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## **Personal assistants: what impact does their round the clock presence have on home adjustments?**

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In France, the regulatory framework of the law passed on 11 February 2005 enabled the financing of disability benefit in terms of hours of personal assistance. In other words, this benefit allows for the financing of home carers to carry out the basic tasks of everyday life. This benefit can extend to round the clock cover, and even more if there is the need. Also, living at home, for people with disabilities which threaten their very survival, has now become an option which no longer involves taking major risks. It is a viable choice.

However, these new arrangements for disability benefits are not without impact on daily life and on quality of life. Living with professionals round the clock is a choice but also a challenge. Many aspects of daily life are significantly impacted. How do disabled people manage with all the implications of professionals being there round the clock? To be able, for example: to maintain their private life? To remain in charge of their own home? To remain self-determined and in control of their life? To protect their family? But also to foster respectful and satisfactory working conditions for the professionals?

The objectives of the survey were to:

1. Obtain information on adaptations made, on choices regarding independence and choices regarding arrangements to protect intimate and private matters.
2. Describe actual adaptations and their uses.
3. Identify aspirations, projects for adaptations, comfort and uses, as well as obstacles and difficulties encountered.

The survey was carried out in the homes of people with disabilities, with their agreement.

The places visited were not the subject of any prior selection regarding their characteristics. Indeed, the objective of the survey is not to understand how the diversity of the built environment and access arrangements influence the organisation of the home. Quite the contrary, it is about discerning the impact

of the virtually permanent presence of personal assistants in everyday life with respect to limitations of physical capacity, on the organisation of the home.

The target population for participation in the survey was based on the following inclusion criteria:

- Being unable to carry out most everyday tasks by oneself
- Living in one's own home
- With at least 20 hours of personal assistance per day, throughout the year

Semi-structured interviews of those directly involved were conducted, but also, a guided tour of their accommodation, in other words a visit of their home led by them, collecting their comments and noting/photographing various adaptations.

If part of French housing stock is now accessible, it is not always adaptable<sup>1</sup> and very seldom is it suitable. Moreover, beyond conventional ownership of the accommodation, those surveyed all went on to make many adaptations to their home with regard to their specific needs but also to those of their personal assistants.

For all those surveyed, the question of space is a major consideration in the choice of the actual home (volume, height), or with regard to adapting the home. This criterion is not a matter of comfort or pleasure.

The issues underpinning this priority are primarily to be able to move freely in each room of the home, or to avoid banging oneself on a daily basis against the walls because of the narrowness of the corridors and uncontrolled movements of the body. So having space in which to live is an aspiration which takes on a whole new meaning when everyday you use a wheelchair to get around. The home visits revealed recurring redistribution of space. Bedrooms have become actual living rooms. Living rooms have turned into bedrooms. Two bedrooms have been joined together to make one bigger one (the people owned their home). Walls have been pushed back. The objective of this redistribution of space is always the same: to extend the bedroom.

There are at least three reasons behind this almost systematic choice in favour of a large bedroom:

The bedroom space is also a place of work and care. Large technical equipment such as hoists are handled there. Care equipment must be to hand (often on a small trolley) not far from the disabled person. Electric wheelchairs must be able to get close in order to perform a transfer between bed and chair. Bed-showers

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<sup>1</sup> Adaptable housing is designed to be able to meet current and future needs of all, at minimum cost.

(shower trolleys) must be able to be manoeuvred around the bedroom but also between the bathroom and the bedroom, etc.

Furthermore, the bedroom space must allow the professionals to move around in order to carry out care and basic tasks of everyday life. For example, getting all the way round the bed must be possible to allow good positioning relative to the disabled person, and maybe with a small trolley to carry various useful utensils and medication. This space must also allow for turning and handling the body, which is essential for many hygiene procedures, for dressing, undressing, etc. This space around the bed also has ergonomic value, in as far as the personal assistants being able to be in a good position, should reduce musculoskeletal damage, which is so common in this industry.

Finally, choosing a large volume bedroom is also explained by the furniture. Beds are usually double because these people live as a couple or in families, or simply prefer the comfort of a double bed. For all these reasons, which are as much about the needs of personal assistants as the presence of technical aids, or choosing a double bed, there needs to be space. The bedroom is not just the sanctuary of a bed and a wardrobe, but a place of many daily activities which require specific facilities and in particular, space. It should be noted that the housing needs are atypical: two large rooms instead of one.

For all those who had or who have found the financial means, work has also been carried out on the layout of the bathroom and toilets. In fact, upon arrival in the accommodation, few found a bathroom big enough for using a bed-shower or a half-turn wheelchair, or even toilets which allowed the use of a commode, a hoist or a rail and the associated presence of one or two personal assistants. Here too, the day to day use by (one or two) personal assistants of specialist equipment of not insignificant dimensions, around personal care/ hygiene and the well being of the disabled person, requires space.

