Ability or disability – design for whom?

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(Received 25 January 2013; accepted 24 April 2013)

The dilemma addressed is how private homes and their residents change when the home becomes a hybrid of both workspace and private space. When assistive technologies designed for institutions enter the home, the everyday practices of disabled persons and their relatives change in interaction with both the institutionalized artefacts and with the multiple actors involved in domiciliary care. Based on ethnographic research of two implementations of assistive technologies in Denmark, the article discusses this dilemma and how it provides the opportunity to rethink how assistive technologies are shaped in the interplay with everyday life in private homes. Through an emphasis on embodiment, script and domestication, the authors illustrate how relations are developed – or not developed – between the disabled person and the non-human artefacts.

Keywords: disability; assistive technology; script; design; domestication

Introduction

Sophie is no longer able to climb the stairs in her home, and Alice faces a situation where she is unable to turn over in her bed at night......

The narratives told in this article concern Sophie and Alice. Sophie is diagnosed with multiple sclerosis and after living with the disease for nine years, she realized that she was no longer able to manage the stairs leading to the first floor in her house. Alice is diagnosed with Parkinson’s disease but is very self-sufficient and has a minimum of assistive technology in her home (Lindegaard and Brodersen 2010). Sophie and Alice are 10 out of 10 disabled people we have followed during the research project ‘Home space or Workspace’. The two narratives are based on analysis of our anthropological field notes and records and reflect the two persons’ own descriptions of what happened. To secure their anonymity, we have changed their names and do not use pictures.

We analyse how the two ‘disabled’ relate or do not relate to the domiciliary care systems through asking one research question: assistive technology – who does it assist and for whom is it designed? The domiciliary care systems discussed are governed by the perception that disabled people are ‘clients’ whose ‘needs’ are to be met through existing assistive technologies.

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The dilemma addressed is how private homes and their residents change when the home becomes a hybrid of both workspace and private space. The dilemma contains two conflicting aspects: the assistive technologies offered by the Danish welfare system have either been ‘borrowed’ from the hospital setting or they have been designed with the caregiver’s well-being in mind.

How to understand ‘disability’ – discussions among disability scholars

Exploring the dense amount of writings related to how disability is to be understood, it is apparent that two disciplinary standpoints dominate, that is, disability studies and medical sociology. The discussion among the two disciplines is whether disability is to be perceived as social oppression, exclusion and unequal rights (Finkelstein 2001a, 2001b; Oliver 2004) or as being caused by impairment and illness (Williams 1999; Bury 2000). Analysing the two disciplinary standpoints, Thomas (2004) argues for a combination: ‘Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing’ (Thomas 1999, 60). Accepting this definition, Thomas (2004) further argues that:

In this social relational definition, disability only comes into play when the restrictions of activity experienced by people with impairment are socially imposed, that is, when they are wholly social in origin. This means that it is entirely possible to acknowledge that impairments and chronic illness directly cause some restrictions of activity. (581)

Our argument for drawing attention to these discussions is that in the two narratives, it seems that the Danish welfare systems interpret disabled persons as ill patients; for example, Alice is made a patient and provided with a trapeze even though her only problem is to turn around in bed, and Sophie is made ‘potential more disabled’ (a patient) when a lift system in her bedroom was suggested even though she was not supposed to be that disabled for the next 10 years. In fact, the majority of people we have studied see themselves as persons who are disabled or have troubles in some situations but ‘able’ in all other situations. Thus, our point and understanding of ‘disability’ lies close to the definition suggested by Thomas (1999, 2004).

Focus in this article is on the multiple relations between the disabled persons, the assistive technologies, the caregivers in the private homes, the relatives, the routines and how all these human and non-human artefacts try to coexist. We acknowledge that effort has been made by among others Oliver and Hasler (1987) and Zola (1991), in their work related to self-controlled rehabilitation, self-help and independence as the goal and their continual use of nouns and adjectives, for example, invalid, disability etc., that tend to taint the whole person. The points made are to be understood as a contribution to the field and an attempt to raise a discussion about whom assistive technologies are designed for.

