

Inclusive Environments: Utopia or Reality? How to Create Inclusive Solutions Starting From People's Needs

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Abstract

Inclusive Design is an approach to design that aims to meet the needs of the widest possible audience, regardless of age and ability, through the realisation of products and services. This approach puts users at the centre of the design process, which means working with people rather than working for them. This article focuses on the application of Inclusive Design and Human-Centred Design approaches specifically aimed at Parkinson's disease. Through the analysis of a design case, the article describes the applied methodology aimed at solving the challenges posed by Parkinson's disease through the design of an inclusive home environment. The case study shows how the Inclusive Design mindset favours a holistic and creative approach, capable of bringing together different user groups throughout the various stages of the design process.

Keywords

Inclusive design
Human-Centred Design
Parkinson's disease
Design for disability

Introduction

The term *home environment* refers to the place where people live and it encompasses the economic, social and cultural dimensions that influence human health and well-being (Evans, 2003; Goldhagen, 2017).

Home environments can be defined as containers of content. McClure et al. (2011) argue that home environments are defined by seven domains of design, planning and management such as products, interiors, structures, landscapes, cities, regions and Earth.

Over the years, the domestic environment has evolved because it has been subject to social, cultural, work and technological changes of which human beings are an integral part.

Just as product and interior design influence human emotions, feelings, moods and behaviour within these environments (Norman, 2004; Pullin, 2009), the physical environments also have an impact on human health and well-being (Alfonsi et al., 2014; MacAllister et al., 2017). There is therefore a close connection between people and the home environment. People adapt to their environments in order to meet their needs and desires, and the built environment links human thoughts and integrity to their social, physical and cultural contexts.

We have all observed this during the COVID-19 pandemic. As a matter of fact, we have witnessed a paradigm shift at all levels: from work life to family life, the pandemic has fundamentally shifted the way in which people work and live. There has been a shift from working in the office to working from home, from physical activity performed in specialised environments to physical activity at home, and even some medical examinations conducted pre-pandemic in health care facilities have changed into remote or teleconsultations.

Home environments are designed and built in compliance with local building regulations and on the basis of the designers' convictions, thus reflecting human desires and spatial needs, but if we shift the focus towards the relationship between *ageing-home environments* and *disability-home environments*, then end-user satisfaction is not respected.

The Relationship Between Home Environment and Disability

The ageing of the global population is a success story achieved thanks to medical, social and technological developments. Nevertheless, there is also evidence for negative impact, as the ageing of the world population also means there is a greater risk of incurring disabilities or chronic diseases. One of these is Parkinson's Disease (PD).

As of 2021, approximately 1.3 billion people — about 16% of the global population — experience disability (WHO, 2022). Disability is part of the human condition (WHO, 2011), temporary or permanent, and can be experienced at any time of life. The quality of life is very often related to the quality of living spaces and objects of daily use.

PD is the most frequent neurological affliction in the elderly, along with dementia (Abbas et al., 2018). PD affects the initiation and execution of voluntary movements, leading to difficulty in performing basic daily activities of living and an impaired quality of life. Accord-

ing to the statistics, in 2040 14 million patients will suffer from PD globally (Pringsheim et al., 2014; GBD, 2016; Dorsey & Bloem, 2018).

Few studies can be found in the literature that deal with the relationship between Design and PD and between home environment and PD (Schwarz, 2006; Davis Phinney Foundation, 2019), rather, the field references deal with the relationship between disability in general and home environments. The scientific contributions from the field (Imrie & Hall, 2001; Imrie, 2006; Farella et al. 2010; Preiser & Smith, 2011; Lauria et al. 2019) point out that a large proportion of home environments are not equipped to be accessible, both in terms of space and as regards the objects/utilities employed within it.

There may be many reasons for this, including urban limitations, the size and shape of domestic spaces, designers' inadequate understanding or lack of knowledge regarding home accessibility, cultural beliefs, poor efficacy of objects and furniture, inadequate services, etc.

