Make it accessible:

The state of assistive technology research, funding, and usage in Toronto

A report from the Tetra Society's Assistive Technology Forum

About the forum

The Tetra Society's Greater Toronto Area chapter planned and hosted an Assistive Technology forum at the Canadian National Institute for the Blind (CNIB) Office on 18 June, 2009. This forum was the first of its kind, and was designed to be an opportunity for collaborating with and eliciting perspectives from the various people connected to assistive technology (AT). The forum brought together approximately 130 community members, including people with disabilities who use assistive technology, parents and caregivers of assistive technology users, researchers, educators, businesses, students, and Tetra Society volunteers.

The Honourable David C. Onley, Lieutenant Governor of Ontario, attended the forum and addressed delegates on disability issues and assistive technology. Rick Ball, the world record holder for single-leg amputee marathon runners, spoke about his personal experiences with assistive technology, and panel shared their concerns and ideas. This interactive panel included Elaine Biddiss, professor and researcher from the University of Toronto; Dale Zimmerman, better known as the "Toy Doctor" from the Toronto District School Board; Maria Cruz, assistive technology user and Tetra Society volunteer; and Esther Dzura, parent of a young man with a disability and founder of the Toronto Power Wheelchair Hockey League. The Forum also included facilitated small-group discussions among participants to identify successes and gaps in assistive technology, and to elicit perspectives on what roles the government, researchers, businesses, educators, and the Tetra Society should play in improving assistive technology for everyone.

This report is a summary of the proceedings from these small-group discussions.

About the Tetra Society

The Tetra Society of North America is a non-profit organization, founded in 1987 in Vancouver, BC that recruits skilled volunteers to design and create customized assistive devices for people with physical disabilities. Tetra's assistive device projects tackle mobility, personal care and communications. They facilitate education, work and recreation. They provide increased access within households–kitchens, bedrooms and bathrooms–and in other environments, such as vehicles or workplaces. In short, Tetra's assistive devices focus on improving quality of life. While Tetra operates in numerous cities and towns throughout North America, the services and talents of its expert volunteers are available to everyone. Tetra shares information on past projects system-wide, and requests for assistive device projects can even be filled remotely if someone lives in an area not served by a Tetra chapter.

For more information, please visit: http://www.tetrasociety.org

Key recommendations

Government

- Adopt a case-by-case funding model
- Make funding information clearer
- Speed up device approval process
- Fund leisure devices

Assistive technology researchers

- Involve users in the design process to improve usability of devices.
- Focus on modular design

Businesses in the assistive technology sector

- Produce affordable assistive devices
- Involve clients in design process
- Adopt a modular design approach
- Improve device repair times

Educators

- Incorporate assistive technology design projects into engineering curricula
- Incorporate assistive technology studies into other relevant programs
- Introduce a volunteer service requirement into post-secondary courses

The Tetra Society

- Increase awareness of Tetra among assistive technology clients
- Increase capacity for projects by expanding volunteer network
- Create a database for people to share assistive device design solutions
- Provide a guide for clients on navigating provincial sources of funding

1. The current state of assistive technology

What is working right now

Assistive technology is levelling the playing field. For people living with disabilities, assistive technology makes the difference between independence and dependence, between employment and unemployment, and between participation and sitting on the sidelines. At the forum, participants shared many positive personal stories. Many find simple, affordable solutions to problems they thought would require an expensive, high-tech one. The Tetra Society and rehab centers like Bloorview Kids Rehab design and build effective custom devices for other participants. Children with disabilities are increasingly able to participate in regular classroom settings, and later in post-secondary institutions and in the workplace, because of the equalizing effects of assistive technology. Mainstream devices also make a difference for people living with disabilities. One person with a hearing impairment seeking a job was able to secure employment as a driver by using a BlackBerry to assist in communication. Computers and other communication devices make it possible for people with disabilities to have their own home-based businesses. For people who are not physically able to get out often, being able to access the computer means access to the world.

What is not working

Despite these successes, forum participants readily identified a number of key challenges with assistive technology.

Funding

Participants stressed that high costs and a lack of sufficient funding are major barriers to accessing assistive technology. Ontario's

Assistive Devices Program (ADP) covers a maximum of 75% of the cost of approved assistive devices. This support is not sufficient for many individuals who require expensive assistive devices such as power wheelchairs, and who are already on limited incomes. The ADP does not provide funding frequently enough to allow users to replace devices that break, become obsolete, or are no longer suitable due to users' changing abilities. The list of products approved for ADP funding does not include new or rare assistive devices, preventing people from getting the devices that best meet their needs. In provinces and territories without assistive devices programs, people living with disabilities grapple with community and veterans' funding sources. Across the board, people do not know what funding sources are available, where to go for funding, or what the criteria and rules are.

