Abandoned by Design: A Critique of Participatory Design's Absence in Assistive Device Development

Abandoned by Design

This paper critically examines the issue of abandonment in assistive technology (AT), specifically in relation to wheelchairs. We draw this critique from literature that reports that 30% of ATs are abandoned within the first year of use. Additionally, we critique the absence of PD from AT development, especially in the context of wheelchairs and mobility-impairment devices. As a community, we must commit to involving people with disabilities as equal partners in designing the technologies they depend on. Otherwise, the unprecedented problem of AT abandonment, often described as wicked, will persist, and the cycle of unmet needs and exclusion will continue.

CCS CONCEPTS • Human-centered computing~Accessibility~Accessibility technologies

Additional Keywords and Phrases: Assistive technology, abandonment, participatory design, wheelchair

1 INTRODUCTION

Assistive technology (AT) enables users to participate in activities that are often constrained by disability. AT is increasingly used by people with varied needs. Every tenth person in the world today requires access to assistive technology, and this number rises to every third person when eyeglasses are included [1, 2]. However, AT has increasingly been associated with poor design and poor utilization. Approximately 30% of all ATs are abandoned within one year of use, which affects users in multiple ways [3]. There are growing concerns around the adaptability of ATs, resulting in increasing dissatisfaction toward them [4, 5]. Accordingly, as many issues in healthcare are associated with wicked problems, AT abandonment also falls into this category [6, 7].

Participation is the primary objective of AT, as it enables involvement in daily living [8] and supports wellbeing [9]. ATs carry significant implications; however, a poorly aligned fit between the environment, the user, and the AT can have serious repercussions on an individual's life [10, 2]. The United Nations and WHO frame access to AT as a human right [11, 2], and WHO also links it to equitable health by stating that people should be able to enjoy the "highest attainable level of health" [2]. Since enabling participation in daily activities is the primary purpose of assistive devices, the importance of AT becomes significant. It empowers individuals to engage in experiences of their choice without barriers [12].

Given the significant role ATs play in everyday life, why do problems of adoption still persist? Why are high rates of abandonment not treated as triggers for deeper intervention? The problem behind abandonment is complex and multifaceted [13, 14]. Various factors can lead to either acceptance or abandonment. These may include changes in health condition, stigma associated with the device, or the user's personal acceptance or rejection of the technology [15, 10]. Other factors, such as environmental conditions and social issues, are also involved [13, 10].

The field currently examines abandonment through the lens of clinical mismatch, lack of technical advancement, user preference, or device complexity. In 1992, Akrich introduced the concept of "projected users," in which the user

represents the researchers' or developers' vision of the user [16]. Developers visualize the challenges and needs of this projected user, determine what kinds of daily activities the user can perform with the technology, and then build their model within this constrained understanding. When developing ATs, many developers often use I-methodology, where user specifications are created based on the developers' own understanding of users' challenges [17]. This can lead to flawed design assumptions by reducing the lived issues of people with varied disabilities into oversimplified assumptions. These explanations locate the problem in the user or the device, but rarely in the process that produces it. Early involvement of users in the design process of ATs can influence the intended configurations [18, 19].

This paper argues that abandonment is not a user failure, but a design process failure: one in which users with different types of disability are either made to fit into one-size-fits-all solutions or are systematically excluded from the decisions that eventually shape their daily lives [20]. End-user involvement is the core principle of user-centered design (UCD), but it is not sufficient by itself. It also requires multidisciplinary teams, where participation from different stakeholders and co-design frameworks come into the picture [20]. Participation of persons with disabilities in the design process is rarely and inconsistently reported. Users are either involved primarily during the testing or evaluation phase, or in the initial phase to surface user needs. In a limited number of projects, such as the MEBot series, collaboration with wheelchair users and rehabilitation professionals approached co-design practices [20]. This limited reporting points to both underrepresentation and under-documentation. It is well noted that even though user testing is reported in the analyzed studies, the collaboration and integration of persons with disabilities as equal partners throughout the process was comparatively rare [20].

Design has now moved beyond being only a tool for beautification and the traditional design of products, such as visual communication design, architecture, and planning. It is increasingly understood as design for purpose, including design for experience, design for inclusivity, and design for interaction. At this point, it becomes important to explore issues through multiple lenses [21, 22]. The role of designers has also shifted toward that of facilitators, applying their unique understanding while working with groups from diverse backgrounds [23, 24, 25, 26, 27]. Participatory design stems from this logic of collaboration and interdisciplinary practice.

