Dealing with In/dependence: Doctoring in Physical Rehabilitation Practice
Rita Struikamp, Annemarie Mol and Tsjalling Swierstra
Science Technology Human Values 2009; 34; 55 originally published online Feb 7, 2008;
DOI: 10.1177/0162243907312954

The online version of this article can be found at:
http://sth.sagepub.com/cgi/content/abstract/34/1/55
Dealing with In/dependence

Doctoring in Physical Rehabilitation Practice

Rita Struhkamp
Annemarie Mol
Tsjalling Swierstra
University of Twente, the Netherlands

By now, the laboratory tradition, crafting transportable knowledge that allows for comparison, has been amply studied. However, other knowledge traditions, notably that of the clinic, deserve further articulation. The authors contribute to this by unraveling some specificities of rehabilitation practice. How do laboratory and clinical traditions in rehabilitation relate to independence? The first seeks to quantify people’s independence; the latter attends to qualitatively different ways of being independent. While measuring independence is a matter of aggregating scores on a priori established dimensions, clinical rehabilitation concerns coordinating different ways of being independent. While independence scales map a linear development in time, rehabilitation participants juggle with time, including uncertain futures in their present. In clinical practice, then, independence is neither a single, coherent, fact nor a clear-cut, stable goal. Instead, professionals as well as patients work by creatively doctoring with the large variety of elements that are relevant to daily life with long-term disabilities.

Keywords: physical rehabilitation; clinical trials; independence; care; daily life

During the past thirty years, the practices of science have been opened up for study. By now, we know a lot about them. The fabrication of

Authors’ Note: We are grateful to all people with disabilities and professionals in the rehabilitation center who allowed one of us, Rita Struhkamp, to conduct the fieldwork that we draw on for this article. For their comments and/or encouragement, we would also like to thank Hans Achterhuis, John Law, