

Designing for Independent Living: The Case Study of an Inclusive Apartment for Persons with Disabilities

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Abstract: Independent living and freedom of choice are closely linked to the social inclusion of PwD (Persons with Disabilities) in society. The paper reports on a recent study focused on investigating and understanding the needs and desires of persons with intellectual disabilities, with reduced mobility and with visual impairments while performing daily activities in order to design user-friendly and inclusive home environments for their life project. The case study concerns an apartment on the ground floor of a building well embedded in a neighborhood urban and social context. It was selected by Anffas Trentino Onlus to train young adults in independent living. Anffas is the National Association of Families of People Intellectual and/or Relational Disabilities, present and operating throughout Italy. Since 2008, important projects have been promoted by Anffas Trentino Onlus aimed at stimulating a personal and housing autonomy in PwD for “during and after us”, or rather when there are no more family members to take care of them. The design process involved a representative focus group of end users. With them and some Anffas staff components, it was possible to implement a participatory design process by sharing and verifying needs, desires, expectations. This approach was adopted in order to jointly develop a design proposal for a new inclusive apartment changing the paradigm from *design for* to *design with*, and building awareness both in the end users and designers.

Key words: PwD, independent living, participatory design, inclusive home environments.

1. Introduction

PwD (Persons with disabilities) “are unable to take part in important activities and aspects of society in an equal manner, simply because policies, societies and environments are not designed to meet their requirements” [1]. According to the UNCRPD (United Nations Convention on the Rights of Persons with Disabilities), independent living means living in society with the same freedom of choice as other people. Through the adoption of effective and appropriate measures, all PwD must be given the opportunity to choose their place of residence and where and with whom they live in order to avoid being forced to live in a particular arrangement. Living in residential institutions for PwD critically interrupts their life plans [2]. The right to independent living concerns all PwD that include “those who have long-term physical, mental, intellectual or sensory impairments which in

interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” [3].

Designing inclusive home environments is a great responsibility for professionals that “should be aware of difference across the range of human abilities, and of associated design considerations” [4]. Considering the voice of PwD as the focus of the analyses, produces positive experiences in relation to well-being, participation and control of your own life [5]. The role of design is important in creating conditions for proper interaction between the person and the home environment building accessibility and usability [6]. The home can be designed to support and stimulate the inhabitants with frailty or disability improving their quality of life [7]. We can contribute to maximizing the health and independence of PwD with modifications and adaptations of the home spaces to a person’s

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disability [8]. Designing accessible and usable homes in accordance with the needs of individuals “can facilitate their engagement both within the home and out in the community” [9].

A concrete possibility to emancipate oneself from parents, actively participate in the life of the community, and exercise an active and recognized role, is to be able to undertake accompanying paths that support the approach to independent living. Therefore, Italian associations and foundations for PwD have set up several projects aimed at stimulating living and relational autonomy, in preparation for both a gradual detachment from the family context (mainly from parents) and the choice of where, with whom and how to live. These projects offer new housing contexts that differ from those experienced in the family home or in assisted living facilities, where PwD can try living in an apartment, in groups or individually, with external support when needed. These projects are important for the “during and after us” debate which refers to the management of the life cycle of PwD when there are no more family members to take care of them. Appropriate home environments are needed for these projects, furnished and equipped for learning to live independently and safely.

The goal of the case study in this paper is to present the methodology and outcomes of the participatory design process of the most recent housing spaces of the project entitled “I’m going to live alone. Pathways of housing autonomy and cohousing” promoted by Anffas Trentino Onlus (hereinafter only “Anffas”). Anffas is the national association of families of persons with intellectual and/or relational disabilities with non-profit organizations in all Italian regions including Trentino that is also called the Autonomous Province of Trento.

Anffas opened its first apartment in 2008 in Trento city. It was a smart home of approximately 70 square meters consisting of a large living room with a kitchen corner, two bedrooms, a bathroom and two balconies. Here young adults with ID (intellectual disability) live for short periods in small groups and in rotation in order

to acquire basic and specific skills for semi-autonomous living. The length of stay is four continuous days per month for a maximum of five years of attendance. The skills these residents can acquire during the training and pathway are functional for carrying out ADL (activities of daily living) and IADL (instrumental activities of daily living) at home and in the community [10].