For this critique, Quintero's review is useful because it frames participatory design not as a single method, but as a communication-based process in which users contribute across design stages [28]. In AT, this shifts expertise away from developers alone and toward disabled users' situated experiences [28]. The Ghana tricycle case illustrates this shift: collaboration with people with reduced mobility helped produce a device that was more widely accepted and expanded users' everyday opportunities [28].

This critique focuses on mobility impairment, specifically wheelchair devices, where abandonment persists and PD as a framework remains largely absent. The first argument section shows that abandonment is not a user problem, but a predictable result of a design process that excludes users and their lived experiences from the start. The following two sections examine the gap between users' surfaced needs and specifications, and what eventually gets developed. They also shed light on how user involvement is misapplied in current practices. The final argument section presents evidence that participatory design works and calls for participatory design to become part of the normal development process.

2 ABANDONMENT AS A SYMPTOM OF DESIGN PROCESS FAILURE

The use of assistive devices often comes with the common issue of abandonment. Literature shows the abandonment of ATs is around 30% when used for the first year [29] and the reported non-use percentage is about 34% at three months of accepting the device in question. In a study, it was found out that 35.9% of participants found problems with their manual wheelchairs. This was found across different brands of chairs, with issues related to weight, vulnerability, and

difficulty in maneuvering [30]. The core idea of assistive device is to empower people with disabilities but it often defines it as the marker of disability [31]. In reviewing studies on ATs and design sprints it was noted that participants often termed ATs by strong negative terms. A notable example comes from a study done by [3] in which a user called the term “devil” to it particularly the wheelchair that they were using noting a deep anger towards it every time they look at it. There are different feelings people with disability have mentioned, which surfaces not only the problems pertaining to the look of the device but different elements of it. Along with the discomfort some mentioned having stigma attached to using a wheelchair among non-disabled people in public spaces, which makes them feel more dependent than empowered [35].

Insights have been drawn from disability models that mention it to be something which needs to be set or cured in order to make these individuals work in a ‘normal’ way [32, 33]. Currently abandonment is seen from a point of view of a mismatch made through clinical lens [19]. An approach that makes engineers lead teams to work on the efficiency, build quality or usage of the device, seeing ATs from the lens of ‘designing for the user not by the users’ [18]. While we are moving towards the world of ease with technological advancements, in context of ATs, the advancements are adding to the complexities further in assistive devices [20]. There seems to be a huge gap in understanding the diverse nature of the problem associated with different people and giving them a one-size-fits-all solution [19] which makes it a Procrustean approach [34]. There seems to be a narrow scope of evaluation majorly in terms of functional or ergonomical limitations [18].

This narrow framing is not accidental but rather structural. Since engineers work in-silo mode, the idea of judging the issue becomes passive, leading to creating further assumptions and iterations which are nowhere close to the real needs of the user [18]. Evidence has been noted in siloing different practices of different professionals. In this context a divide can be seen between the practices of design professionals and healthcare professionals while working towards developing an AT [36, 24]. A major gap in the process of collaboration is communication within different stakeholders. It is seen that research has been done on user preferences, but often times those inputs are left at the initial stages [20]. The design process afterwards is where researchers and engineers seem to draw inferences from their own experiences which reduce user interaction to the very beginning of the process [19]. It is also surfaced that the confusion in power dynamics of different stakeholders arises from the wrongly structured problem statement from the start. The problems in the design of ATs are often described as wicked problems, which also contribute to the confusion of different branches of solution spiraling into nothing [18].

Stemming from the in silo mode of working among researchers and engineers, there seems to be a framework of I-methodology being used. Often times an idea is developed only from the brains and perspective of an engineer as the main actor. These solutions stemming from their experience of the problem faced by a person with disability create a significant gap in perceived reality and actual need of the user [19]. This not only broadens the gap -from initial needs being defined by the user and the outcome - but also creates distrust among different actors involved. The problem also stems from the dynamics of the design process not being divided clearly among different stakeholders [20].

It is found that there are two stages to abandonment of ATs. It is either in the initial phase, where the distribution happens through government organizations or through subsidized incentives wherein the user especially in the case of wheelchairs, doesn’t accept the device, or after accepting they abandon it after three months of use. Initial acceptance of the device often also gives organizations a false feedback which also is mentioned as one of the reasons of no change in subsequent devices [18]. Initial rejection of the device often leads the devices to remain in warehouses which then is either thrown in landfills or are left to be swallowed by the environmental factors [20]. This suggests a predictable outcome rather than an unexpected user failure or attempted by the user leaving no surprise [18]. These devices which

were promised to provide independence lose their entire context the moment it comes in contact with the built environment and daily lived routines [19]. When ATs are made by following co-design and participatory frameworks, it has shown that people find them comparatively more adoptable as compared to siloed devices when being launched. Participatory design not only involves users it also enables user centered approach at every step [3]. A sense of companionship, increased engagement and positive bonding is seen in behavior of users when participation was involved in design process [37].

