

Care and disability

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► **To cite this version:**

Myriam Winance. Care and disability. Mol Annemarie, Moser Ingunn, Pols Jeannette. Care in practice. On tinkering in Clinics, Homes and Farms, Transcript, pp.93-117, 2010, MatteRealities/Verkörperungen. Perspectives from Empirical Sciences Studies. <halshs-00495614>

HAL Id: halshs-00495614

<https://halshs.archives-ouvertes.fr/halshs-00495614>

Submitted on 28 Jun 2010

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CARE AND DISABILITY.
PRACTICES OF EXPERIMENTING, TINKERING WITH, AND ARRANGING PEOPLE AND
TECHNICAL AIDS.

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Chapter published in Mol A., Moser P., Pols J., “Care in Practice. On Tinkering in Clinics,
Homes and Farms”, Transcript, 2010, pp.93-117.

Proof before publication.

(the final pagination has been respected)

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In order to examine the question of care practices in the field of disability, I will start with the contradiction that emerges when one compares two approaches: the *Disability Studies* approach, developed by some disabled researchers and activists, and the “ethics of care” approach developed by certain feminists in the early 1980s in Anglo-Saxon countries. *Disability Studies* is linked to the *Disability Movement* created by disabled persons in the United States and Great Britain in the 1970s (Barton & Oliver, 1997; Oliver & Barnes, 1998; Scotch, 1988). Although it takes different forms in the two countries, the starting point is the same: criticising existing practices such as re-education and rehabilitation, which are interpreted as implementations of a medical model. This medical model defines disability as something that results from an individual, pathological or functional causality and focuses the action on the individual to be “rehabilitated”; this model is also linked to practices of institutionalisation. In the 1970s, disabled people reformulated their experience not as being an experience of being “maladjusted to society,” but as an experience of being “excluded from society.” They became aware that their disability is the result of architectural, social and cultural barriers that society imposes upon people with impairments. This awareness is the basis for what we now call the “social model” of disability, which defines disability as being the result of a social causality. From this, Disability Studies went on to develop the demand that practices and society be changed in order to make it possible for disabled people to participate. The people committed to this movement fight for the ability to control their lives and to decide for themselves what they need. They oppose existing practices that are seen as oppressive and infantilising. From this standpoint they criticise the notion of care (2001; Keith, 1992), inasmuch as relationships of care place those who receive it in a position of dependence and passivity. They defend the implementation of a formalised and functional relationship of help to the exclusion of any emotional dimension. To designate this relationship, researchers use terms such as “help,” “support” or “personal assistance,”

rejecting that of “care” in order to stress the desire for control and autonomy that disabled people are looking for in their everyday lives.

The beginning of the 1980s in the United States saw the emergence of another movement now identified by the term “ethics of care,” which includes different works (Brugère, 2006; Feder Kittay & Feder, 2003; Paperman, 2004, 2005; Tronto, 1993, 2005). What these works have in common is that they look to revise the practices and values relating to care, in order to build an ethic of care as opposed to an ethic of justice. These works begin with a criticism of the autonomous rational subject (the modern Cartesian subject) and demonstrate a relational, affective, emotional me who is built and supported by relationships of care. They thus place the accent on vulnerability and dependence¹ (constitutive for everybody, whoever he/she may be), on the ensuing need for care relationships and on the asymmetry and affective dimension of these relationships. In their opinion, everyone is, at a given moment in his/her life, involved in relationships of care, either as the one who is caring or as the one who is being cared for. The aim of these works is then as follows: to consider the moral norms that allow the development of relationships of care (conceived as relationships of dependency), which although asymmetrical are not relationships of domination. “An ethics of care may be one way to understand the moral commitments and relations that arise among the persons unequally positioned in relations of dependency.” p. 3 (Feder Kittay & Feder, 2003).

I am not going to discuss these works any further, but only wish to stress the opposition between the two approaches.² On the one hand, Disability Studies researchers demonstrate that a disabled person is not a person who is “constitutively or essentially dependent,” but that his/her dependence results from social organisation. They therefore demand the ability to choose and control their own lives, including the possibility to develop a relationship not of care, but of assistance or support, a symmetrical relationship. On the other hand, the theorists of care believe that we are all dependent upon one another, and that we are all involved in affective and asymmetrical relationships of care; independence is a fiction, an illusion.

The aim of this article is to escape from this opposition by making a methodological shift, towards the examination of particular situations of care, that is, the practices and techniques for compensating for inabilities. These techniques encompass recourse to technical aids as well as rehabilitation and re-education practices. In this paper, I

will analyse such techniques through four cases taken from two ethnographical studies. The first study involved observing wheelchair tests that took place at a test centre located inside a major hospital. Approximately 120 models of manual and electric wheelchairs, on loan from the manufacturers, were exhibited in a room measuring 350 m². Benoît, a physiotherapist, received patients (from the hospital or from the outside) who had made appointments and who needed a wheelchair. He showed the patients one or more wheelchairs and allowed them to try them out.³ I was able to observe 34 tests, including those made by Mrs. Sabin, Serge and André that I will discuss in this paper. The other, final example that I use, that of Martine, is taken from an ethnographical study carried out at a day hospital in a re-education and functional rehabilitation centre. My examination of these practical care situations will lead me to make a theoretical shift with regard to the notion of care. Whilst Disability Studies and ethics of care researchers have different conceptions of the person (either as dependent or independent), they both base themselves on the same conception of care in terms of a relationship of aid going from one person, a carer, to another, the cared for; the former – active – helps and supports the latter – passive. The description of the wheelchair tests and the rehabilitation practices will lead me to offer a conception of care in terms of shared work, dispersed in a collective of humans and non-humans (Callon & Law, 1995), each person in the collective being simultaneously an object and a subject of care. I will describe this work as empirical tinkering (Mol, 2006; Pols, 2004), the purpose of which, for the people involved, is to empirically shape an arrangement between the persons and the chair that suits them and that causes the emergence of movement sensations, possibilities and abilities for everyone.