Participants were also concerned that funding criteria are too stringent, forcing people to either use devices that do not meet their needs or to go without assistive devices. People who can walk a little sometimes only receive funding for a walker, when in reality they need wheelchairs to be more mobile, independent and productive. Some people with developmental disabilities require funding for assistive devices such as communication aids, but do not meet the funding criteria for Ontario's ADP or are not eligible for the Ontario Disability Support Program's (ODSP) income assistance. People seeking assistive technology must have a referral from a medical practitioner, which slows down the funding process and can prevent people who are improperly diagnosed from accessing devices they need.

Repair

Devices break down often and are expensive to repair. Parents and caregivers noted that children's devices break down more frequently than do adult devices because they are not robust enough to withstand the abuse children put them through. Repairs take longer than for mainstream devices because parts are not readily available.

Being left without an assistive device during the repair process drastically reduces a person's quality of life and independence.

Upgrades

Assistive technology manufacturers make frequent upgrades to devices and software programs to keep up with advances in mainstream technology. These expensive upgrades are not covered by funding sources, so many people are stuck with old technology that is not as practical as the updated version. Using outdated, incompatible technology also reduces a person's chances of employment, so the difficulties of upgrading are of particular concern for assistive technology users entering the workplace.

Necessary add-ons

Many devices require additional components or accessories to maximize usability. These add-ons are expensive and are not covered by funding sources. Many wheelchair users require a lap tray as a stable surface for eating or working, and most of these trays cost upwards of $60. Cane holders and bags are other necessary add-ons for which there is no available financial assistance.

Compatibility

Often assistive devices are incompatible with mainstream technology, and are sometimes incompatible with other assistive technology devices. Dragon Naturally Speaking is a popular dictation program, but it does not work well when a screen reader like JAWS is also in use. Users have to purchase J-Say, an expensive separate component, to make the two programs compatible.

Multiple disabilities and changing abilities

Assistive devices do not always support the diverse and changing needs of assistive technology users. Some people have multiple disabilities which require them to use multiple devices or to adapt existing devices. Each person has individual needs, even within a group of people with the same disability. A person's abilities and

disabilities also change over time due to growth, disease progression, or therapeutic improvements. Failing to recognize and respond to these dynamic abilities causes many devices to fall short of meeting peoples' needs.

Communication

People need to know where to go for assistive devices funding and what the criteria are. They also expressed a need to know more about what assistive devices are currently on the market, and what solutions can best meet their needs. Many occupational therapists and other clinicians are not fully aware of the variety of existing devices, nor do they know that groups like the Tetra Society can build custom assistive devices for patients. People instead hear about possible solutions from friends, family and other assistive technology users. There is currently no database to connect people to each other and to the assistive technology resources they need.

2. The future of assistive technology

Government

Adopt a case-by-case funding model

In order to be responsive to the changing needs of people living with disabilities, Ontario's ADP should be administered on a case-by-case basis. This would allow case officers to increase support when users need new or different devices.

Information

The Ministry of Community and Social Services, and the Ministry of Health and Long Term Care should put more effort into clearly communicating information about available resources. Simple and concise documents outlining funding procedures and processes could be added to the ADP website.

Speed up new device approval process

Assistive technology users cannot receive funding for new or rare devices that have not been approved by Ontario's ADP. The approval process should be streamlined and integrated with the case-by-case funding model to allow people to access the devices they need.

Leisure devices

Ontario's ADP does not fund devices intended solely for use in leisure activities. While these devices are not essential, they greatly improve their users' quality of life. These devices should be funded on a case-by-case basis.

Researchers

Researchers work at the cutting-edge of assistive technology and play a critical role in determining the direction of assistive technology development.

Participatory design

Assistive technology users are notably absent from research and development processes. They need a place at the table. Forum participants stressed that the design process needs to be open and collaborative, with more communication between users and researchers. Many assistive technology users and their caregivers find that assistive devices on the market do not fully meet their needs, and feel that design problems could easily be overcome if they–the end users–were involved in the design process through focus groups, consumer surveys, and evaluations of design prototypes. This participatory approach to research, while slower, allows researchers to better appreciate the needs of people with disabilities and to design solutions that better address these needs. Professor and researcher Elaine Biddiss at the University of Toronto notes, "Participation in research has many rewards: it can provide a channel by which users can reach a broad, international audience; it can lead to improved products and services; it can be a learning experience for all involved."

Customizability

Researchers need to factor into the design process the diversity and the changeability of peoples' needs. One approach is to develop and test modular designs for assistive devices. Modular designs allow individuals to customize devices to better suit their needs, and to fix malfunctioning technology by replacing modules rather than the whole product. Researchers must work closely with manufacturers in developing a modular design methodology and in bringing modular

devices to the market. Researchers should also incorporate universal design principles into their work.

Cost reduction

Researchers need to work innovatively to develop affordable assistive technology solutions. Otherwise, regardless of how effective they are, they will not reach users.

Businesses and manufacturers

Cost reduction

Assistive technology is often prohibitively expensive. Businesses have limited capacities to reduce these costs, but the growing elderly population means that some devices can be produced on a larger scale at lower costs. Assistive technology companies could collaborate with larger mainstream companies to take advantage of this opportunity to mass produce certain devices. Businesses should also collaborate with researchers to ensure that new assistive devices are designed and built with affordability in mind.