Danish care policy – designed for whom?

In Denmark, disabled and elderly people are entitled to receive domiciliary care and assistive technologies from the municipality. In 2007, Denmark spent 40 million Euros on assistive technology, a figure that is expected to increase in coming years because of an ageing population. ‘This implies a growing need for technological
solutions to enable people with disabilities to be active participants in society and maximize their quality of life’ (hmi 2011).

The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities state that ‘States should ensure the development and supply of support services, including assistive devices for persons with disabilities, to assist them to increase their level of independence in their daily living and to exercise their rights’ (United Nations 2006).

In Denmark, the Danish Center for Assistive Technology improves the quality of assistive technology by helping to ensure that standardized technological solutions are designed, developed and applied in a way that benefits all users: ‘Assistive technology should do more than assist. It must be a natural part of everyday life and meet users’ needs and preferences both aesthetically and functionally’ (hmi 2011).

Even though the assistive technology aims to help people with disabilities to be more independent in their daily lives, observations from our study indicate that many assistive technologies are developed to assist caregivers in their care practices and optimize their workspace. Since 1975, working environment rules were integrated into the Danish Working Environment Act, which applies to all work performed for an employer. The central aspect of this legislation is the extended safety and health concept, which means that all factors causing accidents, sickness and attrition must be taken into consideration in prevention work. The legislation covers such areas as work performance, workplace design, technical equipment etc. Floor space, room height and room capacity have to be adapted to the nature of the work, the technical equipment, materials and furniture in the working area. The legislation applies to all employers, also the people working in private homes. Thus, this legislation causes a conflict, since the domiciliary care system ends up focusing on safety and attrition of the workforce rather than on maintaining a feeling of home and domesticating the assistive technologies for disabled people. Another dilemma is that the municipal care system is not trained to analyse disabled people’s socio-material networks. Instead, the care system is trained to refer to a prefabricated list of assistive technology, called ‘Assistive Technology Data – Denmark’. The procedure is for the staff to suggest and provide the ‘best’ solution for the disabled that they find on the list of possible artefacts. The list is characterized as follows:

The Assistive Technology Data - Denmark (AssistData) contains information about 49194 assistive devices and 927 Danish suppliers of assistive devices. In AssistData, you will find descriptions of the assistive devices, information on technical specifications, test information, prices and the supplier’s contact information. (hmi 2011)

There are pictures of most devices, and there are an increasing number of brochures, video clips and manuals. All product series are classified by their primary function in accordance with the international standard (ISO classification). It is the care system who is responsible for finding solutions from the list and choosing the non-human actors in accordance with the specific lack of ‘function’. Based on talks and observations with care people and disabled people, it seems that the care system tend to take into consideration the isolated lack of function and projection of future needs, and not the actual socio-material network related to the disabled people and their relatives. The focus is on what the disabled cannot do, and not on enabling them to stay independent of help from others. Thus, the system’s perspective is formed by
disabled peoples’ disabilities rather than the disabled as individuals with families, dreams and hopes for the future.

So what are the consequences of this for Sophie and Alice? For Sophie, a tight relationship was created between her and her wheel chair, whereas for Alice, the assistive technologies created an even deeper gap between her wish to remain self-sufficient and receiving help from assistive technologies. Sophie succeeded in changing the existing practice of the domiciliary care system in relation to assistive technologies, while Alice simply refused the assistive technologies suggested by the domiciliary care system. In the following, we explain what contributed to these two very different situations. First, however, we introduce the research project in which the empirical work was researched, along with the theoretical approach behind our analysis.

**The research project and theoretical inspiration**

The article is based on the anthropologic research project ‘Home space or Workspace?’ initiated by the authors in 2008. The project analysed the socio-material relations in the use and distribution of assistive technology in Denmark. The focus was to understand how different users integrate, refuse or negotiate such assistance and artefacts and how ‘human’ and ‘non-human’ actors entered the homes. Do the artefacts remain necessary intruders or are they accepted and domesticated as part of everyday living? Another purpose of the research was to show that a socio-material analysis is able to provide the product developers and designers with a precise and useful analysis.

In the research, we used field studies and interviews with multiple informants from the Danish Sclerosis Society, the municipality, the domiciliary care system, disabled people and the relatives. We visited 10 households, applying a combination of qualitative methods, such as ethnographic observations and qualitative interviews. The research was conducted in the homes, where observations and interviews regarding daily duties and practices were in focus (Shove et al. 2007). We observed how and when the disabled, their families and the domiciliary caregivers used or did not use assistive technologies, and whom the technologies actually assisted. We used camera and video techniques to ensure we gained a detailed understanding of the interaction between the actors and the assistive technology. The qualitative interviews gave us insight about how the informants perceived their assistive technologies as well as their own accounts for when and how they felt ‘abled or disabled’. To ensure our informants remain anonyms, they have been given new names; Sophie and Alice are names given by us. The two narratives discussed illustrates two different dilemmas: (1) an example of a disabled person’s refusal to accept the proposed assistive technologies offered of the municipality, that would make her ‘disable’ rather than ‘able’ and (2) an example of a disabled person staying disabled since no assistive technology help her to be ‘able’.

In the research, we included historical documents, documents containing information about health care and design practices, as well as material about a new Danish concept in social welfare: ‘Welfare Technology’. This concept covers a range of new technological solutions (remote-controlled door/window openers, toilets with douche and drying, robots to assist eating etc.). The strategy behind the concept is to explore whether these technologies enhance the independence of the severely physically and cognitively disabled in their homes.
In our analysis we use the concepts of *embodiment, script* and *domestication*. The use of embodiment is inspired by Moser’s (2009) idea of embodiment in practice, and how the body and the subject of the disabled people are decomposed and recomposed in different settings and practices. In describing a man’s life after a traffic accident, Moser (2009) argues that new heterogeneous networks are created and demolished depending on new practices. Moser describes how two different networks assume different values for the patient and his body, one in which his body is degraded and another in which his body is recomposed to something new. Interestingly, Moser do not put much emphasis on the role of non-human artefacts in these heterogeneous networks. Our point is that the script of the non-human artifacts is developed due to the disabled peoples’ relations to these non-human artefacts, and therefore it becomes crucial to understand the materiality. Mol and Law (2004, 51) emphasize that we all have and are a body but that this dichotomous twosome can be challenged by inquiring into the body we do, which refers to particular actions and activities in the day-to-day practice of acting bodies. Thus, the body is not a well-defined whole; it is not black-boxed, but has semi-permeable boundaries. In our research, we see several examples where the semi-permeable boundaries constitute a challenge in relation to the assistive technologies as non-human actors.

We examine the private home and how continual optimisation of professional health care practices involving multiple assistive technologies often collides with the disabled’s expectations and practices. This concerns both the number of non-human actors in the home, the ‘functionality’ in-scripted in the assistive technology, and also how the design (visual, style, semiotic) influences whether the home feels homey or like an institution. The notion of script (Akrich 1992) is relevant, since it conceptualizes the connection between design and use. Some assistive technologies are designed to assist the caregivers in their work (often in an institutional setting), while others are designed to assist the disabled. This means that the designer has not only in-scripted the user but the whole network, including workspace, safety, longevity, etc. as representations. Oudshoorn, Brouns, and Oost (2005) draw attention to the fact that the inscription in artefacts of representations of user and use results in technologies that contain a script and therefore delegate responsibilities. Artefacts are not neutral actors in the socio-material configurations; they are active and worth examining in a symmetric analysis of human and non-human actors.

But how is it possible to analyse such heterogeneous networks in which the multiple human and non-human actors interact in both dynamic and more irreversible networks? According to Latour (1999), relations between actors and artefacts are not stable but dynamic relations between complexes of material artefacts, conventions and competences. Inspired by Latour and Domestication Theory (Silverstone et al. 1989; Lie and Sørensen 1996), the analysis in this article focuses on how collections of artefacts co-evolve, and how the different actors have different expectations concerning how, where and whom the artefacts are meant to assist.

According to Silverstone et al. (1989) and Lie and Sørensen (1996), a domestication analysis goes beyond function and use and draws attention to what is happening after the artefacts leave the designers or the domiciliary care system. The analysis seeks to explore whether the actors integrate the assistive technologies provided by the domiciliary care system into their homes and everyday lives, and how this process
occurs. It is not a linear progress, but conflicts, dilemmas and negotiations can be identified. Thus, domestication covers both the processes in which the technology is adapted to everyday life and the processes that involve everyday life’s adaptation to the technology. The analysis emphasizes micro-relations in everyday settings, and focuses on how the general symbolism of the artefacts’ codes can be converted into something personal that is connected to the individual’s identity and social relations. A domestication analysis operates with four phases: appropriation, objectification, incorporation and conversion. The appropriation phase occurs when the artefact, for example, the assistive technology, is provided to the disabled person – both physically and mentally. Through objectification, the assistive technology is given its place and made visible. In the third phase, the artefact is incorporated into the daily routines. Through conversion, the user also shows to the outside world the strong artefact-actor relation in identity and values. Thus, a domestication analysis examines the cultural integration – or disintegration – of artefacts, and perceives this as a process that affects technology, actors and space.

Sophie rebuilds her house – but for whom?

Sophie and her husband are living in a house they bought 20 years ago, in a suburb north of Copenhagen. Ten years after they bought the house, Sophie was diagnosed with multiple sclerosis. After living with the disease for nine years, Sophie realized that she was no longer able to manage the stairs leading to the first floor. They decided to rebuild their house by adding a new bedroom and bathroom to the ground floor construction. Due to her disabilities, as part of the domiciliary care system, the family was entitled to receive assistance and advice from the municipality’s architect. When Sophie and her husband saw the architect’s proposal for their rebuild house, they were shocked. They had expected solutions that would meet Sophie present needs and her wish to be more self-sufficient in her home, but instead the proposal was based on her presumed future needs for intensive assistive care. The proposal described a house with ceilings prepared for a track hoist system for lifts, a bedroom prepared for a hospital bed, and a bathroom three times larger than normal size. The house would be transformed from a home for Sophie and her family into a potential workspace for future caregivers.

When we visited Sophie, she met us outside her house sitting in her electric wheelchair. The entrance did not differ from other houses, and nothing indicated that this was a home for a disabled. Sophie gave us a guided tour, starting in the kitchen, dining room, living room and utility room. She then told us to go upstairs to the first floor without her. Here we saw two bedrooms and a bathroom. Until last year, Sophie had been sleeping in one of the bedrooms together with her husband. Now her multiple sclerosis had intensified and she was unable to climb the stairs, so a new bedroom and bathroom had been added to the ground floor. When we came downstairs, Sophie guided us to the newer part of the house. Sophie seemed very happy and proud; she said that the addition was now quite as she liked it. The ceiling had a dormer with a remote controlled window in the sleeping area, and there were sliding doors to a terrace, where Sophie could go out herself. The bathroom is:

...twice the size that I need, but I was not able to convince the municipality consultant about this argument. He told me that in a few years I would be happy that there was lots of room for my disabled care ... that stung.
Two points can be drawn from this. First, it seems that a sort of domestication has been achieved between Sophie and her new bedroom, and that this succeeded when she was able to negotiate the design of the bedroom with the municipality architect. She had a window in the roof that was not just a standard window but a new ‘welfare technology’, a ‘remote-controlled’ window. Sophie had told the architect that one of her friends from the sclerosis network had implemented this new technology in her house, and the architect agreed that this could be a good solution. It seems that the negotiation phase succeeded because Sophie herself had been able to take part in the inscription process by enrolling both her disabled friend and also the non-human actor – the ‘remote-controlled’ window. This new non-human actor was very relevant, because the domiciliary care system’s strategy was to identify places where ‘welfare technology’ could be implemented to enable citizens to be more self-sufficient while also minimizing for domiciliary care costs. By making a connection between the domiciliary care system and its wider strategies for implementing new ‘welfare technologies’, the architect and Sophie succeeded in negotiating a solution that allowed Sophie to relate to her new bedroom. And it was the materiality of the functions of the remote control and the sliding doors that contributed to this domestication. The second point is that the same kind of domestication does not seem to characterize Sophie’s relationship with her new bathroom. When this room was designed, the architect seemed to have decomposed Sophie’s body to a possible future situation in which it is assumed that Sophie, or rather her caregivers, will need more room to care for her. This means domestication of the new bathroom failed for Sophie.

After the guided tour, we sat in the dining room. Sophie explained how the planning process had occurred. She did not hide the fact that she had been very upset when she saw the architect’s first proposal. The ceilings were flat so that it would be easier to install a lift later. The idea was that her home should be prepared for the future course of Sophie’s illness, so that she could receive the care and the means of assistance that her disability demanded. Sophie said:

...but I couldn’t live with those ceilings. Think that during the next maybe ten years I was supposed to lie there and look up and think that I would surely get worse and finally have to be hoisted with a crane from my bedroom to my bathroom – that was impossible.

Thus, the ceiling in the bedroom was redesigned to its present design. Sophie explained that the architect admitted that he also found this solution the most appropriate, but the municipality officers had advised him to design a flat ceiling to prepare for a lift. The architect told Sophie that the argument for preparing for the lift system now was that it would be much cheaper than to wait until it had to be installed sometime in the future when she needed it.

From Sophie’s description, we see that the domiciliary care system, due to their focus on caregivers’ work environment, failed to understand the meanings and functions of the non-human actors that might affect the disabled. They also failed to understand the scripts of the lift system and the flat ceiling. In the planning and design phase of the addition to her home, Sophie was part of a multiple user group, where the experts and professionals were spokespersons who represented her. Sophie became a ‘silent voice’, marginalized or misunderstood in the process in which the
domiciliary care system represented instead the silent voice of another ‘silent voice’
group – for example, the caregivers (Oudshoorn, Brouns, and Oost 2005, 87).

During the visit and interview with Sophie, it became clear that she sees herself as
a self-sufficient woman and not as a patient who needs lots of help from the
domiciliary care system. Sophie can carry out most of her daily routines herself, with
the help of her electric wheelchair, which she really appreciates. For Sophie, the
wheelchair is a non-human artefact that is domesticated for most of her everyday
routines. It assists her in her daily routines, provides self-help that allows her to
maneuver inside and outside the house in her everyday practice. Thus, Sophie has
incorporated the assistive technology and she and her wheelchair seem to be
embodied. As a spokesperson for the Danish Sclerosis Society, she expresses this
strong relationship to everybody, and she describes her identity and status as
‘wheelchair user’.

Sophie’s relation to the new bathroom is quite different, since the new bathroom
symbolizes her possible future need for help, and it is designed for the caregivers’
practice. The plans for the house were designed for her as disabled and not for Sophie
as a self-sufficient woman. She looked forward to a new bathroom where she herself
and her wheelchair would be the main users, and it was alright to have a sink that
was height adjustable and space for a chair to assist her when taking a bath. But the
super-size bathroom with the mechanical lifting system was built as a workspace
viewed from the domiciliary care system’s perspective. The objective was to allow
room for lifts in order to prevent occupational injuries to the future professional
caregivers. It was designed for multiple-use practices involving many human and
non-human actors. This became a dilemma that was a major challenge to architects
and designers – to design a home that was both workspace and home space. For
Sophie, an institutionalized setting was proposed where she and her family could
hardly feel at home.

