
OPINIONES, DEBATES Y CONTROVERSIAS

DOI: <http://dx.doi.org/10.15446/revfacmed.v63n3sup.49345>**Co-design: A central approach to the inclusion of people with disabilities***Codiseño: un abordaje central a la inclusión de personas con discapacidad*Martha Patricia Sarmiento-Pelayo¹

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This essay seeks to position the experiences of people who live with disabilities in their interactions with the built environment that surrounds them. It argues, in part, that a hands-on approach such as *co-design*, which relates the personal experiences of individuals with the processes of design, can promote the inclusion of people living with disabilities. This paper also recognizes the existence and possibility of alterations to the built environment initiated by people with disabilities who, despite their disabilities, transform their surroundings to better their conditions. For these types of processes, the term *user-initiated design* –UID- can be defined, becoming a tool of empowerment for these individuals. These writings briefly develop the concept of user participation in design processes, analyze the use of empathic participation methods utilized in design processes with disabled individuals, and conclude that design directed towards this population cohort requires a participation that involves knowledge based on these individuals, and which should be deemed irreplaceable.

Keywords: Design; People with Disabilities; Human Rights (MeSH).

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Resumen

Este ensayo busca situar la experiencia de las personas con discapacidad en relación con su interacción con el ambiente construido; argumenta que los abordajes participativos como el co-diseño, que involucran las experiencias de las personas

en los procesos de diseño, pueden potencializar la inclusión de personas con discapacidad; reconoce la existencia de procesos de modificación del ambiente construido iniciados por las personas con discapacidad, quienes, a partir de la afirmación de sus capacidades, adecuan sus entornos para mejorar su condición; define, para este tipo de procesos, el término: *Diseño iniciado por el usuario-DIU* y reconoce en él una herramienta de empoderamiento, con este propósito, el texto presenta de forma breve el desarrollo del concepto de participación en los procesos de diseño; analiza el uso de metodologías participativas y empáticas utilizadas en procesos de diseño con personas con discapacidad; y concluye que el diseño dirigido a este grupo poblacional requiere emplear procesos participativos que involucren el conocimiento situado de las personas con discapacidad, considerándolo irremplazable.

Palabras clave: Diseño; Personas con Discapacidad; Derechos Humanos (DeCS).

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Introduction

A disability is a condition that can affect anyone at any given moment, as consequence of a combination of factors at the physical, emotional and environmental levels. The experience of people with disabilities –PWD- could be of interest to all fields of research (1); in particular to that related to the built environment, given the importance of the physical context in human behavior that has been previously recognized

in disability studies (2). To include the experience of PWD in processes of design requires a thorough understanding of mankind's innate ability to design, as well as the mechanisms designed to collect information that are only granted through experience. Thus, this text seeks to position the experiences of people living with disabilities in their interactions with the built environment and proposes that the design directed towards this population cohort requires participation that involves knowledge based on these individuals, and which should be deemed irreplaceable.

This text is structured in three parts: the first briefly presents developments in the fields of design that entail the element of co-design; the second recalls methodological participative and empathic estimates used in co-design, and analyzes them in the context of disability studies and disability rights. In its final part, the text presents the concept of UID, relating it to solutions proposed by PWD in their attempts to make their environments more accessible.

Design and the historical developments that led to co-design

The ability to design is innately human, allowing us to imagine, define and plan the transformation of the environment to make it more applicable to the necessities or aspirations of an individual or group of people. The built environment is the platform that molds human life. This categorizes the built environment as a crucial determinant in the quality of life, and its practice pertains to all aspects of our daily life and thus is of great importance (3). Design, understood as the process that dictates the layout of things, spaces, objects, processes and organizations has been defined as a form of reflexive dialogue with a situation (4), and whoever is involved in such process with the intention of transforming a current scenario into a desired one can recognize themselves as a designer (5).

The term design plays a role in the various fields of knowledge and making. Art, engineering and investigation, among others, use this term to assign detailed processes of determination for future scenarios. Historically, design can be recognized as a subcategory of art related to the execution of professions such as architecture or industrial, graphic or interior design, where it links with the projection of functional elements in the built environment through trends and aesthetic designs. It has also been an engraved process in the rational and rigorous thinking in science, allowing the application of solutions to problems. Nevertheless, design is currently better defined as a dynamic interaction where new phases change the role of what remains in the process (3).

The next segment will present a brief journey through the history of design that entails the practice of co-design.

