

Empathy-Centric Design in Assistive Technologies for Cerebral Palsy and Disabilities: Balancing Aesthetics and Functionality

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ABSTRACT

Design greatly simplifies tasks, enhances daily life, and improves products and services. However, in the rehabilitation of disabled children, design often falls short. This paper seeks to highlight the intricate interplay between design and assistive technologies by shedding light on the challenges faced by disabled users with these products, especially cerebral palsy children. The paper explores literature indicating how these products can negatively affect user self-esteem, rehabilitation, and product adoption. It underscores the significance of integrating semantics and employing empathetic methods to strike a proper balance between aesthetics and functionality in the design development of assistive products. This approach aims to enhance children's perception and societal acceptance of these products, transforming them from standard hospital equipment to more empathy-centric solutions.

CCS CONCEPTS

Human-centered computing;
Accessibility;
Accessibility technologies;

KEYWORDS

Empathic design, Semantics, Empathic-centric design, Empathic research methods, Cerebral palsy, Disabilities, Assistive products, Assistive technologies, Industrial design

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1 INTRODUCTION

Cerebral Palsy (CP) emerged in the late 1800s, associated with complications during pregnancy and childbirth [9]. It's a complex group of chronic conditions affecting body movement and coordination, typically caused by brain damage during fetal development, infancy, or shortly after birth [9]. Globally, around 1 billion individuals have disabilities, necessitating specialized care and assistive technologies [28]. In the USA, approximately three million children had disabilities in 2019, with about 10,000 new cases of cerebral palsy yearly



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EmpathiCH 2024, May 11–18, 2024, Honolulu, HI, USA © 2024 Copyright held by the owner/author(s). ACM ISBN 979-8-4007-1788-8/24/05 https://doi.org/10.1145/3661790.3661802 [40]. While not curable, CP's impact can be improved through education, therapy, and assistive products. However, stigma often leads to reluctance to use assistive devices [29].

This reluctance has been a subject of discussion in multiple academic studies, primarily focusing on the stigma associated with disabilities rather than addressing how design aesthetics can accentuate the disability. Many assistive products tend to resemble hospital equipment, and those designed for children are often rescaled designs from adult products, thus raising the question: Are designers and engineers adequately balancing aesthetics and functionality when designing assistive technology for children? This paper discusses this through existing literature around this topic, revealing a lack of consideration for the product's appearance and how its semantics are perceived by users, thus impacting its adoption.

Assistive technologies are crucial in supporting daily activities, with ten distinct categories (mobility, electronic communication, visual, assistive listening, environmental access, computers, leisure/recreation, independent living, positioning, and adaptive toys) aiding children in various life moments [3, 22]. Despite their benefits, the issue of abandonment is significant and linked to user perceptions and stigma. The focus on functionality often overshadows aesthetics, impacting user acceptance [1]. However, thoughtful design, considering semantics and empathy, can enhance acceptance of these types of devices [5]. Consider the stark difference between a toy walker with vibrant colors and engaging features to entice children, prioritizing aesthetics and consequently a better approach to semantics, and a conventional disabled-focused walker with its simple tubular structures and caster wheels, emphasizing functionality over aesthetics, a weaker semantics approach. Despite some incorporation of colors in assistive products, it is evident that the design often prioritizes functionality over empathetic considerations for the users that would come through aesthetics and more engaging features. This emphasis on functionality frequently overlooks the need for empathetic design tailored to this specific user niche.

While designers often employ human-centered design approaches, there seems to be a deficiency in the identification and use of empathetic approaches toward disabled users, where designers empathize with users' experiences during the development of assistive technologies and properly balance considerations between aesthetics and functionality over the product's design. This prompts questions about the availability of empathy-centric tools and whether universal design principles have been effectively integrated into the creation of more inclusive and less stigmatizing products. Semantics, the language of design, shapes user perceptions and self-esteem. Universal design principles promote accessibility, reduce abandonment, and diminish stigma [5, 13]. As previously mentioned, semantics play a crucial role in the overall development of assistive technology for disabled users. In tandem, empathy empowers designers to consider users' emotions, perspectives, and experiences when designing these products. It helps place the designer in the end-user's shoes to gain insights into their needs, behaviors, emotions, motivations, and challenges [2].

Understanding design, addressing stigma, and fostering empathy can empower users, reduce abandonment, and improve the overall user experience. Semantics, aesthetics, and empathy significantly influence self-esteem, social interactions, and acceptance. Whereas universal design principles should balance accessibility with aesthetics, reducing stigmatization.