3 THE GAP BETWEEN USER NEEDS AND DESIGN REALITY

Major user needs which healthcare literature references are the physical aspect of AT being too heavy or uncomfortable, difficulty to utilize, increase in stigma and a sense of isolation due to the appearance of the AT and cognitive barriers [29, 38, 15]. There is a consensus among both healthcare professionals and design professionals that involving and engaging different stakeholders including the end-user throughout the process can significantly improve the end result in AT [39, 40]. Users have surfaced demands pertaining to minimizing the bulky nature of ATs as it creates unnecessary cognitive load while maneuvering through skewed corridors. Users have also mentioned using colorful linings in cushions of wheelchairs or adding surface embellishments in order to make them more welcoming [3]. Due to factors involved in society like policy and funding for trials and review of AT, these needs are overlooked and are not met with full conviction leaving unsatisfied end user [41, 29]. This issue of unmet needs directly affects users and hence leads to abandoned ATs [9, 42]. Here, it is crucial to note that whenever disability is taken in from a lens of higher authority it can yield a device which lacks basic association with the concerned user it is made for. Time and time again users have surfaced issues with the grip of the handles for the caretakers, the brakes being too rigid, the size being extremely bulky the look of it being too mechanical and medicalized but seldom these inputs are taken into consideration [3].

Even with advancements being done in the industry leading the way forward, the distribution of right product among right user still remains untouched [20]. There are examples within the literature of design methods beings used in AT including charging wirelessly in powered wheelchairs [43], modifications of mobility aids [44], and music-making with older adults [45]. These updates often appear disconnected from ground realities, the lived experiences, the friction these users feel. Usually the needs of users are also often times framed in medical or societal models of disability [19]. They argue how more than one framework is required to surface and understand the complex nature of user needs and the wicked problem of abandonment of ATs [19].

Assumptions often made by engineers create miscommunication and creates a barrier in not providing ATs as per real user needs. The device which promises to give independence to the user in reality makes them and the family, caretakers and people around them more depended on it [31]. Participatory approaches pushes for total collaboration between every stakeholder in each step but it doesn't seem to be seen in the case of ATs especially in wheelchairs. This wrong fit of device intended for people with disabilities leads to uncertainty [18]. Since the inception starts from a perception in silo mode the end product hence enables no new independence or comfort.

4 WHEN USERS ENTER THE DESIGN PROCESS

There have been instances where users are involved at different stages of product development [19], but the impact of that involvement often remains unclear [20]. Even though the sensibility for involvement exists, there seems to be a fundamental misunderstanding about which stage to involve users and in what capacity [20]. A fundamental confusion seems to exist between current practice of PD - where users define the needs and problems from the beginning - and user

testing where users validate a solution that has been developed. It is crucial to note that these are not the same thing and treating them as equal is itself a start towards abandonment of any device. A systematic process in which collaboration between different stakeholders takes place throughout development can be seen as a positive approach towards the persistent issues of low acceptance and rising abandonment [3].

Early involvement of users from the very beginning provides not only design inputs but lived anecdotes that make the overall process more transparent from the start [3]. User involvement in the initial stage with a conscious power structure between facilitator and end user has seen remarkable results in prototyping and product development [46]. Fields such as designing for the deaf and involving elderly populations in road safety initiatives have demonstrated how early meaningful involvement transforms outcomes [19]. Even though significant changes are seen in initial phases, the in-between process of designing, prototyping and manufacturing leaves a mismatch where user involvement disappears entirely [20], user feedback impact on design becomes unclear. There have been instances wherein user involvement only in the later stage has come to the surface - where engineers test what they have already built from their own perspective rather than the lived experience of the disabled community. Since this occurs at the end stage it leaves no scope for designers to change fundamental decisions - because from the beginning the problem identification was never done properly [47, 19].

In much current research, assistive devices are developed with user involvement either only at the beginning or only during user testing at the end, reflecting variability in how user involvement is understood [20]. This is the reason why the final product does not satisfy the end user - the conflation of user testing with participatory design creates a false sense of user centeredness while producing devices that serve no one's actual needs [20], [47, 19].

