Challenges in Assistive Technology Services in Quebec: A Clinician's Perspective

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Abstract — Scientific advancements have made it possible to keep people alive with increasingly severe impairments, and the general population is ageing. The healthcare system must manage a larger number of people with independence difficulties related to physical, cognitive or sensory disabilities. It is vital to optimize healthcare services to manage this challenge and improve quality of life for these individuals. Technological development is one of the most promising ways of achieving this objective. However, it is still very difficult to integrate technological aids into rehabilitation. The aim of this article is to summarize the obstacles to be overcome so that technological aids may be used in rehabilitation to meet the needs of people with impairments, and also optimize their social participation and quality of life. To overcome these difficulties, it is vital to make specialized and general technology accessible to the greatest number of people, with varying levels of ability. Among other things, research has a major role to play in considering the needs of people with disabilities at all levels of technological development.

Passwords — Technological aids, rehabilitation, social participation

Défis de prestation des services d'aides technologiques au Québec : le point de vue d'une clinicienne
Résumé — L'avancement de la science permet de maintenir en vie des personnes ayant des déficiences de plus en plus graves. La population générale est vieillissante. Le système de santé doit prendre en charge un plus grand nombre de personnes qui présentent des difficultés d'autonomie liées à des incapacités physiques, cognitives ou sensorielles. Il devient alors essentiel d'optimiser les services de santé pour gérer ce défi et améliorer la qualité de vie de ces individus. Le développement technologique est un des moyens les plus prometteurs dans l'atteinte de cet objectif. Toutefois, il est encore très difficile d'intégrer les aides technologiques en réadaptation. Le présent article vise à faire état de la situation des obstacles à surmonter pour que les aides technologiques soient utilisées en réadaptation afin de répondre aux besoins des personnes ayant une déficience physique, mais aussi d'optimiser leur participation sociale et leur qualité de vie. Pour contrer ces difficultés, il est essentiel de rendre les technologies spécialisées et générales accessibles au plus grand nombre de personnes, et ce, à des niveaux de capacités variés. La recherche, entre autres, a un rôle important à jouer en considérant les besoins des personnes ayant des incapacités à tous les niveaux du développement technologique.

Mots clés — Aides technologiques, réadaptation, participation sociale

Introduction

As technology becomes more pervasive in our everyday lives it is becoming increasingly important to rehabilitation. Whether as a clinical tool, a treatment modality or as a compensatory aid for a disability, technology is changing the way clients and therapists interact with their environments.

An assistive technology device is best defined as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized that is used to increase, maintain, or improve functional capabilities of individuals with disabilities"[4].

Assistive technology can be a very powerful means of improving outcomes and increasing the independence of persons with disabilities. It can also improve the quality of life and the ability of persons with disabilities to fully participate in all their social roles within their communities. However, without ensuring timely access to appropriate technology, we may be creating additional barriers to integration and increasing the marginalisation of people living with disabilities.

With an increasingly aged population and better survival rates due to improved medical care, we will have escalating numbers of persons with disabilities who will need services in this field. It is essential to look at innovative ways to meet these needs without overburdening the health care sector.

To ensure that services correspond to the current and future needs of our clients, it is important to review some of the challenges faced by clinicians involved in providing assistive technology services today, and identify some of the areas which need to be addressed.

Clinical considerations

Assistive Technology Services Delivery

Providing assistive technology to persons with disabilities is a specialized task. It requires a good clinical background with an understanding of a wide variety of disabilities and their impact on the physical and psycho-social functioning of the individual. In addition, there is an ever-present need to keep abreast of new trends and technologies and to constantly train and retrain oneself in the use of devices which are continually changing and evolving.

Quality services involve more than simply assessing the needs, abilities and interests of a user and his environment and recommending an appropriate device. It requires the time to engage the future user of the technology, providing information on what are the options and demonstrating potential solutions and empowering the individual to take an active part in the decision making process. It has been documented that the increased participation of the users in the process of device selection is one of the key indicators for success in long term use[3].

The configuration, ongoing adjustments and training of the users and their caregivers are all necessary components to achieve long-term success in the use of technological aids. However, administrative support for these components is not always forthcoming, especially when waiting lists for these services are long. There seems to be a drive to closely correlate efficiency with seeing greater numbers of clients, and reducing the waiting times of persons requiring services.