This is a huge dilemma. Home care aims to make it possible for people to remain
in their homes rather than move to institutional settings. Both assistive technologies
and the caregivers are supposed to help people bath, dress, move etc. To do the job,
the caregivers often need assistive technologies in their daily work practices to avoid
work-related injuries.

In Denmark, caregivers do not bring assistive technology with them. Home care
is performed by caregivers who transport themselves from client to client on bicycles
and assistive technologies are stored in the clients’ homes. Sophie’s home was
supposed to be rebuilt as to provide room for all the future assistive technologies and
allow the caregivers to maneuver with lifts. It should also allow room for a
freestanding hospital bed, which it was assumed would later be installed.

It is not only the design of home spaces and the role of non-human actors that
are interesting to analyse. The processes of designing the individual assistive
technologies are also of interest and need some attention in order to ensure that
the design is suited to the users, with respect to who will use them, how they will be
used, and in which settings it is assumed they will be placed. We illustrate this in the
following section, with the example of how the mobile lift was designed.

**Designing assistive technologies – the mobile patient lift**

Since the first mobile lift for moving patients was developed, it has been
domesticated in hospitals and nursing homes as the way to move all patients and
reduce work-related injuries. In Denmark, caregivers are not allowed to move patients without using lifts due to health regulations. However, the mobile lift for moving patients reflects two dilemmas: (1) who are the user? – The patient being lifted or the caregivers lifting the patient? and (2) the scripts embedded in the assistive technology. Focusing on (2), the scripts embedded in the mobile lift for moving patients are related to lifts used in automobile repair shops ‘to lift engines and other heavy parts’ (US Patent 2706120). Inspired by this lift, the first lift for moving patients was patented in 1955 with the title, ‘Floor Crane with Adjustable Legs’ (US Patent 2706120). Modern mobile patient lifts still have the basic elements of the original 1955 design and this raises a dilemma, since the socio-material networks are very different both in context and practice.

It is clear that the context of the two lifts differ; one lifts patients (assisted by caregivers) and the other lifts objects (car engines) – an important and obvious difference that can be understood by analysing the socio-material practice. The practice of using the patient lift is that the patient hangs in a sling made of textile fabric while being lifted between the bed and the wheelchair, the wheelchair and the toilet or while turning over the patient in bed. To use the lift, the patient must lie on a couch or bed so that the caregiver can place a net underneath the patient’s back. Metal rings are fixed to each of the four corners of the rectangular net. To lift the patient, the crane’s arm raises the corners of the net to lift the patient. The patient hangs in the net without being able to help the lifting process, which often makes the patient uncomfortable. Interviews with patients indicate that the script of the lift means that the patients are made to be passive objects that are not allowed to be actively involved in the process of being lifted. Thus, one challenge for designers is to design a lift, where the person being lifted can be in a more comfortable position and is not transformed into a passive ‘object’.

In interviews with domiciliary caregivers, they often mentioned that some disabled people cannot understand what the technology can do for them, and meet the assistive technologies with scepticism. For the caregivers, the lift has become a domesticated artefact that they use in their daily work routines. For the domiciliary care system, it has become an artefact they distribute to disabled people at home. Patient lifts are therefore stored in private homes, bedrooms, bathrooms, or even in living rooms, waiting for the caregivers to come and use them.

Through our research, we identified a new mobile lift design – the LikoLight, which is a portable mobile lift ‘developed for people in need of a light, mobile lift that folds away easily’ (Progressive Mobility and Medical Assistance 2011). The lift makes it possible for the caregivers to bring the lift with them, instead of storing it in the ‘patients’ home. This raises an issue of ownership of the assistive technologies: is it the responsibility of the ‘patients’ to provide access to the assistive technologies, or is the domiciliary care system responsible for providing the service and thus also space for storing the assistive technologies? The introduction of portable assistive technologies such as the LikoLight mobile lift could change the practice of the domiciliary care system, and thus also the practice of the caregivers.