Spotting what works and what does not.

Mrs. Sabin, aged 60, has a cerebral motor deficiency. Two or three years ago, she lost the ability to walk. At first she rented a manual wheelchair. When the rental continued, French social security forced her to buy her own wheelchair, without giving her any warning. She therefore had to buy a wheelchair very quickly from a catalogue, without being able to test it, and this is the wheelchair she currently uses. It is a basic wheelchair, with a metal chassis covered with a blue waxed material, high square armrests, and two detachable footrests. It is heavy and not very manoeuvrable. Mrs. Sabin is small and her wheelchair is far too big for her. It is very uncomfortable and she quickly gets back pain when sitting in it. It is also difficult for her to move it

on her own. She has decided to buy a new wheelchair, and accompanied by her husband she has come to the test centre to try out a new chair, the SP, which one of her friends uses.

During the tests she tries three light top-of-the-range chairs, and finally chooses the SP.

Benoît: You saw Mrs. X with her SP, and you want to try the same model?

Mrs. Sabin: Yes, hers seems more comfortable, you get better back support. In this one my back and my feet hurt, and the two footrests are no good, my feet get stuck between them and it hurts. I want a wheelchair with a single footrest. With two, I get stuck.

Benoît: Are you always in your chair? Have you walked before?

Mrs. S: Yes, I'm going to walk. They are going to operate on me and I hope I'll be able to walk again.

Benoît (repeating and insisting): Have you walked before?

Mrs. S: Yes, until two or three years ago.

Benoît: And are you in your chair all day long?

Mrs. S: Yes.

Mr. S: Yes, or on the sofa, because she can't cope with being in this all the time.

Mrs. S: This one is uncomfortable and when I have spasticity attacks, ... it's impossible, I end up spending all day lying down, it's impossible to do anything else.

Benoît: And can you move on your own, or does your husband always push you?

Mr. S: Inside, she moves around on her own, but when we go out I push her. Because, well, she has trouble moving on her own. Inside she manages, more or less.

Benoît: Yes.

Mrs. S: For me it's hard to push myself because it's too wide and too big.

Benoît: The main problem is the back, it's too high.

Mrs. S: I'd be better off with a junior model, because I'm really not very big!

Benoît: We no longer work in terms of adult/child. Because at the end of the day it's a question of size [...]. You need a small size. So I see you put your bag next to you ... that's important for you ... you want to always be able to do that?

Mrs. S: Yes, I want to be able to put it next to me.

Benoît: Do you sometimes stand up?

Mrs. S: No.

Benoît: How do you go about getting onto the sofa?

Mrs. S: I remain seated. I stay seated and I move from one to the other.

Mr. S: Yes, but you put your weight on one foot.

Benoît: Do you lift up the footrest?

Mrs. S: Yes, often. I often lift them up.

(Test Centre, June 1999)

At the start of the test, the centre manager and Mr. Sabin are next to Mrs. Sabin in her wheelchair, and look at her. Benoît asks Mrs. Sabin questions about what she does or does not do, how she feels in her wheelchair and how she uses it. Mrs. Sabin and her husband both reply to his questions. The research is done in a joint manner. Mrs. Sabin explains what *she does not like*: she gets back pain and her feet slip between the two footrests. She cannot move the wheelchair on her own. Mr. Sabin speaks up to give further details about how she uses or does not use the chair, and how she feels when sitting in it. He points out that she is unable to spend all day in the wheelchair and that when moving to the sofa she puts her weight on one foot. The actors also look at what *she likes*; for example, being able to have her bag next to her. Furthermore, in their analysis they always relate what Mrs. Sabin can or cannot do to the characteristics of the wheelchair. They link actions to wheelchair characteristics; for example, Mrs. Sabin relates her difficulty in using the wheelchair on her own to the size of the chair, whilst Benoît relates it to the height of the back. In this way, through their conversation and by watching how Mrs. Sabin is seated in her chair, they gradually see what is right or wrong with the current chair, and furthermore they do this in terms of the characteristics needed for the new wheelchair: it must be light, small, have a single footrest and a low back, be easy to manoeuvre and comfortable. As the test continues, so does this analysis, taking the form of a physical confrontation between the person and the various different wheelchairs, and of a tinkering with the ways in which they suit one another.

Trying a chair, experimenting, groping, handling

After exploring what a new chair will need, the second stage is to fit the person and the wheelchair together. For one, two or even three hours, the actors experiment, test and successively touch the person, the chair and the “person-in-his/her-chair”; they look, they examine each and every characteristic of the chair and the way in which the person is seated. They explore the position of each limb and/or

whether a given action will be possible. Here the research into what works and what does not takes the form of an exchange of perceptions. The test is long and slow; patience is needed. To care is to take one's time, to "quibble" over details, to examine together, to test, explore and feel in order to make the right adjustments.

