

Depending on Independence An Autoethnographic Account of Daily Use of Assistive Technologies

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ABSTRACT

Assistive technologies (AT) are a necessity for a person with a severe disability to be able to lead a self-determined life within modern societies. Thus, these technologies fulfil an important societal role and have a significant impact on the lives of those affected. This experience report provides insights on the lived experiences surrounding the necessary use of AT from the point of view of a disabled person. Using an autoethnographic approach, we determine the function and relevance of AT in everyday life and illustrate the intended and unintended effects of AT as well as the subsequently arising socio-technical dependencies through representative examples. The results show how the resulting dependencies on AT pose a risk for users, especially in the event of a technological failure. Furthermore, a deployment of AT without the necessary reflection and preparation of backup strategies in case of failure may lead to unexpected and inadvertent, potentially harmful, side-effects. Based on these observations, we elaborate on the implications for different stakeholder groups involved with the design, development, deployment and daily use of AT. We deem the key factors for success to lie in a deeper understanding of the application context, the integration of affected people in the development process as well as a fundamentally reflective approach by everyone involved with AT.

CCS CONCEPTS

Social and professional topics → People with disabilities;
 Human-centered computing → Accessibility design and evaluation methods; Empirical studies in accessibility; Accessibility technologies.

KEYWORDS

assistive technologies, dependence, interdependence, independence, disability studies, autoethnography



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ASSETS '22, October 23–26, 2022, Athens, Greece © 2022 Copyright held by the owner/author(s). ACM ISBN 978-1-4503-9258-7/22/10. https://doi.org/10.1145/3517428.3551354

ACM Reference Format:

Felix Fussenegger and Katta Spiel. 2022. Depending on Independence An Autoethnographic Account of Daily Use of Assistive Technologies. In *The* 24th International ACM SIGACCESS Conference on Computers and Accessibility (ASSETS '22), October 23–26, 2022, Athens, Greece. ACM, New York, NY, USA, 6 pages. https://doi.org/10.1145/3517428.3551354

1 INTRODUCTION

Assistive technologies (AT) have a significant place in the lives of people with disabilities and are paramount to their participation in modern societies. For my¹ personal condition as an impaired person with a high spinal cord injury, I can confirm that I would not be able to survive on my own without AT or at least I would be permanently and constantly dependent on the help of other people. Thus, I am glad to live in this day and age in which we can rely on a fast advancing variety of technologies at our disposal that support me in leading a self-determined life [2]. But precisely because AT are gaining traction and becoming so fundamentally important in terms of enabling people with disabilities, the impacts they have on their lives must be scrutinised and well understood. Otherwise, the disposition of AT with the resulting dependencies can and will lead to unexpected and inadvertent, potentially harmful, side-effects. With this experience report, I want to provide an insight into my

personal use of AT and how they influence me, my health, my social interactions and my surroundings; how they are shaped by the needs of my specific embodiment and shape these needs in return [17]. Or, more generally speaking, I detail their impact on my interdependence. Interdependence can be seen as a complementary frame for AT researchers, previously introduced to Human Computer Interaction (HCI) by Bennett et al. The concept considers access to be relational and simultaneous, highlights the contributions of people with disabilities, and challenges traditional hierarchies of abilities [3]. My report stems from such a relational understanding of disabilities, self-determination and access.

I will describe my individual experience with AT from my perspective as a person living with a severe disability, but also the drawbacks of the lived experiences, from which I draw when thinking through issues of dependence in AT. The chosen examples are intended to guide an understanding of the importance of AT for disabled persons, the impacts AT have on their everyday lives

¹This experience report is predominantly written from the perspective of Felix as the first author with Katta, the second author, guiding and supporting in the development and writing processes for this report. Hence, whenever there is a reference from a first person singular perspective, it refers to Felix if not stated otherwise.

and what it is like to depend on them from a personal perspective. Further, I elaborate on the implications of the insights I make in observing my own practices and involvements with AT to make them relevant for different stakeholders (such as researchers, medical professionals, policy makers, and disabled people themselves). In that, I operate loosely from within the notions of first-person research methods [4].