It is important to understand that providing technology to some individuals is a commitment to ongoing service. One-time evaluations and simple solutions are becoming increasingly rare. Mainstream technology is evolving rapidly and users of technology must be able to adapt quickly in order to continue to participate in all of their daily activities. If services are not provided in an ongoing and timely manner, additional barriers to independence will be created, which can have lifelong consequences.

The arrival of a computer in the workplace with a new operating system might require additional evaluations and equipment to ensure the user is always productive. When the GUI interface was first introduced, blind users who used adaptive equipment in DOS were again unable to fully participate in the work environment. In schools, the use of software providing auditory feedback might leave a student with auditory impairments unable to learn at the same speed as the other students.

Moreover, by enabling new experiences and abilities through the exploitation of technology, it is almost inevitable that additional needs will arise. With limited human resources this certainly will lead to longer delays for assistance and difficulty prioritizing delivery of services: to those who have never received assistance or those who's newly surfaced but equally justifiable requests require attention.

Spiralling needs and long waiting times can lead to frustration not only from the user's point of view, but also from that of the clinician and management, resulting in feelings of dissatisfaction for all. The risk here is that an inability to deal with increasing service requests may actually influence methods, bias recommendations, and reduce long-term planning. Solutions may be simplified, alternative solutions not proposed or demonstrated, or training and support may be diminished to reduce clinical time, and as a consequence there may be a reduction in the potential gains of independence and quality of life afforded by the use of technology aids.

Improving Services

While it is important to make services available to those who truly need assistance, it is also important to review what issues lead individuals to request help from health care providers and identify ways to reduce their reliance on these facilities, reserving care for those who truly have no alternative.

It is essential to evaluate our interventions not only to improve efficiency and effectiveness, but also to better validate the importance of the various components and steps contributing to good service provision.

We must also develop better tools to measure and improve our outcomes. Some tools do exist, such as Occupational Therapy Functional Assessment

Compilation Tool (OT FACT) but few address the specific needs of assistive technology delivery in a simple and user friendly manner.

We also need to find ways to simplify the evaluation process and provide guidelines for new clinicians entering the assistive technology field to facilitate the difficult learning curve.

Finally, we must train and support other clinicians who can ultimately assume responsibility for less complex aids with a slower rate of change, and we must also develop ways to help other clinicians better determine when to refer their clients for assistive technology assessments, and how to select solutions in their domain which will easily interface or at least not impede the use of technology aids used later on in the rehabilitation process.

For example, certain electric beds cannot be easily adapted to accept inputs other than from a standard hand-held control. Persons with progressive disorders would be better served if the bed purchased facilitated access in the future by providing a means of connecting adapted or specialized devices to replace the standard bed controller.

Maximizing Services

For those clinicians who have undertaken the challenges of assistive technology, it is crucial to allow them time to maintain and improve their knowledge and skills. Because of the many complexities that can arise in technology use, it is imperative to provide clinicians with an adequate support system to free up this time.

Support can range from technical assistance to identify and resolve configuration issues, to helping in the training of an individual. The latter is particularly important when extensive time is required for the acquisition of competency in the use of a recommended solution, whether due to the specific needs of the user or to the complexity of the device itself.

Clinicians could also benefit from other services supporting the implementation of technology such as the development of a resource centre which could provide unbiased information regarding existing and newly emerging technologies; additional testing and technical assistance; and documentation and exploration of compatibility issues before problems arise in real-life situations.

To take full advantage of the limited specialized services which are available, we must reserve their usage for the most complex of situations. This means that information on rehabilitation technologies must be made available to the general public, to users of technology as well as to less specialized clinicians and a resource centre could also fill this need.

Client of the 21ˢᵗ Century

In an era where qualified personnel is hard to find, where therapists are overwhelmed with constantly evolving and more complex information, and where products become obsolete from the moment they are released on the market, clinicians are also faced with an increasing client population.

Not only are the numbers greater than ever before, but the clients are also more complex than they have ever been, due to improved survival rates for persons with severe levels of impairment. These individuals often require sophisticated solutions to offer some compensation for their disabilities and improve the quality of their lives.