For those who have completed the training path in the first apartment and matured the desire to continue the experience of semi-independent living in a different context from the family, since 2015 Anffas has been using a second smart apartment located in a co-residence in the village of Aldeno a few kilometers from Trento. This apartment features a kitchen with all major appliances, a living room, three bedrooms, two bathrooms, and a terrace. The length of stay in this case varies from one to three weeks per month. The purpose is to test the cohousing model and encourage processes of social inclusion and strengthening of the territorial network [11].

The outcomes of the experiences in these two apartments and the increasing number of participants entailed a rethinking of the home environments to be used. In particular, the first apartment fails to meet the varying demands of the new participants. Therefore, Anffas expressed the need of larger physical spaces and more inclusiveness, not only for persons with ID (mainly persons with Down syndrome) but also for persons with motor and sensory difficulties.

An apartment for rent to replace it is offered to Anffas by the Trentino Institute for Social Housing. The apartment is located in a district of Trento characterised by social cohesion and social networks that offer concrete opportunities for integration and participation. It occupies a total gross area of approximately 100 m² and consists of an entrance hall, a large living room with kitchen, a hallway, three bedrooms and two bathrooms. It is already furnished and equipped with a home automation system for the security and safety of the inhabitants. It is located on the ground floor and has the main bathroom equipped with aids for PwD, but

following an initial analysis by Anffas the apartment does not seem accessible and usable for the new group of End Users. For this reason, a new collaboration began between Anffas and the Laboratory of Building Design of the University of Trento (hereinafter only “Unitn”) in order to develop a renovation design for a new inclusive apartment (hereafter referred to as “case study”).

In this experience, the term “renovation” denotes a home improvement characterized by non-structural interventions to make home spaces more functional, accessible and usable in tune with the needs of different PwD who may live together and change over time.

2. Method

The methodology used to support the participatory process undertaken for the case study consists of the following three sequential phases: (i) End Users profiling, (ii) surveying and mapping of the existing spaces of the case study before the renovation, and (iii) development of the design proposal.

2.1 End Users

Anffas selected a focus group of future End Users in order to start new semi-autonomous living paths in the apartment to be renovated. The mixed group to be involved in the participatory design process consisted of four adults (two females and two males) aged between 20 and 30, with different anthropometric characteristics, and with mild or medium ID. In addition, two of them also had motor difficulties: one used a manual wheelchair facilitated by the use of an electric traction device that connected and disconnected in complete autonomy to move around indoors and outdoors; the other moved with a walker or with two four-wheeled sticks. Another special feature of the mixed group was the presence of a person who is also visually impaired.

The first meeting with the focus group, the Anffas project leader and a caregiver took place at Unitn. The goals were to get to know each other, share objectives and methodology of the study, and interview the End Users. During the first part of the meeting focused on

establishing rapport and putting participants at ease, the importance of active participation and contribution of all participants in the case study was communicated to these young adults. During the second part informal semi-structured interviews were conducted in order to:

- investigate what these persons were able to do at home independently with or without aids in carrying out basic ADL (e.g. bathing and showering, personal hygiene and grooming, dressing, toilet hygiene, functional mobility, etc.) and IADL (e.g. meal preparation, ordinary housework, managing finances, shopping, transportation, etc.);
- understand needs, wishes and expectations for future life;
- build awareness.

Additional data on End Users (such as specific needs, difficulties in carrying out ADL, facilitators and aids usually used in other home contexts, etc.) were observed and discussed during the mapping of the home environments of the case study described below.

2.2 Survey and Mapping

The survey of the apartment (with larger spaces but very similar furnishings to those already present in the other two apartments used by Anffas for independent living pathways) was divided into two steps.

The first step of the survey was necessary to find out the geometric, dimensional and structural features of all the existing spaces and furnishings. It was carried out using traditional tools including a metric string, rigid meters, laser instruments for surveying, and paper and digital support to record the measurements.

The second step consisted of surveying the physical and visual barriers that limited or prevented the safe performance of ADL. The expected outcome was the mapping of barriers. To this end, all focus group members tested spaces and furnishings during scheduled meetings in the apartment. The home environments were broken down into the functional areas most commonly associated with independent living (e.g. toilet area, bidet area, washbasin area, shower area, washing machine area

were the functional areas for the bathroom). The home environments were examined through usability test sessions conducted with the support of Anffas staff for the evaluation in terms of performance (what the person actually does) and skill (what the person can do if ...).