The professionalization of design

Professions that claim the importance of knowledge and the making of design as the reason for their existence were consolidated throughout the twentieth century as a response to the increasing complexity of the economic and technological modernization. Based on individual solutions defined between an interested person and the specialized artisan, modernity, in its complexity, requires collective solutions defined by qualified specialists: the designers. In this manner, design becomes an integral component in production, and serves as an instrument of standardized conceptions in the built environment, oriented by the dynamics of the market (6). This way of defining the built environment disregards the specific needs of populations that are not in the interests of the market economies. This is the case of disabled populations, characterized by their need to rely on specific responses to defined capabilities.

The comprehension of the relationship between the shape of objects, defined as its aesthetic dimensions, and the technical purpose that they serve, defined as the technological knowledge available, as well as the interfaces that facilitate or hinder the interaction with users, defined as usability, has been part of the historic task of professional designers over the past 100 years.

The traditional focus of the practice of design, since its origins in the Bauhaus, builds on the development of creative and rational abilities —“expertise”— that allow the design professional to negotiate functional and formal requirements in the configuration of an object, interpreting its optics for the needs or aspirations of an intermediate user—for a regulated activity— in an idealized context.

Given that this traditional focus develops living models which are highly improbable, in the midst of the 20th century, the concept of design veered in search of a “scientific basis for design.” This “new wave” sought to produce designs based on criteria of objectivity and rationality (7). These aspirations reappeared in the movement of design methods that sought the inclusion of techniques and scientific knowledge in order to make rational decisions (8). The link between method, science and design spurred discussion around three ideas: 1) “scientific design”, which distinguished industrial production from craftsmanship; 2) “design as a scientific activity”, which labeled it as a systematic and rational approach, and 3) “the science of design”, which proposed the principles, practices and procedures of design (9).

In the mid-60s of the 20th century, the impact of humanities and social sciences on design produced a change in approach towards the participation of the user in the processes of design. In this sense, the idea that everyone has experience capable

of inspiring design gave way to concepts such as usability, as well as methodologies such as user-centered design.

Usability and its implication in the process of design

The concept of usability arose as a response to products that provided functionality but were difficult to use (10). In 1984 Shackel and Benneth developed a formal and detailed definition of usability (11), defined by four interactive components: the user, the task, the tool, and the environment. Works after Shackel generated the definition that preceded the version adopted in the ISO rule 9241/11, which focused on the quality of usability. Usability has been historically considered a scientific activity, guided by the strategic methods and systems of measurement with the purpose of creating verifiable and replicable results. The consolidation of the usability concept allowed for the exposure of flaws with the traditional focus on the practice of design: the act of designing poses a discussion about the participation of “users” in the process of design, and suggests the need to examine the principal arguments regarding whether or not users should participate in said process, and if so, in what moment and by playing which role.

The processes of design that involve user participation deal with the topics of representation in the early stages of design, when the needs and expectations of users are first being expressed. It is believed that the participative approaches to design depict it as a social process, showing that the scope of the activity of design extends beyond designers or the individual designer.

User-centered design

The term *user-centered design* originated during the 1980s in the research laboratory of Donald Norman, in the University of California, San Diego (12). It represents a philosophy towards design which draws users, or consumers, towards the process of design (13). It is a multidisciplinary approach based on the active participation of users to improve the understanding of the needs of the user and the requirements of the task, as well as the iteration and assessment of design (14). In user-centered design, the ways in which users participate can vary. In some models, their role is that of participants in the assessment of usability (15); in other models, user inclusion may be all throughout the process of design and with a participative approach.

User-centered design, under the perspective of experts, is an approach of design consolidated in industrial practice and education; primarily in the United States (16). Through this approach, experts observe passive users, whose contribution is the completion of tasks when given instructions, or their

opinions of products that are already designed. This is also known as the *user as subject approach*, where the researcher acts as the interpreter and the information generated enters the process of design in the form of design criteria (17). This approach is used when the importance lies in the object designed and needs to meet certain requirements. On the other hand, *user-centered design, under a participative perspective*, is an approach of design where users provide their expertise and participate in both the creation of information and activities regarding ideation and conceptualization, ever since the initial phases of design. In a participative approach, the individual roles of designer and user become indistinguishable, and the user becomes a critical component in the process of design (17).