The practice of restructuring spaces and the use of rooms can go as far as redefining an entire floor or even a whole dwelling. So this need for space in rooms which are usually pretty well restricted by their surface area poses a problem. A direct consequence of giving over this space to the bedroom can mean the loss of a living room in the home since neither the surface area nor the financial means can be extended. Yet more reasons may prevail in the restructuring of space and changing the use of rooms: for example one respondent chose to make her bedroom into her dining room to preserve the intimacy of dining alone with her husband. Another opted to set up her office (she works from home) in her bedroom so that the carers could have their own space (in the other room). Yet another uses her entrance hall as a storage space for large specialist equipment, etc.

In all the interviews, the need for a dedicated space for care workers was highlighted. So a bedroom may be kept for them at night, but more commonly, when the size of the home permits, this place is dedicated to the care workers round the clock. Clearly, this space meets at least two requirements: the first, to provide good rest conditions for care workers doing the night shift; the second, to give the staff a place to take a break where they can attend to their own personal activities in privacy and without interfering with the normal life of the disabled person.

This small bedroom is always fitted out. There is always a single bed (meaning it is a strictly functional rest place), a mattress, a pillow, a desk, a chair, and a shelf or storage space. A computer with wifi and maybe a television are generally left at their disposal. Very often the staff bring their own things such as: their toilet bag, their bed linen and towels, their clothes, but also their laptop, smartphone, etc. When arrangements in the room allow, it isn't unusual to find that care workers leave some toiletries or a set of sheets all the time. Each one has their own shelf. The dedicated room is generally occupied at times of withdrawal from the life of the disabled person, often at their request. So, this becomes the place from where they communicate by phone, or by computer, with their family and friends, the spot where they finish university work, the place where they watch the latest downloadable film on line, etc. Thus there emerges a need for a specific space in the home, which enables the staff to spend a short time away from the daily routine of the disabled person, whilst remaining on hand in case of emergency or need.

Another feature of these home adaptations aims to negotiate the best possible relationships with personal assistants, because living round the clock with staff is not an easy choice, even if some do become friends in the long term. It is therefore a real challenge to anticipate or to accommodate, based on experience, the best possible framework for these close, day to day contacts. These arrangements were identified as serving a number of purposes: the preservation of relationships, working together, independence from personal assistants.

During the guided visit in some homes, we observed metal edging in place of skirting boards, metal along some doorframes or for reinforcing strategic angles around manoeuvring in a bed-shower transfer or a patient lift. Conversations during the visits enabled us to reach an explanation: these modifications help to improve the relational economy between personal assistants and the disabled person. In fact, their presence is intended to limit damage to skirting boards and walls, especially when manoeuvring large technical equipment. Damage to the integrity of the home is perceived as a source of possible and lasting conflict,

which it is best to avoid. Along the same lines, a vacuum cleaner which sucks up both dust and water had been bought to avoid the repetition of an unpleasant experience of a vacuum cleaner which broke down after unexpectedly sucking in water.

Activities such as cooking, computer, DIY, etc. can be carried out first hand by the disabled person. Functional assistance will be needed for this to be implemented. To do this, spaces are organised to enable access by the person in their wheelchair with their carers at their side. For example, a space will be provided under the work surface or under the hob. Thus the person can stir the pots, keep an eye on the cooking whilst, for example watching the vegetable peeling. He/she can also carry out some tasks with their carer.

Whilst a bond may develop as a result of these moments spent doing things together, it is just as important to be able to function by themselves without the help of personal assistants. Independence is a major challenge in this daily life which, of necessity, is shared. All the respondents explained techniques, strategies and arrangements to achieve this objective. Let's take, for example, the adaptation of a bedroom. A key element of this is a small table which was specially designed by the person concerned and tailor-made by her husband. This small wooden table is set up on the bed, over the lady when she is in bed. The height is such that she can, place her elbow on it, comfortably and without pain. This positioning of the body allows her to support herself and enables her to make small movements despite muscular weakness. So, the respondent can, for example, eat her meal herself, or even attend to office activities. Moreover, from this table, the respondent is in charge. She runs her world through her various remote controls and there is a small rim round the table to prevent them from falling into the bed and being lost. So, the lights, the computer, the radio, the music and the television all obey her command. This small table also serves as a stand for fixed line and mobile telephones and for a computer. With it, the respondent is connected to the world and, most importantly, to her family, as well as her networks of friends and relations.

Several pointers for the future

- 1) Modular layouts: this research shows us how the size of rooms, ceiling height, the width of corridors etc., are important issues for every day quality of life. We could also consider the technical possibility of designing housing with modular partition walls according to their planned use, as long as inadequate soundproofing standards do not impede the fulfilment of an intimate personal life. Customised division of spaces is a possible pathway for improving living conditions, allowing changes without causing serious disruptions to housing situations.

2) The need to communicate without being physically present 24 hours a day is important as much for organisational as for psychological reasons. It would be interesting to consider the practical arrangements for communication at a distance via sound or light signals incorporated into the building.

3) The survey shows the extent to which the day to day close contact with personal assistants reduces the possibility of intimacy and a private life. The analysis highlights a need for effective and low cost soundproofing.

4) The ability to control people coming in and going out of one's home is an ongoing concern. Also, there are major issues around entrance doors and their control. As it stands, the automated solution usually suggested is rarely completely satisfactory. In fact it should also be possible for the occupant to know who is at the door before opening it.