Clients are also changing in the way they relate to technology. They are more knowledgeable, have a familiarity with technology used in everyday life, and are less likely to be intimidated by its usage. Persons with disabilities are now more demanding and have higher expectations. They are less likely to accept solutions which are more cumbersome to use than those available to others.

Furthermore, users of technology are more likely to have support persons around them who are also at ease with technology and able to deal with the daily idiosyncrasies encountered when using assistive devices.

Consumers with disabilities are also more aware of the potential technology holds for them and want and need access to the same products and services as everyone else. It is important to include persons with disabilities, their support network as well as providers of assistive technology services in the design of technology aids. Their contributions to device development should ensure products better correspond to their needs and expectations[*].

Technology considerations

Technology Trends

Most of the technology emerging in the regular marketplace rarely addresses the needs of persons with disabilities. In fact, although the principles of universal design[5][†] have been available for many years, they are rarely applied as new technologies emerge, increasing the need for specialized products.

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[*] Participatory design is an approach to design that attempts to actively involve the end users in the design process to help ensure that the product designed meets their needs and is usable. It is rooted in work with trade unions in several Scandinavian countries in the 1960s and 1970s; its ancestry also includes Action Research and Sociotechnical Design. Teleaccessible on the Website: http://en.wikipedia.org/wiki/Participatory_design.

[†] Universal design is the process of creating products (devices, environments, systems and processes) which are usable by people with the widest possible range of abilities, operating within the widest possible range of situations (environments, conditions and circumstances).

In addition, in the rush to market new products we often see a multitude of goods which do not meet expectations for reliability, usability, and interoperability with other products.

Furthermore, exaggerated marketing claims have created unrealistic and unattainable expectations which may result in frustration and rejection of technology solutions.

When users of computers first encountered voice recognition systems they were unprepared for the long hours of training and the heavy cognitive component involved in mastering what was touted as an improved and simpler alternative to the keyboard.

Products are also becoming increasingly complex, offering a myriad of options, customizations, cabling and connections. Documentation is often poor or requires a technical background beyond the skills of the average user and we are seeing an increase in the provision of services to assist users of simple devices to properly set up their equipment.

Moreover, user interfaces are not always intuitive to the way people use them. Poor design and lack of user-friendliness often results in disuse of features and options.

Rehabilitation Technology

Products expressly designed for use in rehabilitation are following a similar evolution. The combined impact of these technology trends translates into increased time demands on health care personnel working in the area of assistive technology.

Increased time is required for clinicians to familiarize themselves with new technologies as well as to obtain the products and analyze them to ensure that they are indeed reliable and appropriate to the users needs.

Additional time is necessary to configure and adjust devices appropriately. Although options are necessary to permit customization and enlarge the client base targeted during device development, it should not be at the expense of usability by the clinician and the client.

To meet the needs of persons with disabilities in the future, we must reserve professional services for areas where their expertise cannot be circumvented. Technical assistance in rehabilitation is becoming as necessary as in the regular marketplace to assist professionals in their work.

Product Survival Issues

Some products in the regular marketplace are discontinued because their potential was not identified quickly enough by the rehabilitation field, and by the fact that marketing departments still do not consider persons with

disabilities as a segment of the target population, in spite of changing demographics.

Recently, an inexpensive remote controlled door lock was discontinued before it could be exploited by the rehabilitation market. The reason cited by the manufacturer was poor sales.

Useful products also disappear from the market because they do not pursue a large enough client base. This is common in the assistive technology area, where products may be designed for a specific disability group. Each sector within the disability market is relatively small, so that development of a device for a limited market makes it more expensive. In addition, increased costs can limit sales and if a company cannot manufacture and sell their devices in reasonable quantities their viability might be at risk.

Occasionally, assistive enhancements are designed for mainstream marketplace products which are modified before the adapted product is even released.

Such a case was a product designed to assist blind users use voice recognition. By the time the product was ready for market there was a new version of voice recognition available rendering the adaptive accessibility investment useless.

There is a critical need to establish and facilitate communication between the rehabilitation field and the mainstream marketplace to ensure the availability of accessible and usable products.

Clinical process and funding issues

Multiple Agency Funding Maze

We are fortunate in Quebec to have access to various funds for the purpose of increasing the independence of persons with disabilities. At the same time, clinicians are faced with a variety of agencies each with their own set of regulations, deadlines, and paperwork.