When concerned with lower limb mobility it becomes paramount for all partners to contribute equally throughout the entire process. PD is a process that requires a framework followed from beginning to end - one that does not work backwards, that captures details of every in-between stage and arrives at solutions only after genuine problem understanding [47, 19]. Since assistive device abandonment is a wicked problem it becomes even more critical to leverage participatory frameworks - structured approaches that can hold complexity without reducing it [47, 19]. Such frameworks require all stakeholders to remain open to different scenarios and versions of user needs as they emerge - not locking into solutions prematurely [28]. The question is not whether participatory frameworks work - the evidence that they do is clear. The question is why the field continues to resist adopting them as standard practice.

5 KNOWN BENEFITS, IGNORED PRACTICES: THE CASE FOR PARTICIPATORY DESIGN

Evidence shows that PD can produce successful ATs. It can be seen from the examples that using PD and co-design frameworks makes the final product highly user driven and user centric. Transferring independently is a crucial aspect of using a wheelchair in daily life. To make sure that it is done with ease, inputs from different wheelchair users were taken in the process of designing and developing the product. 12 participants were recruited in the study wherein they were asked to reflect on their experience of using wheelchair and other modes of products in order to gauge the idea of maneuverability in the context of transferring and multi-modality. In this study participants became active participants and self-reporting agents along with significant part of the overall study. This not only empowered the participants but yielded a better understanding towards making a product for transfer; it maximized the overall impact and guaranteed successful power balance among participants. This showed an overall result of satisfactory among the 12 users [46]. Another example is of XoSoft in which more than 40 participants divided into primary and secondary users got involved in making a lower body walking aid. An iterative user centered design process helped in surfacing real issues pertaining to mobility. The result showed opinion of these users to be largely positive after the use and results indicated high user

satisfaction [48]. These examples showed how enabling participant involvement from the very beginning yielded successful implementation of needs of real users and eventually bringing change in the results.

While discussing different stakeholders and participants to come together holistically when designing ATs, it is important to note the factors involved in impacting the success of these processes. Howard et al. identified systemic issues of funding and social environment creates barriers among OTs and designers to come together and practice development and design of ATs [49]. There is also the issue of siloed practice wherein a significant divide among various actors involved in making ATs creates even further gap to using PD as a technique for betterment of abandonment issue [3]. The issue of gatekeeping also led to inconsistencies in the design process of ATs [3]. It is also seen that factors of resource constrained or time management may impact in involving different stakeholders and expediting the process.

It has been seen repeatedly that the acceptance of these wheelchairs especially for lower limb mobility has been abandoned after 5 years of its use. It is also been noticed that the engineered model of the wheelchairs with modern technology that gets launched in the market termed as "innovative solution" lacks the fundamental needs of the real users and their wants seem to be ignored from the context. Ignoring the basic needs of the people with disabilities and not involving the right user in the process of building something for them without including them seems to be quite contradictory. The idea of designing with disabled people, rather than only for them, has already been strongly argued in assistive technology literature [18]. The whole process does lead to a significant toll on the end user but it is also an inefficient use of time, money, resources and above all the trust that gets broken every time each new device is launched under political mandates or policy schemes. In this context, empathy cannot mean studying users from a position of authority; it requires working with them as equal partners and facilitators. [3, 19].

6 DISCUSSION

This paper provides a critical review of research on assistive devices and technologies, especially in the domain of abandonment, and presents a strong argument for understanding abandonment as a design process problem. The review is structured around four key arguments: Abandonment as a symptom of design process failure, the gap between user needs and design reality, when users enter the design process, known benefits, ignored practices: the case for participatory design. Our goal was to understand and surface the abandonment of ATs, and lack of PD frameworks being used in context of mobility impairment with people with lower limb disabilities. We further found relevant data in strengthening our claim that abandonment of ATs stems from a design process issue not a user acceptance issue. Across all four arguments we found a consistent power imbalance among engineers, clinicians and policymakers who majorly hold decision-making power over devices that people with disabilities (PWD) must live with daily, while those same users are systematically excluded from the very design process.