(Serge, aged 41, has a cerebral motor deficiency and uses a manual wheelchair with a customised seat, but he would like an electric wheelchair because his girlfriend cannot push him anymore. At first the idea is that she should be the one to drive it. He is unable to drive an electric wheelchair because he cannot control his hands and arms, which tend to make uncoordinated movements. But at the same time, they have already owned one electric wheelchair that Serge's girlfriend drove, but they had problems getting past certain obstacles and climbing slopes. Benoît therefore suggests trying to let Serge drive with a chin control. Serge, with his customised seat, is transferred onto a small electric wheelchair with a chin control.)

Benoît: Even for someone who is used to it, this is not easy, so you mustn't be impatient; even for an accident victim who does not have these movement problems (*that is sudden uncontrollable movements*) it is hard, the installation takes a very long time ... Afterwards you know a bit more, you have a better idea of the position, but at the beginning it takes time, it's a nightmare ... so you mustn't get cross if we have to experiment and if we don't get it right straight away. [...] *(Benoît tries to position the control in front of Serge's chin, the difficulty being that it must not be too far, so that Serge can reach it and use it without too much effort, nor too close, so that Serge doesn't move it by mistake. He finds a position).* Can we try it like that?

(Serge tries to reach the control with his chin, but does not succeed. He concentrates and tries again, but can't do it.)

Benoît: I suggest we give ourselves fifteen minutes to experiment and to try to find the right position, and then we'll see. *(He changes the position of the control, he tries to lift it higher and turn it. The control is not very flexible, which makes it hard to position it; he ends up finding another position that seems better. He then explains to Serge how it works.)* When you pull down, the chair moves forward, and when you push, the chair reverses; to turn you have to push on the side.

(He turns the chair on, and Serge starts to control the chair. We can see that he is concentrating to control the movements of his head and to watch where he is going. He manages to move around,

to move forward and turn; he sometimes finds it hard to stay in the same direction, but overall he manages to use the control.)

(Test Centre, June 1999)

By experimenting and tinkering in this way, the actors try to answer the question of how the person feels in this chair and what can he/she do in this chair. They explore how the person feels in his/her wheelchair, the way in which the chair makes it possible or impossible to do certain things. They “de-cribe”⁴ and deploy the characteristics of the person and those of the wheelchair. They swap perceptions and compare them, in order to try to define which body, with what sensations and what (in)abilities, is shaped by this wheelchair.

(Mrs. Sabin is sitting in the SP)

Benoît: Right, okay, this is a top-of-the-range chair, it’s different from the one you have, which is a basic chair. The problem is finding the right size. I think this one is too big. I usually advise that one should be able to get a hand between the armrest and the buttock, but no more than that. Now, if you’d like to be able to sit next to the bag... It’s important that the back of the chair properly supports your back, and if your husband pushes a lot, he has to be able to push without too much problem.

Mrs. S *(She has already tried to move a bit and she is immediately enthusiastic)*: Ah yes, this is completely different, so much better, it rolls well *(she tries the chair, makes it move)*. [...]

Mrs. S: The canvas back is much nicer than the other.

Benoît: It’s mainly because it goes round the tubes instead of just over them. So what don’t you like about this chair? What would you like to change? For me, it’s the width ... it’s too wide, but for you it’s alright?

Mrs. S: Yes.

Benoît: Don’t you need a strap in front of your ankles to keep your feet in place?

Mrs. S: No, my feet stay in position on their own, it’s just when I flex my legs, they need a few seconds to bend, but apart from that ... it’s fine ... they stay in place on the other chair, they are always like that.

[...]

Benoît: [...] But there are other questions ... there you’ve got your knees bent, does that bother you?

Mrs. S: No, no problem.

Benoît: Because there’s the same model but with a longer

frame, so you could have your feet further out. Your legs will be less bent.

Mrs. S: No, this one's fine.

(Test Centre, June 1999)

These extracts demonstrate the meticulous joint exploration that is done during the test; this exploration relates to the sensations that Mrs. S feels in each part of her body. Does this chair and its characteristics (wide, footrest somewhat backward, small front wheels, canvas back) suit Mrs. S who is small, who has spasticity attacks (such people usually do not like to have their legs bent backwards for too long) and severe scoliosis? In the two extracts above, from the tests carried out by Serge and Mrs. Sabin, we see a “disassembly” of the body and of the wheelchair. The person's body and the wheelchair are not considered as wholes, but in terms of their parts, with each part being capable of its own particular action. There is thus the issue of whether Mrs. Sabin's feet will stay on the footrest or whether they will suddenly lift up. In Serge's case, there is the question of the sudden uncoordinated movements of his limbs and head. Here, the body is an overflowing body. It has resistance, tested by the actors. The purpose of the joint work done throughout the test is to bring out a “body-in-a-wheelchair.” The actors tinker together to come up with an arrangement between the person and the chair that suits them.

Shaping what works: defining an arrangement between person and chair.

The exploration and exchange of perceptions transform the person and the chair. The search for a suitable position, which the person finds comfortable and which allows him/her to act, involves a gradual shaping of person and chair: one moves an arm or a leg, and then one changes the width of the chair, one adjusts a cushion, a headrest, etc. From the very outset, the manufacturer sees the wheelchair as an object that can be customised, changed and tinkered with to suit the person who will be using it and to suit his/her sensations and (in)abilities.⁵ During the tests, the actors constantly change and adjust the settings of the chair and the position of the person.