When health declines, environmental conditions often cease to match the individual's capabilities, causing numerous Personal-Environmental Fit (P-E fit) problems with negative health outcomes. The definition of P-E fit refers to the relationship between the environment and the person (Murrell & Norris, 1983; Bhidayasiri et al., 2015), understood as the correspondence or congruence between individuals and their environments, a key determinant of a person's well-being and safety (Kristof-Brown et al., 2005).

The objective, therefore, is to improve accessibility and usability in the home environment in relation to the performance of daily life activities, removing all barriers that may limit a person's autonomy and independence.

For these reasons, this article describes an action-research project which aimed to define the guidelines for the design of an inclusive and accessible environment for a Person with Parkinson (PWP), and which can also be extended to other physical discomforts experienced by people.

Accessibility, Versatility and Domestic Adaptability Over Time: Human-Centred Design and an Inclusive Design Approach for Parkinson's Disease

In order to carry out the research project two approaches were used jointly: Human-Centred Design (HCD) and Inclusive Design (ID).

The HCD approach can be defined as an "approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques" (ISO 9241-210:2010; Giacomini, 2014).

ID began as a general approach to design, based on the main Design for All (DfA) and Universal Design (UD) approaches in which designers ensure that their products and services meet the needs of the widest possible audience, regardless of age or ability, without the need for special adaptations or specialised designs. ID is the inverse of the DfA and UD approaches, aimed at designing for disabled and elderly people as a subset of the population, but is part of a more recent international trend towards the integration of elderly and disabled people into society (Clarkson et al., 2003).

The concept of inclusion in the design and development of environments and products is not a question limited to disability design per se, but is, on the contrary, a matter of *equity* and *quality of life for all* (Imrie & Hall, 2001). This mindset leads to putting the users at the centre of the design processes rather than at their margins, and thus means working *with* people rather than working *for* them.

Involving users and listening to them means avoiding aprioristic approaches to design in favour of an anthropocentric approach.

To satisfy the requirements of home accessibility and adaptability, the starting point is to assume an attitude towards design that starts from the ability to pay attention to the *context of use* in which one is called upon to design, and in our specific case this consisted of Fig. 1:

- users (PWP, caregivers and health professionals);
- domestic activities;
- equipment (objects, aids, assistive technology);
- physical environment (indoor and outdoor);
- social environment (the services present near home);
- and finally, the heterogeneous and progressive chronic symptomatology of PD.

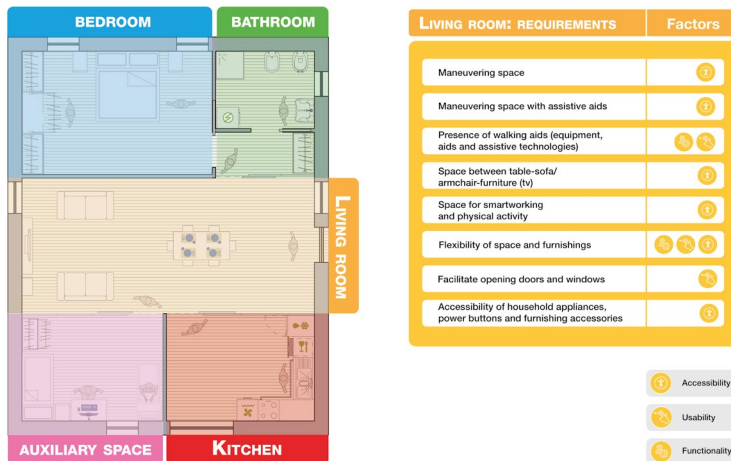


Fig. 1 Home and design requirements (factors).

In the specific case of people with PD, the projection of design solutions over time is realised in the adaptability of spaces, furnishings and equipment, in the possibility of guaranteeing adequate space for movement for wheelchairs and movement aids, and in the possibility of inserting walking aids and technological equipment (e.g. for environmental control, fall detection, etc.) with low-cost and easy-to-implement interventions, while maintaining the configuration of the home as unaltered as possible.

The specificity of the needs that arise with the different stages of the disease and the different consequent levels of autonomy, as well as the different needs for support and care, thus become basic references for the project and translate into the principle of *versatility* and *adaptability* over time, which can offer a plurality of options that may be planned for and easily adopted.