The review highlights debates on framing the users with disabilities in the development of ATs through either by considering them in the last stage of user feedback or just in the initial phases, leads to dissatisfaction in various parameters and eventually abandonment of the AD. Participatory design and co-design practices along with human-centred design is mentioned as a key factor in the acceptance and better uptake of ATs but there seems to be no transparency on how it is understood [19, 20]. It was found that ease of use, comfort, cost, and experience of it are the major factors on the need spectrum of a user. Psychological and social barriers also been named as stigma associated with using ATs. It also puts light on the varied aspect of mobility impairment devices and how PD is still not there especially in this segment while being introduced in hearing aids, robotic upper arm devices and alike. Many researchers argue that involving users in a participatory co-design manner throughout the process along with active collaboration

among all stakeholders have shown significant change in the outcome of the ATs [19, 28]. An active participation from users has shown products with outcomes of great acceptance, XOSoft and YouTransferYouDesign model [19, 28]. It is found that the major causes of why PD is not implemented in the design process are due to these reasons. Limitations in time management, funding, in-silo practices of researchers and engineers, seeing the problem from the lens of a researcher than the user are some of the surfaced problems on why adoption of PD and user-centered design is not taken into consideration. The persistent problem of abandonment despite having awareness of it further confirms what scholars have identified as the wicked nature of assistive technology design. A problem that is extremely complex in nature that regular and redundant technical solution will always fall short [3].

It is also found that the process of involving every stakeholder especially the end users may lead to longer time from initiation to project deadline, and one can argue that usually the time limit is not that much. It is a justified point in context to many ATs as either due to less resources in terms of infrastructure or money can lead to a fast paced process of the design of ATS. But comparing this skipping process tendency to the cost of 30% abandonment [19, 28] , wasted resources and material, polluting environment, wasting space and most of all wasted trust is nowhere comparable. The question from this arises is what is expensive then? The time limit could be a demanding factor but a lead time in which recruitment to interviews and involvements can increase the uptake exponentially as found out. If we measure the benefits against cause it outweighs easily. Furthermore, the physical and psychological long-term effect of using a bad device cannot be compromised at any level. Another issue significantly that arises from our review is the cost of ATs, which can be a limiting factor for some.

The critique argues that people and their lived experiences should have power over the devices built for them. Participatory design is not a new concept to this community - it is foundational to the HCI tradition from which NordiCHI emerges. This critique calls for that same tradition - giving people power over technologies that shape their lives - to be applied urgently and systematically in the domain where it is most visibly absent.

Based on this review, the following implications emerge for assistive technology research and design practice. Below we will present the research implications that can be drawn from the results of this literature review.

7 IMPLICATIONS

Abandonment should be treated as a signal pointing back to design process failure not merely measured as a user behaviour outcome. Currently abandonment data is collected but is not shown back to where the problem lies or the problem originated. Reframing abandonment as feedback would allow the field and necessary stakeholders to examine it thoroughly from the lens of a process and system failure than blaming it on the users [3].

It is required for the stakeholders and those who hold power to situate practices that involve users at the forefront of the project and must not be negated afterwards for the user feedback stage. Current practices either involve users too late or just in the early phases. A systematic approach to collaboration and communication with all actors can improve the fit, usability, and acceptance of the final device [19, 18, 46].

The approach of Participatory design has shown better outcomes in other fields like upper limb prosthetics, stroke rehabilitation and exoskeletons. Lower limb mobility devices should adhere to this process by studying and following the practices. The evidence from parallel fields makes the continued failure unjustifiable [48, 19].

Limited research funding in this area must prioritize and reward genuine user involved innovations. Current models surface opportunities to rapid technical advancements which benefits no one since it stems from an I-methodology. Until funding structures and team dynamics instilled within institutions and research groups change the PD adoption will persist regardless of how much the evidence points towards it [3, 19].

8 CONCLUSION

This critique examined why assistive devices, especially wheelchairs, continue to be abandoned despite technological advancements. It argued that abandonment is not caused solely by changing user demands, but also by a broken design process. Users are often not meaningfully involved in the design process, leading to a disconnect in understanding the real lived difficulties of people with disabilities. This exclusion of users from design decisions appears to be a major factor contributing to the persistent issue of abandonment. Participatory design, where users are treated as equal partners and collaborators from the beginning, has shown significantly better outcomes in other domains of AT, but remains largely absent from wheelchair and mobility-assistive-device development.

The person who pays the price for this broken process is not the engineer, the clinician, or the policymaker. It is the wheelchair user who receives a device that does not fit their life and must either struggle with it or abandon it. This is not only a methodological failure; it is also a failure of trust and values. A field that claims to serve people with disabilities, while ignoring their voices and lived experiences, contradicts its own purpose.

Across the literature reviewed, the pattern is difficult to ignore. What remains is the awareness and shared responsibility to ensure that the right design process is followed, not only by developers, but also by people in power, rehabilitation partners, healthcare specialists, and designers alike. A community built on participation and the open discussion of daily challenges now demands a systematic framework for involving disabled people. What is needed is an approach of designing and developing together.

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