(André, who has Duchenne myopathy, has just been transferred into the TWS, an electric wheelchair, and is telling his mother and the test centre manager how he is feeling, what is okay and what is not, and how he needs to be positioned in order to feel more comfortable.)

André (*inaudible*): ... my right-hand side...

Benoît (*who has understood that André needs to be recentred in the chair because he has the impression he is going to fall*): It's the armrests? You want me to bring them closer (*to the seat*)?

André: No, it's fine. Mummy! I'm going to fall!

Mother: No, we are holding you ... when he doesn't have the table he panics. It's because he has nothing to hold on to.

Father: Yes.

Benoît: But ... it's a bit too wide at the sides. Maybe it will be better if I pull the whole thing closer together. I'm going to pull the whole thing closer to the seat (*Benoît brings the armrests closer to the seat*).

André: You need to push me further back. (*His mother then pulls him from behind*).

Mother: Shall I pull your leg?

André: Yes? (*Very gently, his mother pulls his leg forward, following André's instructions, until he says stop*).

Benoît: Does the back need to be more upright?

André: I need a headrest. (*Benoît goes to get one and positions it*).

Mother: I'll do something so that it pulls less on your legs. (*She moves his legs*).

André: (*Unintelligible*)

Mother: (*She has understood and she repeats*): "I can't do my movements and swing to get back into position..." No, I can see that.

[...]

André: I'm too far back. [...] At home we've added some foam padding.

Mother: Yes ... at home we have made our own cushion, and so it is just the right shape and doesn't push on your legs: it's round. The one from the distributor is straighter. I buy foam, cut it and cover it. On your chair there are two cushions, and we've added a bit at the front so that it doesn't pull on your legs ... But the cushion doesn't matter, we can make another one.

(Test Centre, June 1999)

The actors gradually shape a person-in-a-wheelchair; they tinker around to make an arrangement. To achieve this, they experiment, they test, they pay attention to details and they try to adapt. The back is "a tad too upright," the hand is placed "a millimetre" too far from the wheelchair control. The actors act on the materiality of the person and the chair in an attempt to make them suit one another. They adapt, they make adjustments to person and chair to try to

find how they can “fit one another,” how they can “come to an arrangement.” And every time they find an arrangement, they assess it by once again exploring the sensations of the “person-in-a-wheelchair,” looking to see to what extent “it works.” This process is what I have called the process of adjustment (Winance, 2006b, 2006a, 2007b). Through this exploration and shaping, through this process of adjustment, a position emerges that suits the person, a position in which he/she feels comfortable, in which there is less pain and in which new actions are possible.⁶

To care is to tinker and to doctor. To care is to “quibble,” to handle, to adjust, to experiment, to change tiny details in order to see if it works, to see if the person and the wheelchair can come to an arrangement and get along with one another. Wheelchair tests show the simultaneous work on the feelings and on the body, along with the collective dimension of *care*. In this context *care* refers to sensitivity that is shared and distributed among the actors. The object of care is not one single person but a collective. The work of caring involves attention that is built by the collective and directed towards the sensations and possibilities of action that emerge for the person concerned. This attention is “material”; it includes the object, the wheelchair. The actors touch and watch in order to shape a “person-in-a-wheelchair” capable of certain actions, in order to enable him/her and to give him/her more (or new) mobility (Winance, 2003). Mobility here refers to the ability to make links: to move in the world **and** be moved by it or by the others.

To enable the person: making him/her move and be moved.

Pain prevents action; it immobilises people by focusing their attention on what is hurting. A dual breakdown takes place. On the one hand between the person and this body that hurts, on the other hand between the person and his/her environment. Someone who is in pain withdraws; he/she is unable to act (Leder, 1990; Scarry, 1985). If a person is not sitting properly and is in pain in his/her chair, he/she cannot do anything; he/she is paralysed. To move becomes difficult for him/her; to be moved also. By adjusting and adapting the “person-in-a-wheelchair,” the actors are acting on this dual breakdown (Winance, 2006b, 2007b). Working on a person’s sensations changes both these sensations and the person’s (in)abilities; it opens possibilities for the person by transforming the relations that shape him/her; it once again gives him/her the possibility to get to the world; it allows him/her to move and be moved, to create different relations with

his/her environment. This is the final goal not just of wheelchair tests, but also of re-education practices, of which I would like to give the following example:

On the first day of my stay at the re-education centre, I attended Dr. Ramon's consultations (Dr. Ramon works in re-education and rehabilitation). It is the turn of a young woman, Martine, who has been a paraplegic since her road accident. She comes with her husband and children. She now lives at home, but continues to have her consultations at the re-education centre. Her physiotherapist also attends the consultation. For some time now, they have been working on learning to walk again. In order to be able to walk, Martine has to wear articulated splints on her knees and ankles, to give her support up to her pelvis. She then stands between parallel bars on which she leans for support. The doctor asks her to show him how she walks, so that he can assess her progress. Martine stands up between the bars, concentrating in order to remain upright. She takes her weight with her arms and takes a first "step"; she slowly moves her two legs forwards, placing them in front of her, then moves her hands on the bars. Martine has lost the use of her legs, it is impossible for her to put one leg in front of the other. "Walking" involves taking her weight with her arms, and swinging the body forwards. Before each movement she thinks carefully and concentrates on what she must do. The physiotherapist explains to me that the problem is that she has no feeling below the pelvis; she can no longer feel her legs, they are a dead weight. She must replace feeling with thinking in order to keep her balance and make a movement. Walking is a movement in four stages that uses the entire body; when we walk, we move a leg forward, then an arm, then the other leg and finally the other arm. The purpose of the exercise is not really to learn to walk again, as it is very unlikely that Martine will ever use this method to get around; it will always be far more laborious than using a wheelchair, and will only be useful for certain transfers or short distances. Yet this exercise allows Martine to use all her body, to be aware of her entire body in movement (even if she has to think about it), to regain confidence and realise that certain things remain possible. At the end of the consultation, Martine tells me: "I know I will never walk again, and that the wheelchair is more practical, but

with these exercises I can have new sensations.” (Re-education centre, consultation, 23/06/99)

