O.C.	Order of Canada
OCR	Optical Character Recognition
OT	Occupational Therapist
O&M	Orientation and mobility
PIADS	Psychosocial Impact of Assistive Devices Scale
PWIAS	UBC Peter Wall Institute for Advanced Studies
P.Eng.	Professional Engineer
QUEST	Québec User Evaluation of Satisfaction with Assistive Technology
RESNA	Rehabilitation Engineering and Assistive Technology Society of North America
SIGACCESS	Special Interest Group on Accessible Computing
SGD	Speech Generating Device
STEM	Science, Technology, Engineering, and Mathematics
TADNSW	Technical Aid to the Disabled of New South Wales
UBC	University of British Columbia
UIST	User Interface Software and Technology
UN	United Nations
UVATT	University of Victoria Assistive Technology Team
VA	US Dept. of Veterans Affairs
WCAG	Web Content Accessibility Guidelines
WSP	Wireless Service Provider
W3C	World Wide Web Consortium