

Futures of Disabilities: Is Technology Failing Us?

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Abstract

This paper examines possible reasons why technology may not be living up to its promise for some people with disabilities (including poor policy implementation, low accessibility, cost, disinterest, lack of awareness, prejudice) and describes preliminary results from the first round of a futures-oriented Delphi survey.

Keywords

Futures, technology trends, policy, culture

Introduction

A remark attributed to Marshall McLuhan, that "we shape our tools and thereafter our tools shape us," suggested that technological developments are the basis of social and environmental change. For people with disabilities, the hope has been that the implementation and application of new technologies, in particular wireless technologies, could have the potential for a transformative impact in their lives in key areas like education, employment and social inclusion. There is some evidence that this is happening, in particular for youth with disabilities (White et al, 2011, Takahashi et al, 2012).

But the reality differs for many people with disabilities, in particular the older generation. People with disabilities only make up 22% of the labor force, for example, compared to 69% of their non-disabled counterparts. Jobs for people with disabilities have tended to be in secondary labor markets characterized by subsistence level pay, low level skill requirements, few opportunities for advancement, and a high number of part time jobs (White et al, 2011).

At the same time, wireless networks and new digital media technologies are having a transformative effect on the ways that people collaborate and act together. Approximately 102% of the US population use wireless products and services ("Wireless Quick Facts"). Wireless phone service expenses surpassed landline service expenses in 2007 with youth (those under 25) spending the most on cellular service, indicating that youth are driving the move away from landline use ("Consumer Expenditure Survey," 2009). The networks these services support are likely more important for persons with a disability than for the general population (White et al, 2011). For example, telework as an accommodation has the potential to improve the employment rate of people with disabilities, and tablet computers, eReaders and distance learning could positively impact inclusive educational environments. In terms of educational

attainment, some indicators are positive. The high school completion rate of students with disabilities compared to people without disabilities has narrowed over the past two decades, from 24% in 1986 to 6% in 2010 (Kessler Foundation and NOD, 2010).

However critical attainment gaps persist for students with disabilities, in particular to meet new academic content standards (National Center on Educational Outcomes , 2013). NLTS2 in 2006 noted that “a considerable gap in achievement” in reading, mathematics, science, and social studies existed between students with disabilities and their peers in the general population (Wagner et al 2006). Only 12% of people with disabilities 21-64 have earned a Bachelor’s Degree or higher (“Profile America,” 2011).

Despite the body of disability access law, problems persist for people with disabilities gaining and maintaining access to information communications technologies and the benefits that ensue. In some cases, new technological advances may result in some parts of the population being left behind. For instance, TTY (teletype) use among people with hearing loss is in rapid decline (“Comments of the National Association of the Deaf,” 2010). Yet, there is only limited alternate access via a few pilot programs for a person who is deaf or speech impaired to contact 9-1-1 from their mobile device (“Comments of the National Association of the Deaf,” 2010). Maintaining access is central to the discussion because technological developments far outpace the rules and regulations that govern their use. For example, laws that were in place and applicable to accessing basic phone service, are suddenly unsuitable for access to voice over Internet protocol (VOIP) (Lev, 2013). More often than not, the competing priorities of government, industry and consumers create a stalemate on the progress and implementation of rules and regulations concerning accessible ICT. A prime example is the to-and-fro of rules and regulations governing broadband (Beck, 2014).

Methodology: Futures and Delphi

The Wireless RERC (see end note) is in the process of researching what kinds of physical, economic, social and policy factors serve as the context for the migration from legacy, analog technologies to mobile, digital technologies, and, more broadly, what the futures of disabilities might look like. A specific focus is on the split between migrators and non-migrators, e.g. what is the nature of those who are falling behind, is the gap closeable and what if any are the consequences. As part of this endeavor, the Wireless RERC embarked on a futures visioning exercise in 2013, based on a modified, policy-oriented Delphi method, which serves as the foundation for this paper.

Futures

Different cultures, fields, and disciplines have recognized the future as an area worthy of exploration (Bell, 1997). The aim of “futures studies” is to understand the different possible futures that might unfold, and understand why trends and factors may drive the future in one direction versus another equally plausible one (de Beer, Mogyoros, and Stidwill, 2014). There are numerous theories and methods that futurists have developed, tested, and applied in recent years, including the Delphi technique described below. The fundamentals are that futures studies do not pretend to predict "the future." Rather, the intent is to study ideas about the future, "alternative futures" which should be envisioned, invented, implemented, continuously evaluated, revised, and re-envisioned as "preferred futures"(Dator, n.d.).