This consultation instantly spoke to me. Some authors (Barnes, Mercer, & al., 1999; Oliver, 1990) (Ebersold, 1997; Stiker, 1999) have criticised re-education practices and the ideal of normalisation that they implement.⁷ Here, normalisation means alignment with the social and functional norm of being able-bodied. Yet this consultation seemed to fit this criticism. Martine will never walk again, the lesion of the spinal column is definitive. Yet she is working with her physiotherapist to learn to walk again. Re-reading my notes, I underlined the physiotherapist’s and Martine’s comments at the end of the consultation. They know that Martine will never walk again. And they anticipate the criticism of normalisation.

The aim of learning to walk again is not to re-establish a functionality that has been lost or that is considered to be normal; it is to teach Martine to feel her body and her legs in a different way. Martine “lost *her* legs” in the accident, they became a dead weight, they have become *legs*. During the exercise, she is relearning to feel *her* legs, she is learning that they can once again be *her* body, but in a different way. In other words, through this exercise she is doing and performing her body (Mol & Law, 2004), her body that has legs, *her* legs. But because Martine can no longer directly feel her legs (as the able-bodied can), she is learning to feel them through the intermediary of reflection, of her other senses (sight), and, above all, through the intermediary of a technique (splints and parallel bars). This technique is part of her body. It plays the role of mediator (Latour, 2004) by defining Martine’s experience of her body. Yet in fact, the splints remain separate from Martine.

In the case of a wheelchair, a common materiality and common sensations emerge from the work done.⁸ Not only is the person’s perception of his/her body transformed by the chair, but he/she gradually learns to “feel” the wheelchair, which becomes “his/hers,” which constitutes “his/her body” and which enables him/her to act.⁹ In this way Serge, who has never driven an electric wheelchair, gradually learns to feel the chair’s movements and to feel these movements as movements of his chin and of his entire body. His girlfriend points out that, “It’s good for him to control with his chin, it makes him use all his muscles,” while pointing to his abdominals. She adds, “When he is driving, I can see he uses them all, it’s great.” And a little later: “It gives him more freedom, it won’t always be like that and in any case not outside, but if he wants to move around he’ll be able to do it, it’s good. (...) Because

he really wants that; inside he'll be able to move around on his own, he just needs to ask, we'll position it and he can move ... but of course, outside, he never goes out alone, he'll always have someone with him." The wheelchair is not just a means of getting around, compensating for a loss of mobility, a means to an end. Thanks to this technique (chair and chin control), Serge will be able to "move by himself." In his case, "moving by himself" means being able to move from room to room when he is bored, when someone is annoying him or when he wants to change activities. With his chair, Serge will also be able to move around outside, with someone accompanying him no longer having to push him, but instead driving the wheelchair using a second control; this will make it possible to go for longer walks. This means more freedom for Serge, greater freedom of movement. It is also the sensation of a different body, a body that can move around, a body that can build up muscle, a body that can work. The technical object, the wheelchair, is a source of pleasure (or/and displeasure), of possibilities (or/and impossibilities). For Mrs. Sabin, her new wheelchair will mean more mobility because she will be able to move it herself, greater comfort and well-being, and a lower number of transfers because she will be able to remain in her chair all day long. To care is to enable, to open up new possibilities of action for the person. Throughout the wheelchair test, the issue of the possibilities of action¹⁰ available to the person is explored by the actors from empirical, material and emotional points of view, i.e. by working on the relations that link the person to his/her chair and by making the person into a "person-in-his/her-chair." More broadly speaking, new sensations and new actions are made possible by the collective of which the person is a part. So the object of care is not directly the person, but his/her sensations and abilities for action that appear through the relationship – the attachment – between the person and his/her wheelchair. In this case, care is not a relationship of assistance between an active carer and a passive care receiver, but a collective attention to the sensations and actions that emerge for the person in question; it is an attention to the nature of the relationship that develops between the person and the chair, and, more broadly, to the nature of the relationships that exist within the collective. To care is to organise and to tinker with the different entities of a collective so that they adapt to one another, so that they might live together, so that each might get something out of it, might start to move and be moved by the others.

From collective care to care for the collective

I have shown above that care is given to the person's sensations and possibilities of action. But what person are we talking about? Are we

only talking about the disabled person, the person who we intuitively consider to be the receiver of care? Let us return to the case of Mrs. Sabin.

Benoît: okay ... so what about the height of the back?

Mr. S: (*who has tried pushing Mrs. S in her chair*): Can't we lift the handles up higher?

Benoît: Yes, we can, this is a 35 cm back, so we can go up to 37 cm, or else we can take the 40 cm back which can go up to 43 cm.

Mr. S: Yes, I have to bend over a bit with this one, it would be better if it were a bit higher ...