In this context, I deem it necessary to briefly explain my own impairment and my perception of disability. I live with my physical impairment since a snowboarding accident in 2003, in which I suffered a spinal cord injury to the sixth cervical vertebra. This resulted in a complete sensory and motor paralysis of my body approximately from half of the shoulder down. Besides these medical limitations, there are also physical and social barriers in society that have a substantial influence on my disability. Therefore, I see disability not only defined by my own impairment, but also by the lack of opportunities that society offers me to employ my abilities, which means I operate from a predominantely social model of disability also in my use of AT [10].

I advise that this text is based on my subjective experiences and describes purely my personal insights and convictions. I do not represent the position of any organisation or other people with disabilities – either similar or dissimilar to mine and operates from a specific locality and situatedness [7]. Their experiences and opinions may well differ from mine and result in different implications for research.

2 ASSISTIVE TECHNOLOGIES AND ME

This section describes my personal experiences with AT - the good as well as the not so pleasant. I provide a rough overview of the most important technologies that support me in my everyday life. I describe how I use them and what I need them for. In the first section, I list the specific AT that I need to master a typical day and explain for which activities I use them. In the following sections, I illustrate how AT has influenced me and my life through three specific examples. These examples are chosen in such a way that they 1) clearly describe the contexts and effects of the use of AT, 2) are easily comprehensible and 3) have a representative potential as they relate to other AT.

2.1 A Day in the Life

Table 1 contains an overview of some of the AT I use and what I need them for. The enumeration of the AT outlines a common daily routine of a common day in my life. I identified them by tracking my daily interactions with objects and technologies for several days and reflecting on my notes, a common procedure within autoethnographic approaches [20]. The mentioned AT are things, products or systems that support and help me with my impairments to perform functions that might otherwise be difficult or impossible for me to achieve. These devices support me to improve or maintain my daily quality of life by easing or compensating for my disability and/or the ways my environments are built without having my disability in mind. This can be a very simple object like an eating aid or a more complex application like speech recognition on a computer. The technical complexity, however, says nothing about how important or useful an artefact or application is for me. The third column of Table 1 lists the activities that the AT enable me to carry out independently. On the one hand, this shows what the AT empower me to do, but on the other, it also illustrates how dependent I am on them and what activities I lose or have to manage drastically differently in case of failure.

2.2 Example 1: Early Voice Recognition vs Pen

The accident that caused my disability happened in my final year of high school. After about a year of hospitalisation and intensive therapy in a rehabilitation centre, I returned to school with the aim of graduating the same year. However, there turned out to be one problem: it was unclear how I could perform my written exams and exercises. With my limited hand function, I could not write fast and well enough, neither by hand nor on the computer, to get my work done in what would have been deemed a reasonable amount of time. Despite the long and intensive rehabilitation, my handwriting was like that of someone just starting their schooling and learning to write. The recommended solution from my therapists and from school was that I should use a speech recognition software and dictate my work and exams from now on. Following their advice, I bought (very expensive) software and started working with it. But in 2003, such software was not yet very sophisticated and I was deeply unsatisfied with the reusults. But the therapists and teachers in their positions as "experts" explained to me that the software had to get to know me, and I had to get to know the software in return before I could expect it to function more seamlessly. And if I just trained regularly, it would get better and better with time (and patience).

So I trained - for hours and hours, but the progress was sluggish. During the training, I began to scribble my spoken sentences on a piece of paper with a pen. This helped me to formulate the spoken language more in line with what would be expected from a text in written language. At the beginning the scribble was nothing more but a wobbly line. But after many hours, during which I trained with the software, I noticed that the scribbles developed more and more into a recognisable script. While I intended to train the software to recognise my voice better and perform more in line with my expectations, the process had, in return, unexpectedly trained my own body to perform the task I meant to relegate to an AT. After a while, my progress in handwriting was greater than with the software. Hence, at some point, I only concentrated on my handwriting skills. And lo and behold - after several fully written notebooks, my handwriting skills were sufficient enough for me to take the final graduation exams on a regular basis without the support of any software. This baffled both, my therapists and my teachers. Until this day, I am grateful for the poorly functioning language software that inadvertently returned my handwriting skills back to me. I am convinced that this would not have happened with today's much more sophisticated software and that I still would not be able to write a text by hand or fill out a form on my own. This example shows me how much the use of AT can promote or hinder one's own abilities - even if this might be contrary to the initially intended purpose of use.