Delphi

One technique for arriving at possible preferred futures is known as the Delphi process, a set of procedures for eliciting and refining the opinions of a group - usually but not always a panel of experts (Dalkey 1967, Brown 1968). It is a group communication process aimed at

“allowing a group of individuals, as a whole, to deal with a complex problem” (Linstone and Turoff, 1975). The aim of a policy Delphi is not to achieve consensus but to generate a wide range of views: in short to act as a forum for ideas and to explore a range of positions on different topics related to the issue (Bijl, 1992). For this study, the primary issue focus of the Delphi is on the migration from legacy technologies to advanced communications services and wireless technologies. Migratory trends are interpreted broadly, to include macro trends (e.g. analog to digital, fixed to mobile, and content migration including social media, cloud, and smart/connected everything) and micro trends (e.g. print to electronic text, TTY to mobile, etc). The overarching theme is as indicated above, to seek to understand the nature of the ongoing gap between the potential and the reality of technology, and to use visioning techniques to develop alternate futures for people with disabilities.

Three basic research questions inform the development of the Delphi:

RQ1. What kinds of physical, economic, sociopolitical and policy factors serve as the context for the migration from legacy, analog technologies to mobile, digital, Internet Protocol (IP) based technologies?

RQ2. A) What are the implications for positive impact from these migratory trends on people with disabilities? B) What are the implications for negative impact from these migratory trends on people with disabilities?

RQ3. What practical policy solutions are available for raising the positive impact in order to continue the improvement of the lives of people with disabilities?

In preparation for the Delphi, Wireless RERC researchers concluded a literature review and environmental scan designed to identify plausible factors to answer RQ 1. The research team

identified search filters and possible impacts which could be affected by migratory trends (see figure 1 below).

Figure reference:

In preparation for designing the Delphi survey tool, researchers conducted a literature review and environmental scan designed to identify plausible factors to answer RQ 1: *What kinds of physical, economic, sociopolitical and policy factors serve as the context for the migration from legacy, analog technologies to mobile, digital, Internet Protocol (IP) based technologies?* The research team identified search filters and possible impacts which could be affected by migratory trends.



Fig. 1. Literature Review and Environmental Scan Schematic

The review/scan included a cross-reference with categories of opportunities and barriers (such as education, employment, social inclusion) which in turn were analyzed and broken down into subcategories (such as health services, emergency access, entertainment, commerce, travel, etc). In the final analysis of the literature, 16 areas of focus were identified as being integral to migratory trends in technology and disability access: defining disability; cloud computing; near field communications; wearable devices; 3-D printing; ageing; shifts in familial patterns;

environmental changes; employment; economic fundamentals; policy time lag with technology; implications of a more transparent policy process; privacy; secondary health conditions; health/environmental impacts; and veterans. Following multiple assessments of the literature review, the research team drafted the first Delphi questionnaire consisting of 44 open and close ended questions. Round 1 of the Delphi was distributed to 303 experts; ultimately the panel consisted of 50 respondents of whom 36% self-identified as having a disability. Participants were asked to identify their backgrounds, which were varied: education/academia (39.6%); policy/law (18.8%); business/industry (16.7%); other (14.6%); disability organization or interest group (8.3%); communications/media (2.1%)

Discussion

The closed questions broadly addressed the 16 focus areas identified above, asking respondents to rate the issues as very important, important, slightly important or not important.

The top seven issues identified by respondents as important or very important were:

- The potential of digital technologies, such as apps, specifically in communications (98%)
- The level of the adoption of technology relies heavily its accessibility (94%)
- The life expectancy of people with disabilities has increased, and for the first time a generation of people with disabilities are outliving their parents (94%)
- The time lag between innovation and policy/regulations affects accessibility and technology inclusion for people with disabilities (92%)
- Affordability's influence on the technology adoption rate of people with disabilities (90%)
- The role of the family caregiver is expanding to performing medical/nursing tasks (88%)
- People with mental health issues face more stigma than people with other types of disabilities (88%)

For the open questions, the issues that attracted most attention were diverse, with one in particular drawing a lot of comment: “What is the best way to capture or reflect the diversity that underlies the concept of ‘people with disabilities’?” Other popular themes concerned the disproportionate impact of economic realities; the need to inform policy makers about the potential of technological changes to help people with disabilities; the question about what systems are needed to support the aging population; and concern about privacy issues impacting people with disabilities.

The research team analyzed all the responses to the first round, and produced a preliminary summary in four clusters. As described above, these clusters reflected the issues that the Delphi panelists saw as being the most important and those that received the most feedback.