The evaluation method was direct observation accompanied by thinking aloud: the users were observed while performing the tasks of the various ADL and IADL, and they were asked to say aloud their thoughts and reasons for the difficulties encountered while completing the tasks.

2.3 Development of the Design Proposal

The design proposal covered the indoor and outdoor spaces of the apartment including mainly reversible interventions since it was not possible to change the size of the rooms since the apartment was not owned by Anffas but only rented. The imperative was to test and improve: starting from what was available, the furniture could be modified, integrated or fully replaced, colors on the walls are changed, etc.

In developing the design proposal, the participatory approach of actively involving the focus group was continued. The home renovation was not to start from the individual activity of a professional, but from a cooperative and collaborative activity of working group consisting of End Users, Anffas staff representations and Unitn.

Brainstorming sessions and working group meetings were organized for the design phase. The brainstorming sessions mainly involved Unitn, which, after analyzing the survey and mapping results, produced preliminary solution ideas. The aim was to identify an initial list of possible solutions to be presented and discussed during the subsequent scheduled working group meetings.

The working group meetings were always held within the apartment. Working together in the physical environment to modify allowed for verification, rethinking and imagining directly on site.

In this context, in order to optimize the

communication with the participants, presentations were projected. Each presentation, made more effective by the use of illustrative images, was structured to remind needs and difficulties emerged during the test sessions and to propose possible answers to be evaluated together. The intent was not to transmit one-way information, but to discuss in order to get feedback and share choices that could be important for the life project of the End Users.

During these meeting, it was possible to deepen issues not fully investigated in the mapping phase; obtain confirmation of the strengths and weaknesses of solutions previously tested at home and/or in different contexts; collect opinions and points of view of both End Users and Anffas staff; agree together on the priorities within the environments home in relation to the quality of life domains; build together the renovation design proposal of the home environments case study.

3. Results and Discussion

The survey, which addressed issues related to both mobility with aids and the use of furnishings and equipment, helped refine the picture of the needs, desires, and expectations of future users.

The data collected during the investigation of the apartment were first codified and reported in summary tables, and then returned in technical drawings. This process of creating a systematic visual representation of critical issues was called mapping of the accessibility and usability of home environments of the case study.

The design for the case study focused on the physical spaces excluding the previously installed home automation system. A review of the home automation system was not necessary for Anffas because its characteristics were very similar to those already successfully tested in other housing settings.

Drawings and guidelines collect the results. These include a general plan of the renovated apartment (Fig. 1) with related elevations and other drawings articulated by home environment.



Fig. 1 The plan of the inclusive training apartment for the independent life of End Users of Anffas Trentino Onlus.



Fig. 2 3D model of the interior and exterior spaces of the inclusive apartment for independent living of End Users of Anffas Trentino Onlus.

In order to have a realistic preview of the case study concept design a 3D model of the apartment has been drawn (Fig. 2). 3D Rendering (Fig. 3) and a 3D video

were produced. These materials allowed the focus group a virtual tour of the renovated apartment visualizing the outcomes of the participatory design process.



Fig. 3 Architectural 3D rendering views of the inclusive apartment for independent living of the End Users of Anffas Trentino Onlus: kitchen area, dining area and living area (top), bedrooms (middle) and bathroom (bottom).

Rethinking the living spaces of the case study for different End User (i.e., including not only persons with ID but also those with motor and visual impairments) was an important experience and challenge aimed at identifying improvement interventions for an inclusive home.

Fundamental was the development of a collaborative environment, both relational and physical, that allowed everyone to contribute actively in the surveying, mapping and design development phases. To this end, Anffas played a crucial role; its staff always accompanied and supported the focus group during all the activities of the

design process. From the beginning, but especially during the ADL simulation tests and the working group meetings, the Anffas staff helped to understand the wishes, preferences, and expectations of the focus group, explaining in many cases the possible alternatives and the consequences of a specific solution. When forced to make a decision on behalf of the person with a disability, the best interest of the person should be replaced with the best interpretation of the person's wishes and preferences. In addition, the Anffas staff reported a critical review of previous housing experiences in the first and second apartment with similar and different users. This allowed deepening the analyses and overcoming previously encountered critical issues.