Benoît: Okay, the monoblock footrest is good; the back is a bit low, it's easy to get a 40 cm back. But Mrs. Sabin, won't that be uncomfortable for you when you move (*he puts his fingers higher up against Mrs. Sabin's back*)? there, move, I'll be the higher back ... how's that?

Mrs. S: It's okay ...

Benoît: It's not uncomfortable? Move without my hand and then with it ... (*he places his hand then removes it, repeating the process several times*).

Mrs. S: Ah, that's better.

Benoît: Without?

Mrs. S: Yes, it's better without.

Benoît: Yes ... so a higher back will be a problem for her.

Mrs. S: Yes, it's better without your hand.

Mr. S: Why?

Mrs. S: You see, with his hand it's uncomfortable.

Benoît: The solution is to pull the handles up, like this one (*he shows a chair with higher handles*), you pull the handle out from the back. But it's a lot of money to achieve very little.

Mr. S: I'll make do with these. I'm a little bent forward, but well ... [...] As I do a lot of pushing, I'd like bigger front wheels, it's easier.

Benoît: A good compromise would be these wheels here. They are a bit bigger than your wheels and the ones on the chair at the moment, and as they are hard they roll better.

Attention is not directed solely to Mrs. Sabin and how she feels in the chair, but also to Mr. Sabin and how he feels when he pushes the chair. In other words, the object of care is not "Mrs. Sabin-in-her-chair" but "Mr. Sabin-who-pushes-Mrs. Sabin-in-her-chair." The actors' attention is focused on the sensations and possibilities of action for each person. Hence the search for an arrangement which suits everyone. In Mrs. Sabin's test there is a dilemma. Easier handling for Mrs. Sabin means

discomfort for Mr. Sabin, who often has to push. It seems to be difficult to reconcile handling that will be comfortable for both of them, especially as the two handling situations relate to opposing qualities of the wheelchair (a low back for Mrs. Sabin, but high handles for her husband). A compromise is needed between the possibilities of action for Mr. Sabin and the possibilities of action for his wife. Such a compromise means adapting the chair: they keep the low back and low handles and replace the front wheels with slightly bigger ones.¹¹ Attention is thus shared because it is focused on the collective, on all of the individuals comprising it, on the sensations, on the possibilities of action for each separate individual and for everyone together and finally on the nature of the relationships that unite them. André, his wheelchair and his mother are then linked by relationships of strong dependency resulting from a temporal evolution: the illness getting worse, the wheelchair becoming old and worn, etc. At the moment, André cannot do anything without his mother; she has to be with him constantly, whether it is to move him or to drive the wheelchair for him, both inside and outside. The decision to change the chair comes just as much (if not more) from the mother as from André himself. To give André the chance to drive his chair, even if only to a limited extent, is to change their relationship, to reduce their **feeling** of dependency, to make it possible for both him and his mother to regain some freedom of movement.

In my fieldwork I have noticed that the request for technical aid (wheelchair, bath seat, adapted shower, etc.) comes just as often from the carer (whether a member of the family, a friend or a professional) as from the person requiring care. For the carer, technical aid means the chance to change his/her relationship of care with the disabled person, to “reverse the direction of care,” and to make it understood that he/she also needs care and is not just a carer, but must also be helped, particularly in the provision of care. He/she must be helped to help. When one includes the mediation of a technical aid in the relationship of care, one is caring both for the carer and for the disabled person. The technical object makes it possible to share the care among the members of the collective, be they the disabled person, family or professionals. It changes their sensations and their (in)abilities. It modifies the relationships of dependency between them; it adds distance or proximity, and may be the source of freedom of movement for them. People in the collective are thus at the same time objects and subjects of care. Furthermore, they are also all responsible for the quality of care given in the collective, even if they hold different posi-

tions and have different abilities. People may find themselves in asymmetrical positions because they do not have the same abilities. Nevertheless, in this case of the wheelchair, the care appears to be symmetrical and shared. Symmetrical means that each person gives care to the other. Shared means that everyone in the collective is giving and receiving care. With this issue in mind, I am now going to examine the question of *good care*.

Care as a search for compromise. “*Le mieux est l’ennemi du bien.*”¹²

Benoît, manager of the test centre, tells me about his job. After talking to the person and those with him/her (family, friends, professionals), he shows them one, two or three wheelchairs and lets the person try them out. “(...) The problem is that when they arrive to see me, they don’t really have any criteria for making their choice, except maybe ‘inexpensive’ and ‘the lightest.’ So I try to develop criteria, to see what they want.” The aim of the tests, which last between one and three hours, is to let people choose the wheelchair “that suits them best.” While he explains his work, he tells me about what he calls his “philosophy of things,” which he sums up as being “*le mieux est l’ennemi du bien*” (the perfect is the enemy of the good). Over time, he has learned that it is sometimes necessary “to avoid giving too much advice; giving too much advice is not a good idea (...); people have a wheelchair, the one that suits them best, but they don’t know why they have that one. You need to keep things simple.”

Wheelchair Test Centre. May 99.

In this extract, Benoît gives us the keys to understanding what “good care” means in his practice. First of all, *good* is defined in comparison to *the perfect (or the better)*. But what is this *good*, what is this *perfect*? To answer this, let us return to the examples. In the example of Mrs. Sabin, Benoît repeats several times that he feels the wheelchair she has chosen is too wide for her, with Mrs. Sabin replying that it is the right width because she wants to be able to have her bag next to her. In this example, the *perfect* would be a narrower chair, with the *good* being a wider chair with room for the bag. We can take the example further.