The participative design approach

The term *participative* is used widely in various fields to imply a way of creating environments, objects, services and experiences that are more considerate and adequate to the cultural, emotional, spiritual and practical needs of people. In design, collective creativity has been practiced for the past 40 years or more, under the name of *participative design* (16). The participative approach of design arose in Scandinavia, coupled with the struggles of union workers to achieve democratic control in their work environments (12). Participative design is a principle of collaborative design. In collaborative design, participation is emphasized through the rethinking of the process of design that relocates users as co-creators (18). Currently, participation in the process of design, more than the identification and improvement of adverse conditions, seeks to explore and identify future opportunities (16). Co-design refers to the creativity found in the processes of design where designers and people without formal design training work collectively (16).

Participative and empathic methodologies used in the processes of design for/with people with disabilities

The concept of exclusion through the built environment (2), coupled with an increase in life expectancy, has accelerated the importance of design methods and solutions focused on the design of environments with greater benefits in use; therefore, designers have increasingly approached the final user.

When design and disability merge, they relate with terminology such as *universal design*, *design for all*, *accessible design*, *barrier-free design* and *inclusive design*. These terms give way to a variety of methods that support user-centered approaches, where people can become involved as subjects or partners in the process of design. This text will only focus on the methods where the user is actively involved in the process of design, through participative or empathic methodologies.

Participative design as a methodology

Participative design is investigation, and has its own methodological orientation just like investigation does. Participative action, in turn, is the approach that this type of design is based on (19). Here, design constitutes and provokes investigation results as co-interpreted by the designer-researcher and the participants that will use the design (19). The participative design methods are part of a wide democratic philosophy that studies the participation of people in the processes of decision making (20), and are of interest when the approach of a project equates the principles of participation with the empowerment of PWD (21).

Thus, the objective of participative design methodologies is the tacit approach to knowledge that belongs to many users and designers in a given situation, where knowledge resides in artifacts, practices and interactions (19). In the field of disability, it can modify the misconception that all people within the same disability category have the same needs.

There have also been diverse approaches developed that redefine this kind of participation in the field of empathy. *Empathic design* explores our intuitive ability to relate ourselves with the experiences and wishes of others (22). Empathy is the “altered subjectivity that is produced due to immersion in a particular context” (23). Investigation in empathic design deepens the understanding of the designer, in a way that intangible concepts such as feelings, emotions, dreams, aspirations and fears provide the designer with clues that may inspire products with a better functional balance, which, in turn, provide pleasurable experiences of use (23).

Empathic exemplification is comprised of a series of techniques that resemble physical challenges, such as the use of wheelchairs or the restricted mobility of a certain body part, and in turn helps designers to relate better to the experiences of others. Empathic strategies are used in the field of design when we want to understand in a better way the experiences that are rooted in social, emotional and cultural desires. The use of empathic methods such as real people, empathic exemplification and *shadowing*, provide the designer with textual, visual and verbal information regarding the interaction of expert users with their material contexts.

Empathic exemplification places the designer in the role of the expert user and supports the processes of understanding their experiences; in this manner, it secures appropriate and relevant results (23). In the field of disability, empathic methodologies sensitize the designer with regard to the experience of PWD and have the potential to question their values and beliefs.

Consequently, this text presents the concept of co-design as the creativity found in the processes of design, where designers and people untrained in the field of design work collectively.

Convention on the rights of people with disabilities CRPD and Design

Design is the way to plan and create the complex entities that provide a framework for human culture. It creates human systems and subsystems that work either in accordance or in conflict with nature to support human fulfillment (24).

The dominant design paradigm, until now, has been “design for the market”. The main purpose of this trend is to create products for sale. Many products designed for the market meet some of the social needs, but the market cannot satisfy all of them, especially those relating to populations that do not constitute a “class of consumer” in the market, such as people with low incomes or special needs due to age, health, or disability aspects (6). Consequently, social inequities result when the market only acts as a catalyst of the built environment. In recent years, there has been a change from a design for the market mentality towards a more socially responsible design (6). The latter connects to the principles of co-design where the active partnership of users and the importance of their experiences in the design process are valued.

In the context of disability, the values of dignity, autonomy, equality and solidarity are of particular importance. The value of dignity ensures that people with disabilities are honored without regard to social or economic utility, and the value of autonomy opens an unforced space for voluntary action. Therefore, issues surrounding human dignity and human rights provide a framework for exploring moral and ethical problems that lie at the core of the design professions (24).

As a researcher and a designer I have reviewed the methodologies utilized in the processes of co-design where disabled persons also participate. The next section leads a discussion particularly about the experience of people living with disabilities and their ability to modify their environments.