It is clear from Sophie’s descriptions that portable assistive technologies are not yet domesticated within the domiciliary care system and in Sophie’s home the recommendation was to implement a solution in which the lift system was built into the house. Thus, it seems that the domiciliary care system had already decomposed Sophie’s body to a future state. Interestingly, Sophie seems to have accepted this, despite the fact that she did not perceive that her body was decomposed yet. The
description of the mobile patient lift suggests that in the process of re-designing the engine lift to a patient lift, the patient was not considered the user, and the patient’s ‘comfort’ was not considered a design criterion; and the designers have not inscribed the complex socio-material context into the lift.

ALICE – disabled, but still a woman
During our research, we also met Alice, who lives in a house with her two children. Alice is one of about 5% of Parkinson’s patients who were diagnosed before the age of 40. Alice is very self-sufficient and has a minimum of assistive technology in her home. When we asked her to list them, she mentioned her bathing chair, which enables her to sit down while taking a shower, a trolley to help her serve food in the dining room and crutches and a wheelchair to use when she goes to the shopping centre with her children. The day we visited Alice, she had just received a tele-care device from the domiciliary care system. This device enables her to call for assistance at night. Due to her illness, Alice has muscular rigidity, and she sometimes has trouble turning over and changing positions in bed.

Before receiving the tele-care device, she used a Bariatric Trapeze, a triangular device hanging above her bed (Figure 1), but as Alice said, ‘...but the Bariatric Trapeze was scaring away my new boyfriend. He peeled it off and I have not mounted it again.’

Alice has a double bed in her bedroom, and she told us that the trapeze helped her change positions at night. The design and script reminded her of a hospital or nursing home, and her children did not like it either. After the trapeze was removed, Alice explored the assistive technology market to find an alternative, but she could not find any sort of hanger that did not look like a gallows. The gallows was meant to help Alice when she had trouble changing position in bed. ‘A little lost bodily function’, she called it. But instead of helping, the trapeze became an artefact that

Figure 1. A trapeze over a standard double bed.
decomposed her body to be disabled and changed her relation to her boyfriend and children. Actually, it changed her daily practice and her identity. She discussed the problem with a professional therapist:

The occupational therapist told me to ask the municipality for a hospital bed with guard rail . . . but I am not that disabled. I love my bed and do not want to sleep alone for the rest of my life.

It is obvious that there is a conflict between how the domiciliary care system perceives the problem and how Alice and her relatives perceive the problem. The artefact offered does not suit Alice’s situation and her daily practice. Embodiment between Alice and the trapeze has not developed and Alice stays disabled in the sense that she will rather have trouble turning in bed at night than have to install the trapeze again.

The domiciliary care system seems to be designed to function through lists of available assistive technologies. In Alice’s case, the lists did not include a double bed with a handle. The only solution the lists contained was a single bed designed to function in a whole different setting (e.g. hospital settings) than a home space setting that included a boyfriend and children. Since the care system failed to provide Alice with a bed and a handle that met her needs, embodiment between her and the assistive technology failed – it became a stranger to her. For Alice, having a Bariatric Trapeze or a hospital bed in her home did not improve her quality of life or make her more ‘able’. It reminded her of her handicap and visualized it, and frightened her boyfriend. The trapeze was originally designed for hospitals and does not fit into traditional homes – either in size or style, and required Alice to reorganize both her home and her identity. The script of the trapeze and the hospital bed is so domesticated into the hospital context that it is very difficult to bring it into a private sphere. Although it has many functional properties, the script is not open. Hospital beds are made for hospitalized patients and are compatible with non-human actors like bed tables, hygiene standards, long corridors, longevity etc.

In introducing the hospital bed as the sole solution to Alice, the professional therapist assumed that Alice’s whole body was disabled. But it was only a small part of Alice that ‘does not work’. Suggesting a hospital bed is like saying that it is the ‘whole Alice’ that does not function. The care system and the bed enact Alice as disabled in a much broader sense. She is a mother and a girlfriend, and in these ‘relations’ a hospital bed does not work.