Compatibility

To improve compatibility of assistive devices with one another and with mainstream technologies, manufacturers should be in regular, open dialogue with researchers, other assistive technology manufacturers, and mainstream businesses.

Usability and customizability

Manufacturers need to ensure that assistive devices meet their users' needs. To this end, assistive technology users consistently reported that their needs would be better met if they were involved in the design process. To improve the customizability of manufactured devices, manufacturers should work together to develop standards for modular and compatible designs.

Repair times

Manufacturers need to have spare parts for assistive devices readily available to shorten repair times.

Educators

Engineering curricula

Assistive technology design can compliment undergraduate engineering design courses. The assistive technology design process emphasizes fully understanding the problem faced by the client, thinking creatively and innovatively about solutions, iterating through potential designs, experimenting with prototypes, and analyzing and fine-tuning the final product. This process parallels the design process currently taught in engineering classes. Throughout the design process, communication with the client, sensitivity to her needs and having an understanding of the broader context of her situation and of disability are paramount. Working with a client with a disability is an opportunity to fulfill the responsibility engineers have to make peoples' lives better. Ultimately, through their involvement in assistive technology design, students can make a real and measurable positive impact in the life of someone living with a disability. Many assistive devices are relatively simple and could serve as an excellent introduction to design for first year engineering students, while more complex devices may be incorporated into upper year design or thesis courses.

Beyond engineering curricula

Assistive technology studies could also be integrated into programs such as occupational therapy, physiotherapy, speech language pathology, and physical education. Beyond these programs, business and economics students, for instance, could study the economic merits of people with disabilities and assistive technology users being active in the workforce. Public policy and politics

students could study the funding of assistive technology programs; sociology students, discrimination or social worth among people with disabilities; and anthropology students, perceptions of disability and worldwide use of assistive technology.

Service

Ontario high school students must complete forty volunteer hours to graduate. This requirement does not exist in most universities and colleges. Forum participants suggested that the volunteer service requirement should extend into post-secondary education, and that programs should be developed that allow students to donate their time to design and build assistive devices. In this service program, students would learn about disability issues and assistive technology.

The Tetra Society

Awareness

Many participants were unaware of the Tetra Society prior to the forum. They expressed the need for better advertisement of Tetra in the Toronto area. Although Tetra is doing good relevant work, its small public presence hinders its growth. Various news and online media should be used to promote Tetra, including newsletters, advertisement on public transit, blogs, advertisement in newspapers or on TV, and advertisement on websites of other organizations with similar objectives as Tetra. Tetra could also join or host events to promote its services and encourage discussions about the contemporary challenges of assistive technology.

Capacity building

Tetra needs to expand and strengthen partnerships with assistive device users, caregivers, and other non-profit and for-profit organizations. Such collaborations could expand Tetra's volunteer

base, facilitate outreach to potential clients, and provide physical workspace for building assistive technology. As partnerships grow, Tetra can facilitate personal and professional networking among stakeholders. Tetra needs to do more of the good work it is already doing. It also needs to expand its fundraising efforts in order to grow, particularly if it plans to hire a permanent staff.

Communication

Tetra can do a better job connecting assistive technology users to each other and to the resources they need. Tetra should expand its database of completed projects and to include assistive technology users' personal designs. This would allow Tetra volunteers to search through existing designs to assist in developing new ones. Many assistive technology users and caregivers develop their own assistive devices, and this database could connect them to solutions that have worked for others with similar challenges. Tetra could also create tools that would help users and caregivers navigate the sources of funding and support for assistive technology.

Responsibility

At the forum, people were curious about how Tetra addresses the fears that devices designed by volunteers are unreliable. People may elect to not use Tetra's devices because they fear they will be unsafe or ineffective. Tetra should establish standards for assessing the safety and reliability of its innovations. Tetra should also include the user in the design process, offer frequent follow-ups, and provide maintenance and repairs for devices.

Participation

Tetra should host more open forums like this one to give everyone a say in assistive technology issues. Future forums could have longer small-group discussions, as this is where the good work happened.

Outside Tetra's mandate

Tetra can indirectly play a role in advocacy for people with disabilities by educating key organizations and governments about the importance of accessibility and assistive technology. To achieve effective advocacy, it may be appropriate to create a dedicated branch of the Tetra Society for advocacy in the GTA. However, the branch's activities must not influence the non-profit status of Tetra.

Conclusions

Assistive technology is working well.

People with disabilities can do more and more with the help of innovative custom devices, and can participate more fully in society than ever before.

But it can be a lot better.

This means more of the same.

But some things need to change.

Assistive technology needs to be more affordable, researchers more responsive, educators more involved, funding more flexible, information more accessible, and design more collaborative.

Tetra has a big role to play, but they are not the only players.

Governments, researchers, businesses, and educators need to do their part to support assistive technology users.

Contributors

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