Device	Function/Explanation	Enablement/Dependency
holding bar over bed	- hold on without finger function - pull up torso	- sit up in bed - turn my self over - get dressed and undressed - get out of the bed
wheelchair fixing device	- holding mechanism to fixate the wheelchair to the bed	- facilitates transfer between bed and wheelchair - reduces the risk of falling
manual wheelchair	- ultra lightweight - foldable - extra strong grip on push rims	 covering medium distances on a level ground loading into and out of the car
shower wheelchair	- water solid - cutouts in the seat area	- Body wash / shower - using the toilet
elevator	- big enough to fit a wheelchair - reachable buttons	- get to and from my flat (2 nd floor) - get to the garage
applications in the the car	- transfer device - hand throttle - hand brake - steering aid	 perform a safe transfer load the wheelchair on/off the passenger seat steering the car safely
voice recognition software - for PC - for smartphone	- dictate long texts - dictate input for chats and mails - execute frequently used commands	 writing documents for work and university participate in digital communication
eating aids	- specially formed fork, knife and spoon	- eating without help
mobile phone with assistance and emergency numbers	 - easy call when I unexpectedly need assistance - easy call in case of emergency 	- get help when needed
credit card with NFC payment	- easy payment of small charges	- handling small purchases e.g. at the grocery store
hybrid manual wheelchair	 senses my activity on the push rim provides adequate support with an electric drive 	 covering long distances on a semi level ground locomotion that is easy on the joints
smart thermostat	- digitally programmable, network- compatible thermostats	- regulation of temperature at home

Table 1: List of AT I use during a normal day, what it does and which activities it enables

2.3 Example 2: A Small Hook with a Serious Catch

With my degree of disability, transferring between a wheelchair and my bed comprises a big challenge. At the same time, the ability to master the transfer on my own means a great degree of independence. That is why I trained specifically in the course of my rehabilitation to tackle this hurdle. I'm glad I succeeded, even though I have to keep myself fit all the time so that I don't lose this ability. Moreover, it is difficult for me to carry out the transfer when I am not at the peak level of my fitness, for example, due to an illness. Therefore, a few years ago, I constructed an individually fitted mechanism together with my therapist, with which I can firmly connect the wheelchair to the bed. This makes the transfer easier and safer and I can manage it even if I am not entirely fit. In the beginning, I only used the mechanism when I really needed it. But as time went by, I used it for every transfer, because it makes the process so much easier and is therefore a relief in everyday life, allowing me to use my energy for other tasks [15]. When the holding mechanism was once unavailable due to damage incurred, I realised that I had lost the ability to transfer between bed and wheelchair without using the mechanism. The device could be repaired quite easily, but the fact of having lost such a hard-earned function without noticing until it was too late hit me hard. For me, this means that if I spend the night in a bed different from the one at home (e.g. when travelling), I now need help to get in or out of the bed when previously, I could just more easily plan for these aspects of travel. I have decided to specifically train this skill again during my next stay at the rehabilitation centre to counteract the loss of function due to the AT. After that, I plan to only use the mechanism when I absolutely need it.

This example should demonstrate how quickly you may become unintentionally dependent on AT. As in this case, it can lead to the loss of important functions and, thus, to a certain loss of independence when the AT become unavailable – potentially without anyone noticing that this loss has occurred until it becomes a significant issue.

2.4 Example 3: A Hot Winter Night

Having a high spinal cord injury my body's own temperature regulation is significantly reduced. This means that I get too cold or too hot quite quickly, depending on the ambient temperature of the environment I am in. Some of this can be countered with appropriate clothing, but at home I try to keep the room temperature in an optimised range for me. To achieve this, I installed digitally programmable, network-compatible thermostats (so-called "smart thermostats") on my radiators. This enables me to set the desired temperature very precisely and individually for each room. If the temperature still fails to suit me, I can quickly and easily make the desired change via my smartphone. In general, the system works quite well for me and I am happy with the usability and the overall improved energy balance for my body.

