Assistive Technologies, Risk, Legal & Ethical Considerations

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Abstract

In the summer of 2016 the United Nations declared that access to the internet is a basic human right when it amended article 19 of the Universal Declaration of Human Rights. With this declaration the UN affirmed the increasing roles that technology plays in our day to day lives. However technology advancements, like the internet, do not affect all populations equally. While some may benefit from the use of technology others may be left behind or shutout completely. One such group are individuals with intellectual disabilities (ID). Persons with ID represent two both sides of the technological coin, simultaneously they are a population that stand to benefit greatly from the use of technology, in the form of Adaptive Technologies (AT) while at the same time have the most to lose due to exploitations in the technology used. Due to these facts, a number of ethical issue are raised. This paper will examine the ethical issues that surround the use of technology in populations with ID.

Introduction

The integration of technology in our daily lives probably doesn't surprise anyone anymore. In fact we come to expect it and more often than not, we welcome it with outstretched arms, maybe sometimes against our own better judgement. In the summer of 2016 the United Nations declared that access to the internet is a basic human right when it amended article 19 of the Universal Declaration of Human Rights.(West, Catherine Howell and Darrell M., 2016) With this declaration the UN affirmed the increasing roles that technology plays in our day to day lives. Generally speaking the benefits of technology from connecting people from around the world with the push of a button, to analyzing large data sets and automating mundane repetitive tasks can all good things that can benefit everyone. However, technology doesn't always benefit all populations equally. While some may benefit from the use of technology others may be left behind or shutout completely. Barriers of cost, availability and complexity are major hurdles that can limit the adaption of technology by specific groups. One such group are individuals with intellectual disabilities.

As defined by the US Department of Health and Human Services, "Intellectual and developmental disabilities (IDDs) are disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems …The term "developmental disabilities" is a broader category of often lifelong disability that can be intellectual, physical, or both"(US Department of Health and Human Services, 2016)

As defined by Assistive Technology Act of 1998, an assistive technology device is "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" (Section 3, a, 3). (105th Congress, 1998) Thus assistive products and adaptive technologies cover an expansive rage from mobility aids, like walkers canes and wheelchairs, cognitive aides that can assist with memory and attention, computer software and hardware systems including voice recognition screen enlargement or readers and closed captioning as well as physical modifications to environment like grab bars and ramps. (NICHD, National Institute of Child Health and Human Development, 2018)

Persons with intellectual disabilities represent two both sides of the technological coin, simultaneously they are a population that stand to benefit greatly from the use of technology, in the form of assistive technology while at the same time have the most to lose due to exploitations in the technology used. Due to these facts, a number of ethical issue are raised. This paper will examine the ethical issues that surrounding the use of technology in populations with intellectual disabilities. The rest of the paper will be organized in the following way. Section two will examine assistive technology their risks. Section three will examine legal issues. Section four will examine the ethical issues presented in the use of assistive technologies. The final section will a summary of concluding remarks.

II. Assistive & Adaptive Technologies, Use & Risk

The first question we should ask ourselves is what are the capabilities of technology to assist individuals with intellectual disabilities? While it could be said that the capabilities of technology are only limited by the ingenuity and creativity of the designers, developers and engineers that develop and build technology. In actuality, the limiting factors for any assistive product or technology is ultimately determined by the individual or the caregiver. According to

Boot et al. “the most frequently reported barriers were related to lack of funding and cost of [assistive products] AP, lack of awareness about AP and inadequate assessment.” (Boot, F. H., Owuor, Dinsmore, & MacLachlan, 2018) As the spectrum of intellectual disabilities very from individual to individual so to do the technologies that can be used to provide assistance. Mobile computing devices like tablets and smartphones, on-screen keyboards, screen readers, trackballs and touch screens, augmentative and alternative communication, digital assistance such as Amazon’s Alexa, GPS, brain-computer interfaces and even Big Data applications have the ability to offer individuals with intellectual disabilities many number of benefits chief among them being autonomy. “Within Western medical ethics, there is a broad consensus that respecting patient autonomy is required for good practice. That autonomy is a goal of those developing [Assistive Technologies] should not surprise us then, as it is becoming a cornerstone of ethical thinking in medical contexts.”(O'Brolcháin, 2018) A study done by Lancioni et al. illustrated the potential of smartphones to assist persons with intellectual and sensory disabilities with daily tasks. Results of the study “indicate[d] that the smartphone intervention was suitable to support correct start and accurate performance of daily activities by persons with intellectual and sensory disabilities” (Lancioni et al., 2017) thereby increasing the individual’s ability to function on a more autonomous level.

For caregivers of persons with intellectual disabilities the steady advancements in communications devices as well as rapid developments in sensor technologies and broadband communication networks such as 4G LTE and 5G cellular networks, have crated possibilities to remotely monitor and support the needs of individuals with intellectual disabilities in real time. Real time monitoring while at the same time allowing for greater independence and autonomy for the individual. However there has not been a lot of research conducted in this area. It is

interesting to note that as pointed out by Boot et al. “it's people with ID who remain an underexplored focus for research and practice.”(Boot, Fleur Heleen, Louw, Kuo, & Chen, 2019) Yet at the same time there is an increasing interest in studying assistive technologies monitoring capabilities in persons with dementia. While its understood that these two areas are not exactly the same, there is a significant amount of overlap in the challenges faced by both communities, that any advances in one could potently benefit the other.