Lastly, the design solutions identified for the specific case of PWP can be used in numerous and diverse other contexts (ageing and other disabilities) in which the full accessibility and safety of the living environment, its full domesticity and friendliness and its adaptability over time can contribute to improving autonomy and quality of life.

Research-Action: Home Care Design for Parkinson's Disease

The research program *Home Care Design for Parkinson's Disease* (Tosi & Pistolessi, 2022), carried out in 2020-2021, involved different research groups belonging to university departments of the Università degli Studi di Firenze and Universidade Federal de Minas Gerais (Brazil) (Design area), Università degli Studi di Torino (Medical area) and Università Cattolica del Sacro Cuore (Milan) (Sociology area), as well as the participation of the Confederazione Parkinson Italia and Accademia Limpe-Dismov.

The *context* was analysed adopting two empirical methods: the interview, divided into two phases (phase 1, exploratory structured interview and phase 2, specific structured interview) and the virtual observation, carried out via Skype and via Whatsapp. It involved twenty-five PWP and sixteen informal/formal caregivers, all resident in Tuscany. The methodological setting of the study was defined by taking into account the limitations imposed by the COVID-19 pandemic.

The results underline how the home environments that create discomfort/problems are attributable to the size of the bathroom, the presence and size of stairs, and finally the presence of small spaces such as the closet Fig. 2. Data shows that 72% of the subjects wish for housing solutions with adequately sized bathrooms to ensure access and wheelchair rotation in addition to the space required to install grab bars and a shower seat. Furthermore, respondents (n=10) place great importance on stairs. Although they are aware that stairs, depending on the level of PD symptomatology, can be an incentive to reduce freezing, they prefer single-story housing solutions. Furthermore, 39% of the subjects stated that they would like to have more accessibility within the kitchen environment, even for those who are forced to sit in a wheelchair or use a walker.

The greatest problems arise from the house wall units and the kitchen base units, but also the appliances provided. 28% of the subjects ascribe great importance to adequate space in the rooms that make up the home, and finally, to home usability/accessibility for walkers and wheelchairs. Finally, 22% of the subjects interviewed declare their need for rooms that offer suitable size wheelchair access, open space solutions (at least to ensure this solution between the kitchen and the living room) and spaces inside the house where it is possible to perform physical activity. In conclusion, 89% of the subjects who took part in this study stated that flexibility and versatility could be a valid alternative to static walls, believing that a space that changes with the changing needs of the PWP and the caregiver is a valid idea (Pistolessi et al., 2022).






HOME ENVIRONMENT	Description of problems and areas of intervention
VERTICAL PATHS 	- Some users complain about the presence of steps or staircase;
HORIZONTAL PATHS 	- Lack of large spaces to ensure the passage and rotation of the walker or wheelchair to ensure home accessibility and to limit freezing; - Lack of space or unsuitable spaces between the objects of use in the house, such as table-chair, chair-sofa, table-kitchen, etc.; - Lack of space to allow wheelchair rotation in some rooms of the house; - difficulty in passing through narrow doorways or tight spaces (e.g., corridors); - Difficulty in walking due to the presence of obstacles in horizontal pathways (sofa, chair, bed, furniture, etc.); - The presence of height differences in outdoor space (terrace, garden, etc.);
ROOMS DIMENSIONS 	- Useful space in the bathroom to allow access to the caregiver during PwP hygiene and cleaning; - Lack of sufficient space for physical activity, physical therapy and/or recreation activities;
ACCESSES 	- Difficulty in opening and closing doors and windows;
FURNITURE, AIDS AND ASSISTIVE TECHNOLOGIES 	- Lack of grab bars and/or support elements in the most critical points of the house (corner where changing gears are expected) for fall prevention; - Lack of space to install grab bars in the bathroom; - Difficulty in reaching low furniture. Some users complain of difficulty in bending over to equip themselves with objects placed in the kitchen base units or in the lower cabinets; - Difficulty in getting out of bed or armchair (beds, armchairs and static sofas). Many PwPs support motorized beds, chairs and sofas; - Poor knowledge of aids or assistive technology for PD or other motor impairments.

Fig. 2
Global mapping of problems and needs.

The aforementioned results were subsequently used to create the guidelines.