User-initiated design (UID)

The phenomenon of design practiced by non-professionals has been studied, for example, in the field of industry, in order to understand participation of non-designers in the decision-making processes in the manufacturing of a product (25), in the field of innovation, where it seeks to understand the needs of users who transform existing products applying innovation and acting as lead users (26). More recently, the phenomenon has been studied in order to understand the active participation of

users in the digital culture (27). This concept has been analyzed by a significant number of researchers who confirmed that the phenomenon is not recognized or referred to as design (28), and this is due, in part, to the fact that it is undertaken by individuals who are not designers and do not recognize themselves as such. Because of this, the phenomenon has not been properly labeled.

The UID label has impacts on the way in which we understand the processes of design, the mechanism of ideation, and the experiences that these designs propose.

The *processes of design* are not linear, but they do possess defined stages. Here we are concerned with the initial stages of the process, those that inform and inspire the exploration of open questions. This initial stage, described as fuzzy due to its ambiguous and chaotic nature (16), is the one which determines what will be designed, and for each case of UID, it has been assumed by a person with the capacity of expertise; this suggests that designers further explore this factor.

The mechanism of ideation has two levels of imagination: one which makes formal projections and one which simulates the emotional, mental, and sensory encounter with the imagined (29). The first imagines the object, while the second, the experience. In this way, the true qualities of that which is designed are existential and arise from the encounter with the tangible. Users who initiate processes of design bring this complexity to the discussion.

In the field of disability, UID is the phenomenon that many people with disabilities represent when they negotiate daily with inaccessible environments (30). This topic has been studied recently by the author in an investigation that explores designs proposed by people with disabilities in domestic environments, as well as the transformation of such process and the impact that such activity has over these people.

UID recognizes that PWD have an understanding based on the context of disability (31); also, that their experience is the product of daily practices in common places where their bodies interact with materiality, one designed to be inhabited by “able” bodies (32). On the other hand, it claims that their design proposals respond to a particular existential experience (28); furthermore, it places at the center of the design-disability intersection the definition of design proposed by Lucy Suchman: “*design is not the creation of intrinsically significant objects, but instead the cultural production of new forms of practice*” (33).

Conclusions

The built environment, as a reflection of the thinking, culture and development of a society, is not a neutral place. All the objects that constitute it, such as public and private spaces, edifications,

technological objects or of daily use, graphic and communication products are expressions and symbolic practices of the way in which a society thinks, feels and builds —thus reshaping human existence. Design is located at the base of the configuration decisions of the built environment. It is during the process of design decisions that we observe integration or segregation, inclusion or exclusion —where something is preserved or left behind. Therefore, design must be considered as a form of expression of what we, as a culture, are and desire to be.

Today, the strength of discussion and practices surrounding the concept of design as a tool that serves the interests of the production sector, along with a professional dynamic which favors the interests of the markets, is general. Almost a century after the professionalization of design, the balance in perspective of equity and social justice is not at all favorable.

Nevertheless, during the past few decades, new approaches have allowed progress in the direction of socially-responsible design (6), connected with the principles of co-design, where the active collaboration of users and the importance of their experiences in the process of design is valued. Alternative approaches link design with the responsibility of creation in surroundings and focus on inclusion and participation. These types of approaches in design offer new perspectives in a manner that allows full access, use and enjoyment of the environment to people with disabilities.

Contemporary design attempts to incorporate concepts of citizenship, justice and participation, in hopes of enabling full accessibility and usability in order to identify users as partners in the process of design.

For PWD, the strategies of collaborative design, which unite experts and users in the experience of participation in the processes of design, are emancipatory, because they restore their power to create and recreate the environment. People with disabilities, just like any other user, also have needs that go beyond functionality, including emotional, spiritual, social and cultural aspects in their interactions with the environment.

Given the specificity of the capabilities and needs of this population, which are not resolved within the availabilities of the market, PWD tend to engage in actions that modify their immediate surroundings, space modification, objects and activities in order to better their own conditions. Experts of design should recognize these forms of UID, given that these solutions are thoroughly linked with the daily experiences inhabiting their very own existence.

The inclusion and participation of people with disabilities in the conception of the environment is not only a positive

decision of some designers, but a right related to autonomy and equality. For people with disabilities to be involved in design as cocreators will empower them to create and recreate their environment. Additionally, when UID is identified and accepted as part of the process of design it can be emancipatory.

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