Regarding the issue of double manoeuvrability, for both Mr. and Mrs. Sabin the *perfect* would be a lower back and higher handles, with the *good* being a low back, low handles and medium-size front wheels. The *perfect* is thus what, “*in absolute terms,*” suits the person

concerned. By “in absolute terms,” we mean without taking into account all of the relationships surrounding the person which link that person to other entities, which *attach* him/her to them (Gomart & Hennion, 1999; Latour, 1999), without considering the world in which the person lives, without taking into account to what the person is attached and what attaches the person. The *good* is an arrangement of people and things that is a compromise, allowing a life together and allowing motion and emotion for all those involved in the collective. The example of André throws light on this point.

André has two problems. First, his wheelchair is old and is about to fall apart. Second, he can no longer drive it, his mother has to drive it for him and has to accompany him wherever he wants to go. This is why the family wants to buy a new wheelchair. But André’s chair is a PP, which was withdrawn from the French market after a series of accidents. So André cannot buy the same model and has to change brand. The test is long and very difficult. Benoît ends up advising the family to try one final repair and adaptation of the old wheelchair. Someone good at D.I.Y. can change the control, which would avoid the need to change the wheelchair. Then, during an ethnographical course with a distributor, I learn that the PP has been modified and it is now possible to buy one. When I return to the centre I pass this information on to Benoît, who has a think, hesitates, and finally says that it is preferable to leave things as they were decided at the end of the wheelchair test, repeating that “the perfect is the enemy of the good”. For André the *perfect* would have been to change chairs. A new wheelchair would be more reliable and safer than his old one, with recent electronics that are compatible with a wider range of controls. But this solution is the *perfect*. It does not take into account André’s history with *his* chair, nor that of the collective of which he is a part. The process of adjustment continues throughout the use of the chair. A rest is added, or a strap to hold the feet, and slowly the person and the chair get used to one another. The person is taking the shape of the wheelchair, adopting a given position because the chair holds him there, while the chair is taking the shape of the person (for example, the cushion keeps the shape of the sitting position). A new wheelchair of the same brand is anything but the same as the old one. Furthermore, there are complex relationships of dependency, interdependency and *attachment* between André, *his* chair and his mother. The *attachment* is physical and affective. It is impossible to change the chair as this could destroy the collective that is holding and shaping André. For André, it would mean risking losing everything, losing comfort and the (few) activities that are made possible by this collec-

tive. This *perfect* (a new chair) might prove to be a *worse*. However, for his mother, the current arrangement has become unbearable, she feels trapped. In this case, the *good* means only changing the control of the old chair, modifying one single link in order to try to extend possibilities for everyone, to alter their relationships in a tiny way by once again giving a possibility of movement to both André, and his mother who cannot stand it any longer. The *good* is not intended to “change all the (i.e. *their*) world”.

To care is to be sensitive to the attachments that support people, attachments which are sources of both constraints and opportunities, which are openings and closures. The *good* is always a relative good. It relates to a given situation. What suits people is negotiated within that situation (Pattaroni, 2005; Pols, 2004); the *good* is a compromise that combines comfort and discomfort, abilities and inabilities for each person in the collective. In Serge’s case, the *good* means alternating moments when he drives with moments when his girlfriend drives. The *good* reconciles his desire to drive with the recalcitrance (Latour, 2004) of his body, as demonstrated in the following quote:

Serge’s girlfriend: The problem, as I well know, is that he wants it so much that he makes a huge effort. He wants it so much ... and I’m worried that afterwards things will go wrong because the effort required is too much. With the head wand (*a curved stick fixed to the forehead to allow the person to drive the wheelchair*) it was the same thing, he managed to do it, but it required such an effort that he was exhausted, he couldn’t do anything afterwards. (...)

She then talks to Serge, who is trying to drive the chair: Don’t worry, stop trying, you’re getting tired and **it’s all your body that is annoying you and getting in the way**, we’ve seen that you’ve understood and that you can do it, don’t tire yourself out. [...] He’s tired now ... Stop contracting, stop trying, **your whole body has had enough, your whole body is tired and has given up** (*She presses against his stomach and tries to unbend his arms*).

The *good* is finding the arrangement that works; the *perfect* is an arrangement that is likely to break down, with the different components falling apart, because the perfect is what suits the individual alone and apart from the others –humans or non-humans. At the end of the day, the objective of good care, through gradual shaping, is to define the way in which humans and non-humans can work together, organise themselves and *live together*. The most suitable arrangement

is always a compromise, source of abilities and disabilities, source of movement for all concerned.

This arrangement, with differing degrees of duration and stability, is the permanent object of the collective's work of care. Care requires patience and time.¹³ It has a fastidious and routine aspect. When André sits in the new chair, he immediately calls his mother because he is scared of falling, and she asks him how she should position him. The father interjects: "Here we go again ... it's always the same, move this, move that ... it's always the same," and the mother, talking to us, says: "Every morning it's the same nightmare, it takes over half an hour." Then she turns to André, speaks to him, moves around him changing the position of each limb in turn. A person has to be installed in his/her chair every morning and all the adjustments have to be made, even though with the repetition of care a mutual understanding and complicity can develop. As Benoît says, the installation is always difficult, "it's a nightmare." After a while, "it's a bit easier, you know the position better."