Technology Cluster

The Delphi panel generally acknowledged that digital technology and its applications will become more important in the lives of people with disabilities, and that increased use of accessible digital technologies will increase levels of communications and social inclusion opportunities for them. The level of adoption of technology was seen as heavily dependent on its accessibility. In addition, questions of privacy emerged as an area of concern, ranging from the specific (“Blind users don't want text-to-speech to read aloud for anyone in earshot to hear”) to the general (“the key should be for everyone, that they are able to disclose (and/or keep confidential) the personal information most relevant for them under the circumstances they choose”), with many caveats about the changing nature of privacy as technology evolves.

At the same time, many respondents were sanguine about the promise of change that technology embodies, the hope that one day having a disability will not be perceived as synonymous with having a deficiency. One vision offered was when having a disability will not

impede communication with people across all linguistic groups, including ASL, while another respondent pointed out that by definition a disability is a functional limitation, but once technology is sufficiently adaptive and nonintrusive disability can become virtually irrelevant.

Cultural Understanding Cluster

This cluster embraced a number of concepts, in particular the rise in the life expectancy of people with disabilities, but also covered what proved to be a question that attracted heavy feedback, on how to capture or reflect the diversity that underlies the concept of “people with disabilities.” The Delphi question about how, for the first time there is a generation of people with disabilities outliving their parents also attracted a lot of attention, with a particular focus on the challenges of technology migration in the face of the needs of that older population. There were pleas for keeping some technology simpler for older generations with disabilities. In the words of one commentator: “There is currently little to no consideration of the needs of older technology users in the US... The issue is not just physical hardware adaptation, but also software and services.” Concomitantly, there was a general consensus on how the role of the caregiver is expanding, the need to acknowledge that change and to provide caregivers with more support. There was a clear agreement with the notion that people with mental health issues face more stigma than people with other types of disabilities.

Economic Realities Cluster

A major hindrance to higher levels of technology adoption by people with disabilities was seen to be the question of affordability. In the blunt words of one respondent, “technology needs to be accessible and affordable both, or else it is useless.” The explanations offered covered a range, from low expectations from parents and schools to lack of knowledge of successful role models; dependence on government support and fear of leaving it for unsure work situations;

limited availability of affordable housing in safe areas; transportation challenges, and more. But the biggest factor by far was the lack of educational opportunity and resources, and the resulting poor employment options.

Policy Cluster

There was strong support from the Delphi panel for the notion that the time lag between innovation and policy/regulations affects accessibility and technology inclusion for people with disabilities, but little consensus on how to tackle this issue going forward. One futures-oriented suggestion was to create and maintain an emerging technologies roadmap, intended to convey the likely impact of new technologies on people with disabilities (and, presumably, incorporate it in the policy development process). Otherwise, there were several calls for the disability community to get more involved directly in the policy process (to ensure policy makers buy in through knowing someone with a disability who has experienced improved quality of life because of technological changes) as well as for “technology professionals” (especially those in the disability community) to call the attention of policy makers to what is happening. One trenchant opinion called for a process to get policy makers to see both the analytical data and financial impact of providing new and enhanced technologies, and hear from consumers who are directly impacted by receiving and using the enhanced technologies. A sour counter comment saw policy makers as the problem, not the solution. “If indeed we want to see emerging technologies exist, it is better if Congress stops making policy.”

Conclusion: Technology as Transformer?

One of the general research themes early identified was to seek to understand the nature of the ongoing gap between the potential and the reality of technology. Preliminary analysis of round 1 of the Delphi seems to indicate that the respondents felt technology *can* have a

transformative impact on how people with disabilities are perceived, with the suggestion that technology is not failing us, our attitudes are. For example the expert respondents overwhelmingly deemed digital technology such as apps, and by extension the wireless devices they operate on such as smartphones and tablets, as the most important migratory trend.

Where could this trend lead? Due to the relatively short development cycle of apps (compared, for example to operating systems and hardware), as well as their wide availability and generally low cost, the apps market has a low barrier entry for people with disabilities. Mobile apps serve to extend the functionality of smartphones and tablets and in some cases, augment dedicated assistive technology. By design, mobile apps (not just those created for people with disabilities) are meant to assist the user with some task. In a sense, mobile apps universalize “assistive technology,” making it in the broadest sense, applicable to all people at any given moment in time.

Could this shift the paradigm of thinking about disability and access from niche to norm? Such a line of thinking seems to presuppose the transformative power of technology on perception and attitude towards disabilities, but when asked specifically about perception (“*Can you conceive of a time when having a disability will not be synonymous with having a deficiency?*”), there was a clear divide among responses.

The work of the Delphi is ongoing. The second Delphi round will ask participants to refine each idea, commenting on its strengths and weaknesses for addressing the issue and to identify new ideas, and ultimately develop a shared understanding of how the panel views the issues.

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