Alice’s case brings forward the issue of ‘able’ or ‘disable’, since a functional tool that she could grab to turn over at night would assist her to be ‘able’ to help herself, whereas the script and institutional look of the Bariatric Trapeze ‘disabled’. Furthermore, the hospital bed, which is a single bed, ‘disabled’ her in relation to her boyfriend, and as a result, this assistive artefact failed to be domesticated in Alice’s everyday life and practice.

Thus, Alice’s case illustrates that the design of the assistive technologies is important, especially when it embeds particular expectations in relation to purposes and practices. The concept of scripting highlights the range of contextual, practical, material and semiotic factors and needs to be taken into account when analysing actual practice. Even though an artefact is prescribed, the scripts remain open when exposed to the hybrid use practice (Akrich 1992).
Concluding remarks

In this article, we have discussed the use and design of assistive technologies. We identified a dilemma between what is perceived as home space and what is perceived as workspace, and thus a dilemma concerning whom designers are designing for when they develop assistive technologies. Is it disabled people in their homes or the caregivers who assist them? The narrative of Sophie illustrates that it requires the adoption of new perspectives and approaches by the domiciliary care system – for example, understanding the practice and everyday lives of disabled people.

Based on the two narratives of Alice and Sophie, it is obvious that the domiciliary care system is too eager to find already existing assistive technologies that can assist disabled rather than understand the everyday practice in which the assistive technologies must become embedded. Our research emphasizes that ‘staying self-sufficient’ is very important for the disabled. For Sophie, her electric wheelchair, her adjustable sink and her bathing chair maximized her self-sufficiency and her staying ‘able’. Some of the other assistive technologies were never domesticated, because she felt that they ‘disabled’ her rather than ‘enabled’ her. An important lesson to be learnt is that assistive technologies should ‘enable’ disabled and not ‘disable’ them. This may seem to be a simple conclusion, but as our research illustrates, the emphasis on the caregivers’ work environment seems to have become the focal issue when (re)designing disabled people’s homes.

The Danish policy of staying as long as possible in one’s own home has caused a conflict between two sets of regulations: those related to disabled people’s rights to assistive technologies and those protecting the caregivers’ work environment. In this conflicting ‘space’, regulations protecting the work environment have overruled the rights of disabled people.

Based on our ethnographic study and the analytical concepts used, we argue for conclusions that designers and the domiciliary care system have to consider when designing and selecting assistive technologies for disabled. Artefacts that are to assist the caregivers could be designed so they are easier to bring or hide when not in use. Assistive technology design embeds particular expectations concerning purpose, context, practice and use. The scripting of the assistive technology is most obvious when artefact designs configure the user in specific and practical ways. Although an artefact is prescribed, the scripts remain open when it is exposed to a multiple-use practice.

The two narratives illustrate that providing assistive technologies to disabled does not automatically mean that the artefacts become domesticated. Domestication does not mean merely that the domiciliary system provides the assistive technology, as done to Alice. The domestication process stopped at the objectification phase, since Alice did not incorporate the artefact into her daily practice. Domestication of an artefact means that the disabled person shows the world outside a strong artefact-actor relationship with regard to identity and values, as seen in the case of Sophie and her wheelchair. Therefore, in order to analyse how disabled domesticate assistive technology, the whole socio-material network must be analysed – e.g. built through the disabled’s active development of relations to non-human artefacts. Through such analysis, we gain an understanding of why some assistive technologies are domesticated while others are not.

Our research has caused us to ask why nobody has designed a comfortable double bed for disabled living in their private homes with relatives? Why is it difficult to re-think and re-design new assistive technology to assist all the human and non-human actors in the socio-material network? Design for disabilities in home space
could be a major future design possibility. The hybrid space between humans/non-
humans and home space/workspace opens up for new lines of enquiry regarding the role of artefacts in the domiciliary care system. Designing assistive technologies demands that developers, designers, care providers and politicians acknowledge the complexity within which assistive technologies are to be used. This requires an understanding of who is to use which assistive technology and where.

References