Clients with disabilities are multi-faceted and often present complex needs. Funding for a variety of these needs may be handled not only by different funding agencies but different therapists at various times during the rehabilitation process.

In addition, since different agencies address different needs for the same client there is also a lack of coordination in the way solutions can be implemented, which can lead to increased costs.

Funding requests to the agency that pays for electric door operators, accessible thermostats and other home modifications may have a waiting list of months to years. It can be difficult for the therapist who is doing a recommendation for an electronic aid to daily living (EADL) permitting the control of devices in the home, including these future accommodations, to

assess and justify the needs to another funding agency. Furthermore, if we assume that the therapist who performed the home assessment had the experience to recommend appropriate modifications (and that is not always the case) there is still a risk that by the time the home modifications are instituted, the technologies included in the EADL may be incompatible with the solutions. In some cases repeat assessments are required.

True costs of assistive device selection

In an era where expenditures are carefully scrutinized and managers of funding programs may be judged by how well they control their budgets, it is not surprising that solutions are often determined by the cost of a product. Since each agency balances its own budget, the selection may turn out to be more expensive than it appears.

Expenditures related to clinical time provided by professionals in a variety of publicly funded programs are rarely factored into the equation.

Some suppliers may offer support to the clinician and the client, providing loaners and technical assistance, and as a consequence, may charge a premium to cover this service. This can be of key importance to clinicians working in isolated environments or new to the field.

There is a culture of insularity which must be changed to help find solutions which are truly cost effective from all perspectives. With a changed mindset, the device which requires less clinical time, allows a user to be more independent, and which allows for adjustments reducing the need for future assessments, may be found to be far less expensive. In a similar fashion, the supplier who charges slightly more but supports clinicians and clients could be found to be the most valid choice. Improved communication and cooperation between the stakeholders is vital before changes can take place.

Regular Marketplace Products

It is costly to live with a disability in Canada. "Having a disability increases a person's chances of being poor"[1]. Everyday needs consume a good portion of disposable income and persons with disabilities often have expenditures related to their disability which the average consumer does not. Living in the province of Quebec with long winters, means persons with disabilities may encounter additional burdens when it comes to moving about, maintaining social contacts etc. and technology can afford some compensation for these problems.

Many funding agencies do not subsidize regular marketplace products due to the very fact that they are available. Furthermore, when new technologies enter the marketplace they are often costly. Since many individuals with disabilities have limited means, their ability to purchase these products

remains relatively small and there are risks that potentially useful products will not remain in the marketplace.

Ironically, when clinicians attempt to promote the development of accessible products or other accommodations in the regular marketplace, they are confronted with developers who wish to justify increased costs with improved sales. Without assurances that investment in accessibility will have some potential to increase profits it is unlikely that many companies or their shareholders will embrace the required features for purely altruistic reasons.

Consequently, there is a continued reliance on specialized products in the rehabilitation market, and a subsequent need for the assistance of persons employed by publicly funded programs to provide solutions. Given the limited resources available today and projections of an increasing number of aged and disabled individuals in the future, it is critical we find alternate ways of encouraging the development of accessible products and services.

Funding Issues, Regulations and Legislation

It is interesting to note that various levels of government offer subsidies for research and development[‡] in local industries and for expansion of facilities[2]. Subsidies are also available in many areas for renovations and property improvements but rarely are there requirements tying these subsidies and incentives to increased accessibility accommodation except at the most superficial level.

Furthermore, few levels of government themselves have set the example of requiring the products, services and buildings that they use, build or purchase to be truly accessible. Governments have enormous purchasing power and as a result can influence development of products to meet their standards. Consequently, should a purchasing requirement be instituted favouring accessibility, the number of available products, services and facilities would increase[§].

Some funding is available in Quebec to persons requiring accessibility modifications to their housing[**]. However, the services of health care professionals are often required, to identify needs and write the necessary justifications. There are ways however, to improve universal accessibility by

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[‡] The *Services aux enterprises*, a business portal supported by the Quebec government, lists some of the criteria for funding for development.

[§] Section 508 of the telecommunications act in the US had an immediate impact on many industries interested in providing their products to various government agencies. Teleaccessible on the Website: http://www.section508.gov/.