This research explores empathy in design for children with cerebral palsy, delving into current literature on assistive technologies to offer insights into their impact on users' lives.

2 CEREBRAL PALSY

Cerebral palsy, a term combining "cerebral" (related to the brain) and "palsy" (movement and posture issues), encompasses chronic conditions affecting body movement and coordination, often resulting from brain damage during fetal development, infancy, or shortly after birth. Coined in the 1800s, the term was likely introduced by Sir William Osler [30]. Dr. William John Little, a British orthopedic physician, began studying the condition in 1861, initially referring to it as "Little's Disease," focusing on children with spastic diplegia characterized by stiff and spastic muscles, making movement difficult [32]. Initially, Little attributed the disability to birth complications, suggesting oxygen deficiency damaged brain tissues controlling movement. However, Dr. Sigmund Freud proposed prenatal factors during brain development as possible causes, linking them to cognitive, visual, and convulsive issues [43].

About 10% of the world's population lives with a disability [44], necessitating specific medical, educational, and economic support [11, 23]. In the United States, over three million children, or about 4.3% of those under 18, have disabilities, with cerebral palsy affecting approximately 10,000 infants annually [40]. Despite misconceptions, cerebral palsy is not contagious and persists throughout an individual's lifetime [4]. While not curable, education, therapy, and assistive products can enhance the lives of those with cerebral palsy [1]. However, user experience is often neglected, leading some individuals to avoid certain products due to concerns about stigma [7]. This highlights the enduring stigma surrounding disabilities.

3 ASSISTIVE TECHNOLOGY DESIGN AND STIGMA

There isn't a standard form of therapy for the recovery or support of Cerebral Palsy users; however, once healthcare professionals determine the type and level of cerebral palsy, a plan for the recovery is the expected direction [39]. This plan often comprises follow-ups, exercises in rehabilitation clinics, and using assistive technology to support mobility and muscle development [17]. Assistive technology is a critical tool in enhancing the social inclusion of disabled children and is often associated with computer applications, electronic communication devices, and powered wheelchairs [22]. However, it is essential to recognize that the area in which assistive technology is placed is incredibly diverse and encompasses a wide array of devices categorized into at least ten distinct groups [3][22]. These devices go far beyond traditional notions of technology, extending into various moments of a child's life.

- Mobility: this first category revolves around mobilityenhancing devices, including but not limited to orthotics, walkers, wheelchairs and scooters. They aim to empower children to move freely and independently, fostering their participation in various activities and socialization.
- Electronic Communication: In communication, assistive technology offers devices that produce artificial or real-life speech, thus enabling children to interact effectively with others and express themselves.
- Visual: visual aids such as magnification devices come to the forefront when tackling reading tasks and facilitating learning and engagement for children with visual impairments.
- Assistive Listening: hearing aids are invaluable in the category of assistive listening by assist-ing children with hearing impairments in perceiving and engaging with auditory information.
- Environmental Access: these devices are often identified as infrared control units and provide children the skills to independently use several household appliances like televisions and gadgets, besides enhancing their sense of control and autonomy.
- Computers: the world of technology extends to computers, offering not only conventional applications but also specialized software designed to facilitate cooperative play and interaction with peers and, therefore, promote social engagement.
- Leisure/Recreation: hand-held electronic toys for independent play and entertainment. These objects enable children to enjoy recreational activities tailored to their preferences and abilities.
- Independent Living: assistive technology devices like buttoning or reaching aids are designed to enhance independent living by helping children with physical disabilities manage daily tasks more effectively.
- Positioning: proper body alignment is crucial for comfort and health. In this category, we can identify devices like vinyl-covered rolls and bolsters, which can play a pivotal role in ensuring children maintain the correct body posture.
- Adaptive Toys: battery-powered toys that children can control using switches fall into the adaptive toys category. These toys can foster engagement and play while accommodating the child's specific needs and abilities.

Understanding and identifying the full spectrum of assistive technology devices is paramount to providing inclusion and welfare of children with different disabilities[16].

By identifying the contexts where assistive technologies are applied, designers can acquire crucial insights into the appropriate positioning of their products and the diverse considerations essential for their development. These considerations may encompass a range of factors, including product functionality and features, ergonomic considerations, user experience design, material selection, and more.