The guidelines are a set of recommendations and/or operational indications, aimed at guiding actions, types of behaviour or a *modus operandi*, or at proposing a structured set of good practices and possible alternatives for the development of project solutions addressed to specific sectors.

The guidelines produced for this research project were intended both to respond to explicit needs and to interpret implicit ones, and should also respond to their possible evolution over time.

The guidelines are designed to address as broad and heterogeneous an audience as possible, comprising current and future designers, but also people directly affected by the disease, their families and healthcare professionals.

The sheets that make up the guidelines are composed of four parts, one dependent on the other, providing different graphic and descriptive levels, as follows Fig. 3:

- dimensioned 2D drawings with the minimum dimensions to be respected;
- description of the technical aspects to be taken into account;
- renderings;
- finally, indications regarding products, aids and assistive technologies available on the national and international market;

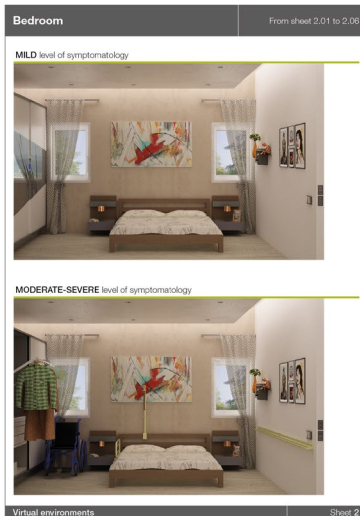
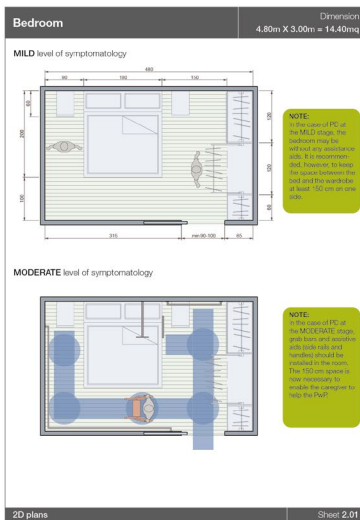


Fig. 3
Bedroom. The four parts that make up the guidelines.

Every single environment has been represented with its possible evolutions in relation to the evolution of the person's needs over time, demonstrating the fact that if PD changes, in severity and intensity, and in a different way from person to person, then the environment in which he or she lives may also change over time to meet the new needs of the PWP. For this reason, the environments are represented with three levels of evolution: mild, moderate and severe symptoms. The first, referring to the mild level of symptomatology, considers the PWP to still be able to perform all, or almost all, common household activities independently. The technical tables show the person without any aids or assistive technology. The second, referring to the moderate level of symptomatology, considers that the PWP suffers from postural instability but is still physically independent. The technical tables show the person using the walker, and grab bars are placed at strategic points in the room, such as corners, where the change of stride is expected to take place. Finally, the third, referring to the level of severe symptomatology, considers the PWP to have difficulty walking and performing

household activities independently. For the latter development, the technical tables show a person using the wheelchair, both grab bars and other aids for movement are present, and the presence of a full-time caregiver is envisaged Fig. 4.

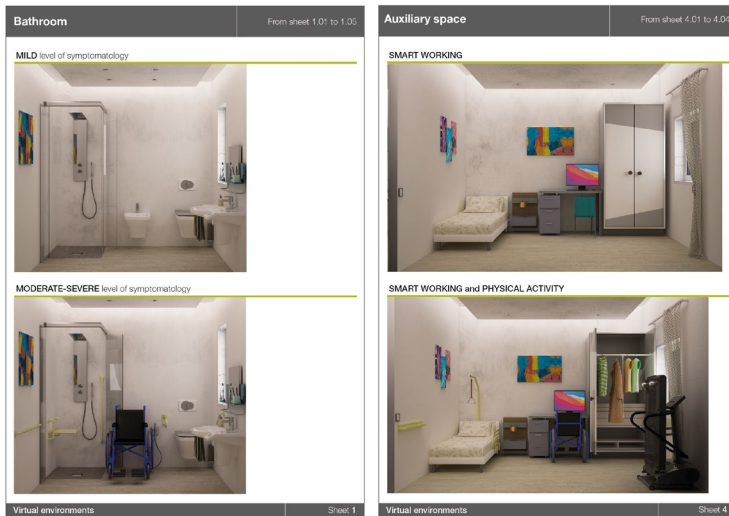


Fig. 4 Bathroom and auxiliary space: the three levels of PD evolution (mild moderate and severe symptoms).