[**] The site of the *Société d'habitation du Québec* includes information on their accessibility programs: http://www.habitation.gouv.qc.ca/programmes/adapter_ domicile.html#ou_applique; other agencies include the SAAQ (http://www.saaq. gouv.qc.ca/index.html) and the CSST (http://www.csst.qc.ca/portail/fr/).

creating accommodation adjustments which meet the needs of a variety of users, ultimately reducing the demands on these professionals.

These solutions may initially be more costly to implement and may not be used because there are funding limits to *individual clients.* The investment of clinical time to find solutions is rarely factored into the costs of subsidized accessibility solutions in housing.

As an example, mechanical or electric height-adjustable counters are available to make kitchen activities accessible safely. Because, the initial expenditure for such products is higher than simply lowering a countertop and sink, they are rarely considered. When an individual moves from an adapted residence, their personal accommodations may be inappropriate for the next occupant. Instead of modifying the counter's height for the new resident with an adjustable system, additional costs are engendered by assessments, paperwork and additional renovations. Occasionally, due to agreements with landlords prior to a renovation, if no suitable candidate can be found, the apartment may have to be restored to its original standard-height countertop.

This means that in spite of investments in clinical time and renovation subsidies, we are not contributing efficiently to the creation of a bank of accessible lodgings which could ultimately reduce future requests for services as well as costs.

One of the goals of subsidizing housing accessibility renovations should be to maximize public funds by contributing to sustainable long term solutions. Improved collaboration between funding sources and health care is necessary to find ways those policies and services could better support this goal.

Proposals for change

If we consider the projections for an increasing client population in the future, it is evident that even with increased numbers of clinicians, we will have difficulty coping with mounting demands in the area of assistive technology. We must become more aggressive in resolving some of the problems related to technology use if we are going to be able to meet the needs in this area of health care over the next 10-20 years.

Research must become proactive in studying some of the issues and finding solutions which are both practical and applicable in a way which increases the ability of health care professionals and other personnel to respond rapidly to those who are most in need.

It is imperative to empower persons with disabilities and support ways for them to find their own solutions whenever possible.

We must create some type of permanent forum aimed at improving communication between the various stakeholders[††] and facilitating the transmission of the concerns and the needs of health care and other interested sectors (education, employment, housing, etc.) and their clients to developers and manufacturers.

The development of a facility for the testing of devices in realistic environments, for identifying and monitoring potential new technologies, products and services could serve as an information resource to users, clinicians, developers and others, providing them with valuable information

We must also develop a resource which could lead to a paradigm shift in the way costs for accessibility are analyzed and allocated. We must encourage research which will improve the present models of service delivery and subsidies and identify the true costs of various solutions and interventions.

We must also find ways to better measure benefits which can be obtained by making accessibility accommodations and products available to the greatest number of individuals and relate this to improvements in service availability and reduced wait times. We must progress in our methods of measuring outcomes resulting from technology use to better reflect the gains of improved independence and quality of life.

We must also develop strategies to optimize the time of the available clinicians, by simplifying and streamlining ways of obtaining subsidies, and encouraging the development of universal accessibility in products, services, public and private buildings, facilities and institutions.

Finally, we must study how present and future policies and legislation can facilitate or restrict technology use by persons with disabilities.

With access to reliable information, we can better justify the use of technology in the future, and to that end we must create a resource which stimulates and facilitates research, collects data, serves as a clearinghouse for information and ultimately could serve as a hub for supporting and promoting accessibility and enhancing the development of a more inclusive society.

Conclusion

Leadership is going to be necessary to promote and improve accessibility and technology research to meet the future needs of the population of Quebec. It is crucial to establish a resource which would facilitate the development of partnerships of collaboration between researchers in universities, developers of technology, government, funding bodies, health care agencies, clinicians and support staff, and end users of technologies.

[††] This should also include the education sector, and representatives of a variety of government agencies, as well as organizations representing diverse client needs such as the Independent Living Centre, etc.

The creation of a centralized resource could offer a unique and more coherent method of providing this leadership. A Centre for Accessible and Adapted Technology, under the auspices of an institution, either a university and/or a health care facility, could have a significant impact on improving the availability of technology solutions in the province, improve service delivery and facilitate integration of persons with disabilities into all areas of community life.

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