The last question we need to ask ourselves is what risks the use technology might expose these individuals to, as well as privacy issues that can arise from the use of technology. This is a slightly easier question to answer because we already know many of the risks associated with technology. The use of any technology decreases our personal privacy, from emails to GPS, data sent over the wire or through the air can be captured by third parties, malicious or otherwise, while breaches of service hosting providers can reveal troves of data. These vulnerabilities would be no different for individuals with intellectual disabilities. However, assistive technologies have the potential to introduce increased risk beyond that data loss and privacy concerns. If for example an assistive technology requires always-on access to the internet and access to a network is unavailable or becomes unavailable during use and there are no fail-safe measure to alert the individual or caregiver, may put the individual in an unsafe or vulnerable situation.

III. Legal issues

By and large a majority of the legal case law for assistive and adaptive technologies currently centers around it’s uses in public schools. In these cases usually center round the access to assistive tech and the school’s response to incorporating the technology into the student’s Individual Education Plan (IEP). This is primarily due the Individuals with Disabilities

Education Act (IDEA) and the Technology-Related Assistance for Individuals with Disabilities Act which mandate that schools uses assistive methods to assist in the education of individuals with intellectual disabilities. (Martín, July 2017) summarizes over 20 cases from the past fifteen years of actions brought against public school districts related the use of assistive technologies. The cases summarized focus on topics of choice, acquisition, implementation, maintenance, IEP issues among other topics. In these cases the courts grant a fair amount of leigh way to the schools in ways that they implement assistive technologies usually only ruling against them when there has been gross negligence or outright failure to meet the requirement under the IDEA act.

IV. Ethical Considerations

There a number of ethical questions that can be asked with respect to assistive technologies. Perhaps the biggest ethical questions that are presented by the use of assistive technologies center on consent and privacy and autonomy.

Consent. Consent is something that most if not all of us take for granted with respects to technology as we freely give our consent for access new services. Consent can problematic for persons with intellectual disabilities for a number of reason. First as they may not understand what they are agreeing to in the form of Terms and Conditions or other legally binding agreements. Second, consent may not be theirs to give freely as it may legally rest with a caregiver. This second condition is particularly problematic when using recording or tracking technologies that agreed to by the caregiver and not the individual. Which then raise questions about autonomy.

Autonomy. “Autonomy is very closely related to conceptions of liberty whereby the user has the right to make his or her own decisions regarding the use of [Assistive technologies]”

(O'Brolcháin & Gordijn, 2019) While choices made by caregivers maybe well intended, those choice have consequences that are borne by the user. Chalghoumi et al argue that technologies should be accessible and ultimately lead to better outcome but never overshadow the autonomy of the individual.

Privacy. Privacy raises similar questions as consent. What expectation of privacy do individual have and how much control of that privacy do caregivers ultimately have? In terms of assistive technologies the question becomes what protections are in place to protect the privacy of the users? Do assistive technology companies need to guard personal data of their users more vigilantly?

Accessibility. Another ethical consideration is what responsibility do technology companies have in designing technology products that are accessible to people with intellectual disabilities? Lazar et al. suggest that standards bodies have an opportunity to address accessibility principles early in the development of emerging technologies. “Because [information and communication technology] (ICT) occupies such a central role in society and the pace of technology change is constantly accelerating, it has become critically important to ensure that accessibility requirements are addressed at the design stage of ICT product and service development. After they have been released to the market, accessibility products and services may be difficult to retrofit – and by then, people with disabilities have already been left behind by the latest innovations.”(Lazar, Stein, & Brewer, 2017) While Boot et al. suggest the creation of advocacy groups that can lobby technology companies on behalf of users with intellectual disabilities.

Awareness. As was mentioned earlier in the paper awareness of assistive technologies is one barrier that was mentioned that hinder adaption. Awareness also speaks to the need to further

the study and research of assistive technologies. One way to combat the lack of awareness is to "set up education and training programmes for health professionals, people with ID and their careers concerning ID-related health topics and AP needs. The aim is to increase knowledge and awareness of AP needs for people with ID[as well as establish] Training related to AP assessment and acquisition should be included within national health education programmes." (Boot et al., 2018)

Wealth. It should also come as no surprise that the wealth of individuals, families, communities or nations has a determining factor in the quality and distribution of assistive technologies. It is because of this wealth that "in most high-income countries, the current trend for living situations for people with ID is moving towards greater social inclusion and community living." (Boot et al., 2018) What responsibilities do we have as global community have in providing access to assistive technologies in more equitable and fairer manor?

V. Conclusion

Assistive technologies have been proven to be invaluable resources to persons with intellectual disabilities. While technologies of the present and future have similar assistive capabilities, they also have the potential to exposing vulnerable individuals to risks that they may be ill prepared for. With these advancements we need to be able to weigh the potential benefits gains against the ethical questions posed to ensure that individual served is exposed as little risk as possible while simultaneously gaining as many benefits as possible.

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