Conclusion

The starting point of this article was the debate between Disability Studies researchers and the theorists of the ethics of care about the notion of *care*, with the former rejecting it and the latter defending it in order to construct an ethic. Whilst at first sight these two movements are in opposition to each other, they are based on an identical conception of care as a relationship of dependency between an active carer and a passive receiver of care. Analysis of the wheelchair tests opens up a different conception of care. In this case, care is a shared work, carried out jointly by the collective. It revolves around assembling and arranging the entities of a collective so that they fit together. To care is to tinker, i.e. to meticulously explore, "quibble," test, touch, adapt, adjust, pay attention to details and change them, until a suitable arrangement (material, emotional, relational) has been reached. The work of care involves a transformation of what these entities are, of their materiality and their sensations, of what they do and, above all, of the way in which they are linked to one another.

When looking at care practices, the theorists of the ethics of care demonstrate that people are defined through their relationships with others. They reveal not an autonomous individual, but a relational me, involved in relationships of dependency. We are all undoubtedly at the centre of a network of care relationships that supports us and

makes us who we are. The analysis of the wheelchair tests demonstrates the same thing. People are held and supported by their relationships with humans and non-humans. However, we hear Disability Studies researchers defending the notion of an autonomous subject. Indeed, whilst we are all part of networks of relationships, it is undeniable that some of these relationships are felt as relationships of dependency, whilst others are not. This difference must be taken into consideration and explained (Winance, 2007c). Analysis of the wheelchair tests offers certain elements of response, shifting the questions of in/dependence towards those of arrangement and movement. It suggests that through tinkering and adjustment, *care* involves *modulating* the relationship and balancing the positions of each member of the collective (simultaneously the subject and object of care). Modulating the relationship means determining the proximity or distance that separates or unites two people, distinguishing between the attachments, transforming dependencies, etc., so that people construct themselves in their relationships with other entities as people with given qualities, (in)abilities, dispositions, and, in one way or another, as people who are *independent*, who might move by themselves. In all four cases it can be seen that the purpose of the wheelchair tests and re-education practices is to define the way in which a person, by attaching him/herself to different devices, can separate him/herself from others. At the end of the day, the aim of care as shared work is to construct a person who is both *attached* and *detached*, “*dependent*” and “*independent*,” *moving on his/her own and being moved by others*. This question about the perceived nature of the attachment outlined in this paper will need more analysis.

Acknowledgments

I would like to thank J. Barbot, E. Fillion and A. Mol for their careful reading of this article and for their suggestions for improvements. I also thank Christopher Hinton for his help in translation.

Notes

¹ These works distinguish between different types of dependency: inevitable dependencies caused by disability, growing old or childhood, and avoidable dependencies resulting from social arrangements. (Feder Kittay & Feder, 2003).

² Certain authors combine the two approaches, in particular Hughes, Mckie, Hopkins, & Watson, 2005; Watson, Mckie, Hughes, Hopkins, & Gregory, 2004.

³ This test centre is one of just two that exist in France. Elsewhere wheelchair tests are done either in a re-education centre or at home – either by home help services who ask distributors to bring some chairs to test, or by the distributors themselves. Test practices are thus relatively unequal, depending on who is doing them and under what conditions. A test centre is an ideal place for observation, because the manager has acquired skills specific to the matter in hand. I nevertheless observed that other professionals possess the same skills. For example, I was able to observe one distributor and a regional department for aid and information - part of the French myopathy association – whose practices and skills proved to be similar to those of the test centre manager.

⁴ Here their descriptive work is very similar to a sociologist's work of description, as defined by the sociology of sciences and techniques (Akrich, 1992), with the difference that it is material.

⁵ The extent to which a wheelchair can be customised depends on the model and the price.

⁶ On the question of (in)abilities as performances emerging through a heterogeneous network, see also Moser, 1999; Moser & Law, 1998.

⁷ For an analysis of the performativity of approaches and their normalising effects, see Moser, 2000. On its historical and political aspect, see Winance, 2007a.

⁸ S. Kurzman (Kurzman, 2002) analyses the process through which an orthosis becomes something that makes one's body. More precisely, he focuses on the way in which patients and orthoprothesists develop a common language that allows them to understand how to align and adjust the orthosis to the body. He does a detailed analysis of the constant process of translating the sensations felt by the actors and the mobilisation of different norms of reference (subjective experience, "normal walking," biomechanics, etc.).

⁹ In other words, the process of adjustment shifts the separation between what is one's body and what is one's environment. It is a process of constitution, of *personalisation* (inasmuch as the wheelchair shapes the person, his/her qualities and (in)abilities), and not a process of familiarity (Thévenot, 1994) that leaves unchanged the distinction between what is/makes one's body and what is the world.

¹⁰ New possibilities of action go with new impossibilities. The wheelchair testing is a trial that forces people to make concessions, to evaluate what constraints they accept for regaining some freedom. About this process of concessions in the case of people with muscular dystrophy, see Callon and Rabeharisoa, 1998.

¹¹ Wheels with a small diameter make it easier for the person in the wheelchair to manoeuvre the chair, especially when turning around.

¹² Literally, this expression might be translated: “the perfect is the enemy of the good.” The dictionary’s translation will be “it’s better to let well alone”. This last translation does not exactly correspond to the French expression. It is why I keep the literal translation.

¹³ Care has different temporalities. Care is generally associated with the notion of a duration, but analysis of the wheelchair tests shows a more one-off aspect of care in the case of Benoît. I would like to thank Janine Barbot for drawing my attention to this point.

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