In the design stage, the following guiding principles were formulated for decision making and problem solving:

- eliminate anything that is not needed, limits, hinders and/or is a source of danger in the performance of ADL and IADL;
- replace with new furniture with shapes and materials that meet everyone's needs;
- integrate with objects and aids to enable or facilitate the performance of ADL and IADL.

The most complex home environments to modify were the main bathroom and the kitchen area because of the different needs of the End Users and the ADL to be performed. These rooms required the design of new furniture configurations, the replacement and relocation of appliances and sanitary equipment, and the installation of aids. In particular, the bathroom required the replacement of the toilet, bidet, and washbasin with new ergonomic sanitary fixtures and equipped with aids in order to facilitate autonomy in hygiene and personal care activities by enhancing the personal resources of End User. It was decided to reserve the toilet only for Anffas staff because of its small size.

Bedrooms were reorganized by placing new furniture and objects so that those using mobility aids

could also have access and usability.

In the entrance and hallway, all obstructive elements were removed and good diffuse lighting was recommended.

In the dining and living area, which must accommodate a variety of functions and meet the needs of both residents and guests (e.g., eating meals, watching television, reading or chatting on the sofa, listening to music, storing books and objects, welcoming friends, playing cards, etc.), the design has included a few well-positioned furniture elements for carrying out manual, social and relaxing activities.

The design phase ended with the development of an interior design shared by all participants and characterized by obstacle-free indoor and outdoor pathways; adequate maneuvering spaces and access to furniture for residents using different mobility aids; furniture and objects that can be used as much as possible while sitting or standing without using ladders, chairs or stools in order to avoid possible falls; and appliances placed at a comfortable height even for the wheelchair user and equipped with clearly visible and easy-to-understand control devices.

In the case study, it was important for all End Users to facilitate the viewing and recognition of furniture and objects. The design proposal differentiates the colors so as to create visual contrast against the background, in particular, the color of doors, furniture, and what is hanging on the walls (e.g., equipment, hangers, handles, and switch plates).

In order to facilitate the view and grasping of the objects in the cabinets and to prevent everyone from assuming awkward positions, it was recommended that kitchen furnishings be equipped with internal organization systems such as full-extension drawers and baskets. In addition, in order to prevent confusion and discomfort in users and to enable them to methodically carry out the ADL, the design planned to contain in the furniture only necessary items in an organized manner by using dedicated drawers, dividers and functional accessories for the order.

4. Conclusions

Adapting the home to the needs of a PwD means not only intervening in the living environment, but also starting autonomous and independence paths that are affected by so many factors, such as the limitations, wishes, potential, and perceptions of the PwD and those who live next to them [12].

Wishes and needs of PwD are no different from those of all other people. Difference may be the supports needed to be able to voice and realize their expectations.

The work done in this case study represents the effort to transform home spaces into “places” charged with meaning for the life project “during and after us” of PwD.

The case study offered an opportunity to design an inclusive training apartment for persons with different disabilities with an approach similar to that of *Self Directed Support* applied to home environments. *Self Directed Support* is based on active citizenship and on the fact that PwD can decide what supports and services to have and how to use them. *Self Directed Support* is helpful in eliminating institutionalization and segregation; it complies with many articles of the UNCRPD (e.g., with the article 14 on freedom and security of the person and Article 19 on independent living).

The case study is an example of a housing intervention for PwD started from the perspective of End Users, and not decided by institutions or technical designers without directly involving beneficiaries. Involving beneficiaries with different disabilities in the different stages of the case study was important to recognize and understand requirements, perceptions, and wishes, and to share all the information. It was a collection of explicit and implicit, visible and invisible needs that became the assets of the design and a path made of meetings, discussions and trials that created in the End Users a sense of ownership of the project.

The case study is a small but important example of how it was possible to make inclusive living design by starting from the needs of PwD, involving them and changing the paradigm from *design for* to *design with*.

A pathway and design to enhance both physical and mental autonomy for End Users stimulated greater awareness of living spaces and their importance for a future life project.

The replicability on the territory of such interventions and the active network among them is an opportunity to spread inclusive living and to have a real impact on society.

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