But last winter, for no obviously apparent reason, two of the thermostats encountered a problem and stopped working. The heating valves were completely open and the thermostats could not be adjusted either via the buttons on the unit or via the smartphone. My flat quickly became very hot and since it was already late in the evening, I had no option available to organise anyone to reset or dismantle the thermostats (both can only be performed with specific tools and full finger function). This lead to me having to endure a sleepless night, during which I tried to keep the temperature within a bearable range by constantly closing and opening the windows (thankfully, it was cold enough outside for this to work), until I finally could get help the next morning.

After this experience, I constructed my own personal device with which I can reset the thermostats on my own, echoing practices of empowerment for disabled makers more generally [13]. Additionally, on the radiators that are out of reach for me, I reinstalled the old-fashioned but reliable mechanical thermostats. This means that the temperature control in the flat is no longer as effective and pleasant, but it is safer and more consistently within my control. The example is intended to illustrate how important the reliability of AT is, even when a technology is not recognised as assistive in all circumstances of use, and that the exit strategy (e.g. reset) must similarly be accessible without barriers. Furthermore, I should have thought about the consequences of a malfunction in advance and only perform the change when I have an exit strategy or a backup plan that works for me. However, the question remains whose responsibility it is to account for alternative modes in the case of malfunctioning or nonfunctioning of technological artefacts in assistive contexts.

3 PERSONAL REFLECTION

It was my intent that the explanations in the previous section provide a comprehensible insight into my life experience with AT as a person with a disability. It is important to me to emphasise the extent and importance of AT, but also to create awareness of the interconnections, the arising dependencies as well as the scope of possible consequences of use, functioning, bad functioning, malfunctioning and nonfunctioning [17].

Without AT, my life would look very different and I would never have access to some of the experiences that I treasure in my everyday life such as:

- living on my own in the area of my choice (regardless of the location of my family or the regional supply situation of caregivers),
- having a job (as a product developer of medical devices) that I choose based on my interests and talents and not defined by my impairment,
- enjoying hobbies like cycling, bird watching, etc., and
- being social with friends, family and community.

All in all, I am very grateful (and a little proud) to be able to live a self-determined, satisfying and fulfilling life, despite my severe disability. Table 1 provides practical insight into how much AT supports me in my everyday life. At the same time, it also shows how much I depend on it and what fundamental activities I lose if one of the ATs fails. In addition, the examples described have shown that the application of AT can also be associated with unintended advantages making the AT at least partially obsolete as well as veritable disadvantages.

4 DISCUSSION

In this section, I discuss what these observations may mean for dealing with AT and disabilities and how the insights can be used by the different types of people involved with AT, be they researchers, designers, policy makers, therapists or disabled people themselves. At first, the fundamental objectives of AT for people with disabilities should be elaborated, which requires us to challenge existing convictions and the general focus on "doing good" [5] or a singular evaluation oriented solely on the 'usefulness' and potential of AT, but also on possible side effects, as has been argued for general purpose technological research previously [8, 22]. The goal is not just to compensate the impaired functions of a disabled person but the objectives have to be thought of in a more holistic way.

4.1 Implications for Researchers and Designers

It is important to have a basic knowledge of different models of disability and to position specific works within those – at the very least with a basic understanding of the big two, namely the medical and the social models of disability [10]. Findings from disability studies can help to develop a better understanding for these [9, 12, 18, 19, 21]. Such a position requires the proper comprehension of

the context of the application and the fundamental objectives of an AT that is to be researched or designed. One way to achieve this is to involve disabled stakeholders in the whole development process. This means not only taking part in user surveys, but also employing people from the "target population" as project members to help shape the developments. Mankoff et al. already stated how relevant for good AT it is to include disabled people directly in technology research about them [11], drawing on a long tradition of disability rights activism also echoed in a notion of "rights not charity" [16] - or adapted for technology research: "access not benevolence". The list of fundamental activities enabled by AT shown in Table 1 together with the in-depth examples I provided reveal how serious a failure of one of the used AT can be. Therefore, the reliability and quality of AT is a fundamental requirement. The scenario for a failure should be considered and the possible consequences analysed. If necessary, exit strategies or a backup plan must be developed along with the product itself. One strategy achieving this can be to have different levels of support included in the technologies so that people might be able to choose between comfort and training where applicable. Besides the intended effects of AT, possible side effects should be considered equally - including those that may make technological support unnecessary. Again it is helpful to have a clear understanding of the context of the application and to work in close cooperation with the intended (and even unintended) users.