Furthermore, this identification provides valuable guidance to aspiring designers in academia, elucidating the extensive landscape of assistive technology and proposing avenues for research and benchmarking of existing products. Having the scenarios in which these products are also facilitates the use of empathic-centered tools such as Empathic Modeling. This method is commonly employed to foster a deeper understanding of another individual's perspective, whereby the participant gains insight into their limitations by simulating them, thereby cultivating empathy and emotional connection with others [2].

While recognizing the significance of delineating these areas, there is a pressing need to establish guidelines and methodologies to enhance the application of universal design principles in product development and academia, especially in industrial design. Despite this recognition, the exploration of empathy-oriented methods and semantics, with a specific emphasis on disabled users and assistive products, remains an underexplored area [1].

Assistive devices extend beyond mere tools as they become essential companions on the journey toward independence and participation in various aspects of life. Although assistive technology offers numerous advantages to users, a significant proportion of these assistive technology products/devices are abandoned due to the stigma attached to these devices and the user's perception of them [31][34].

The acceptance of disability is intricately tied to how individuals perceive themselves and their interactions with others. It's essential to recognize that specific cultural characteristics can have an important role in shaping disability integration into one's self-concept [14]. Consequently, these norms have a significant influence on the embrace of disability and the choices individuals make regarding the use or abandonment of assistive devices. Cultural characteristics can establish the roles and activities people are expected to engage in, which can significantly influence stigma and the adoption and utilization of assistive devices [35].

Stigma often surrounds the visual aspects of assistive technologies. For instance, the association of disability with wheelchairs is a consequence of the primarily used wheelchair pictogram to communicate a disabled-accessible area [19]. Not only can the pictogram highlight disability, but assistive products themselves can accentuate the visibility of disability [8].

The development of assistive technology often focuses on functionality, potentially neglecting the importance of aesthetics or other aspects related to the user's needs, motivations, or desires [8]. This tendency to prioritize functionality over other aspects (e.g. visual appeal, motivations, etc.) has the potential to significantly influence perceptions regarding assistive technology [31]. Adopting a more deliberate, thoughtful, and integrated approach to the design of these products carries the promise of reshaping societal attitudes and perceptions toward disability [2]. Nevertheless, it is essential to remain aware of the symbolism embedded in the aesthetics of these devices. Promoting empathy and its understanding among design practitioners can be accomplished through diverse methods, such as directly engaging with real individuals or simulating activities that mimic the challenges disabled users face, serving as a form of experiential learning, a strategy commonly employed in empathy design [7]. Products designed through empathetic approaches that remove stigma can elicit desire akin to any conventional product.

4 SEMANTICS AND THE NEED FOR EMPATHY

In 1984, Krippendorff and Butter introduced the concept of semantics in product design by identifying it as the study of the symbolic attributes in human-made artifacts within their cognitive and social contexts of use [38]. This understanding of product semantics is connected to the dynamic relationship between the user and the product, along with the significance that objects assume within practical and societal frameworks.

Regardless of the specific choices designers make regarding color, shape, form, and texture, products essentially transmit messages through a subset of language structures concerned with meaning termed "semantics" [20]. The level of discomfort experienced by users when using assistive technology varies according to how "unusual" are the product's aesthetics and how it is perceived in a social context [31]. This perception can significantly influence the user's self-esteem and capacity to initiate and engage in social relationships.

In its unique way, a product conveys insights not only about its own attributes but, in certain instances, about the individuals who possess them. A product articulates characteristics through its design and functionality, which individuals then interpret and assign value to within their particular social environment [27]. This interpretation can lead to varying responses, including acceptance or rejection, liking or disliking. Therefore, it is essential to recognize that a product's semantic content and expression possess the potential to either fortify or weaken the assistive technology role in this intricate relationship and consequently influence opinions, feelings, principles, and connections within the individual [6].

Design professionals have long advocated for the universal design approach, aiming to create products and environments accessible to all users, regardless of age, ethnicity, or disability [21]. While promoting awareness and emphasizing users' full capabilities, practical implementation often leads to higher costs and potential stigma due to distinctive appearances [21][24][45]. Usable design tends to result in distinct accessible areas and products, further segregating users [14] and reinforcing associated stigma [46].