Conclusion: Opportunities for Designers

The paper explored the issue of the accessibility of home environments and the usability of objects and aids intended for the care of PWP, discussing the opportunity to overcome this gap through the use of HCD and ID approaches. The literature review emphasised how unsuitable current home environments are to accommodating individuals in need of care and assistance. The results confirm that a large proportion of the homes studied are not suitable or may not be suitable in the future to accommodate the PWP and their caregiver.

The paper focuses on the practice of design involving collaboration between research organisations, health-care professionals and end users. Cooperation between various research groups has been a determining factor in proposing solutions in line with end-user needs.

According to Giacomini (2014), design, if human-centred, can produce as a natural result disruptive as well as incremental innovation, making a concrete contribution in terms of product innovation and business competitiveness.

Designing inclusive solutions (products, environments and services) means responding to the needs and desires of the most disadvantaged sections of the population, but it also means responding to the widespread needs of broader sections of the population for whom the increased usability of products, environments and services will result in conditions of greater well-being, time and energy savings, and a general improvement in the quality of life.

Many solutions designed to meet the specific needs of equally specific user groups can be successfully addressed to a broader range of users.

Examples include the kitchenware produced by the OXO¹ company and the *No Spill Cup*² designed by designer Soneji, an inward-curved cup that allows the PWP to drink without spilling the contents

inside. Most interesting are the formal experiments in the framework of the project *Rethought elderly furniture & accessories that support and empower life & lifestyle*³, carried out by the design studio Lanza-vecchia+Wai. The motivation that prompted the two designers was to generate enthusiasm, desirability and sense of ownership, through the design and introduction of new functions for some aids designed for the elderly the aesthetics of which are still too hospital-like today. While IKEA, through the *ThisAble*⁴ project, allows anyone to download free 3D models of its products: through artificial intelligence and 3D printing, they may be implemented with additional solutions to enrich and enhance the lives of consumers, especially those with special needs. As for smart objects, of particular interest is Microsoft's *Emma* project⁵, a wearable device that can compensate for upper limb tremor. To conclude, there are interesting floor concepts that create the illusion of a 3D staircase, such as *Staircase Illusion*⁶, and the study conducted by Gál et al. (2019), which are useful for reducing freezing situations, or the *SensFloor*⁷, a floor equipped with sensors that can monitor the direction and speed of movement and detect people's falls.

It can be argued that products immediately identifiable as *products for the disabled* can represent a possible source of frustration for the end users. Although necessary and potentially useful, these products can be experienced as the stigmatisation of the user's diversity in relation to other people, and they are often rejected by those who could, on the contrary, use them with unquestionable advantage because of their appearance and their incontrovertible difference with respect to *normal products*.

The objective of Design is the realisation of products and environments that, starting from the specific needs of people with reduced physical, perceptive or cognitive abilities, are easily usable and desirable by all people.

The design challenge is to consider in the design brief the stated and/or tacit needs and expectations of users, but also to anticipate their interaction with the proposed system. The relationship between users and designers is based on extreme trust. Whenever the former use products designed by a designer, they rely on the latter trusting that he has carried out his work in an ethical manner: it is therefore up to the designers to become aware of and respect this trust (Saffer, 2010). As Buchanan (2001) states, designers often forget the meaning and full force of the words *human-centred design* as a fundamental affirmation of human dignity, which gives design the responsibility to continuously search for what can be done to uphold and enhance the dignity of human beings as they lead their lives in various social, economic, political and cultural circumstances. On this basis, it is possible to state that the purpose of design is to communicate and rework not only the information but also the personal stories and experiences that contribute to generating complex human-product interaction: although influenced by extremely subjective factors and the personal experience of each individual user, it can be designed on the basis of universally shared patterns and characteristics.

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