Due to the rapid development of technologies and the intrinsic motivation of researchers and developers who want to improve the lives of people with disabilities with all their commitment and inventive spirit, there is a danger that the use of AT becomes an end in itself. Despite good intentions, the original goals of a certain AT are sometimes not defined clearly enough or abandoned during the process [6] and a sober consideration of the advantages and disadvantages (or effects and side-effects) may not be feasible anymore, if overridden by other constraints.

4.2 Implications for Educators, Carers, Medical Professionals and Policy Makers

For people who work in one of these areas as professionals, it is equally beneficial to be aware of the fundamental objectives of specific AT and the previously referred to models of disability. Before providing specific AT to people with disabilities, providers need to be aware of the intended effect and the range of potential side effect of these technologies as they relate to the situated contexts of the disabled person they are implementing AT for. Therefore, it is necessary to have a good knowledge of the technologies and to practise open communication to ensure that identified advantages and disadvantages are communicated to all stakeholders according to their communicative preferences. In the course of providing certain technologies to people with disabilities, it is essential to consider their individual living situations and to understand the individual application contexts and socio-technical ecologies of care [1]. Further, policy makers have to provide the framework conditions that enable individualised care along the preferences and desires of the disabled person themselves. We identify here the risk of overriding personally established strategies or use intentions

disabled people might have with the assumed potential of use often persuasively communicated by technologists.

4.3 Implications for Disabled People

Disabled people have a nuanced understanding of their own life situation as long as they are allowed to share it on their own terms and along their individual communicative preferences (see, for example, for autism contexts [14]). Therefore, it is especially important for them to become aware of the different kinds of impact specific AT can have on their lives. An open and honest communication from all involved can make the difference, even and particularly if these conversations might be fraught with power dimensions that make the refusal of AT difficult to communicate and follow through. An already widely used form of experience exchange wit AT is to provide self-organized peer counseling through social networks. I hope that more and more people will participate in this type of communication and develop collective strategies in having conversations around AT. In my opinion, users have a certain responsibility in the interaction with AT as well. We need to actively take on our expert roles and reflect on the consequences and possible side effects before we integrate a new technology or technique into our lives. I would like to further encourage anyone who is interested in AT to get involved in research, development, design, supply or communication - be it as a regular collaborator, as a testimonial or in providing constructive feedback. In line with Mankoff et al. [11], it is my conviction that the involvement of people with disabilities to represent their own interests is an essential contribution to the development of AT.

5 CONCLUSION

This experience report was written with the motivation to contribute to the understanding and discourse about Assistive Technologies in the context of disabilities. I intended to accomplish this by communicating my personal experiences and insights to a broad audience of AT stakeholders. Therefore, I described my own impairment and explained my understanding of disability. Subsequently, I listed the AT most relevant to my everyday life, illustrated in which form I use them and which activities they enable me to do. By discussing some representative examples, I could illustrate the potential influences and effects the application of AT have for me specifically. On the basis of this understanding, I identified relevant implications for different stakeholder groups concerned with assistive technologies. In conclusion, the implementation and advancement of AT for people with disabilities holds huge opportunities but we need to turn more honestly towards their risks as well, particularly to their risks of failure or malfunctioning. We expect that a deeper understanding of the socio-technical aspects of the intended application context, the analysis of different dependencies AT might introduce or amplify, the integration of affected people in the development process as well as a responsible approach by everyone involved could help to utilize the opportunities AT promises and minimize the risks that might come along with them.

ACKNOWLEDGMENTS

Part of this work has been funded by the Austrian Science Fund (FWF) project T 1146-G.

ASSETS '22, October 23-26, 2022, Athens, Greece

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