There is a considerable lack of attention to the aesthetics of assistive technologies, especially when considering how competitive the market is for these products [6]. Despite the widespread adoption of human-centered design, which fundamentally underscores the importance of designers embracing an empathetic approach to understanding the user [2], this method seems to be overlooked in assistive products for children. This neglect leaves a gap that emphasizes the significance of the object, where a "form follows empathy" approach could enhance the adoption of these products and the overall user experience [5].

Although the existing literature has yet to explore specific strategies for empathizing with children with disabilities and recognizing them as such, the integration of Empathic Modeling alongside Role Play can effectively immerse designers in the experiences of disabled users [2]. Empathic Modeling enables designers to comprehend the limitations, frustrations, and stigma associated with disabilities, while Role Play immerses designers in the context of the project being developed. For example, designers can adopt a child's perspective by sitting on the ground to draw and performing basic tasks at a child's eye level, gaining insight into their environment, perspective, movement limitations, and perception and accessibility of the products around them, among other contextual factors. Integrating these methods collectively enhances the development of projects for children, particularly those requiring assistive products, by offering insights from the perspective of disabled children. This approach can increase the acceptability of the product and empathy towards the user, even among able-bodied individuals [3], thereby contributing to the overall reduction of stigma and the adoption of the assistive product.

Disabled children and their families often feel pressured to accept assistive products chosen by healthcare teams despite any stigma or negative perceptions associated with them [31]. This is often due to a lack of information provided by healthcare professionals about available services and the financial burdens associated with assistive devices and care [15].

Caring for disabled children incurs significantly higher costs compared to typically developing children [36], attributed to increased medical needs and specialized therapies [33]. These services encompass rehabilitation, environmental adjustments, assistive devices, personal support, respite care, home healthcare, and mental health services [10, 25]. Financial concerns affect about 40% of families in the United States caring for disabled children [18], leading to additional income-seeking efforts or even employment reductions [26]. Direct out-of-pocket expenses for these families are more than double those of families with non-disabled children [26], with caregivers often facing heavy health-related costs, particularly related to transportation for their child's physiotherapy [41].

Given the challenges caregivers face with children with disabilities and the profound impact assistive products can have on these children's self-perception, designers, renowned for creating products to enhance users' lives, bear the responsibility of reevaluating how we design products for disabled users. This is crucial for fostering inclusion and acceptance and reducing the stigma surrounding disabilities.

5 CONCLUSION

Design and semantics play a vital role in assistive technologies and significantly impact the lives of those with cerebral palsy and other disabilities. Societal stigma often affects user experience, highlighting the need for a new approach to developing these devices. Embracing user-centered design principles focused on aesthetics, empathy, and usability can empower individuals, decrease abandonment rates, and reduce stigma. By prioritizing aesthetically pleasing and empathetic designs, assistive technology can revolutionize users' daily lives, making tasks more accessible and enjoyable.

Thoughtful design, adopting a "form follows empathy" approach can enhance user acceptance through semantics, this approach can be performed using existing empathy-focused methods such as Emphatic Modelling and Role Play, however, it is essential to emphasize that methods directly focusing on disability are not yet identified, thus the application of many methods currently available are subject to the experience of the designer using them and the individual's understanding of disabled users. Semantics, the language of product design, significantly influences users' emotions, perceptions, self-esteem, and social interactions, underlining the crucial role of these devices in users' lives.

While universal design offers enhanced accessibility, it can be hindered by higher costs and distinctive appearances, potentially reinforcing stigmatization. Incorporating universal design principles has the potential to produce aesthetically pleasing, widely embraced, and less likely abandoned products. Our literature review revealed that specific design universal design principles are often incorrectly applied, which may impact the development of assistive products by designers lacking a foundation in these principles. We propose that by developing and elucidating design methods tailored explicitly to disabilities with a strong focus on user empathy, we can strengthen the development of assistive products and offer designers, academics, and students more straightforward guidance.

In conclusion, prioritizing design and semantics in assistive technology is vital for fostering inclusivity, enhancing user experiences, and reducing stigmatization. By actively considering users' experiences and needs, we contribute to an empathetic and inclusive society, empowering individuals with cerebral palsy and other disabilities. Further research aims to evaluate empathy in designing solutions for children with cerebral palsy, seeking insights into their effects through mixed-methods research. With recent IRB approval, two studies are underway to gather data on children's perceptions of assistive products and develop empathy-focused methods for addressing the limitations of disabled users in product development. Stemming from this paper, these studies are designed to complement each other, offering strategies for improving assistive products in the design and academic communities.

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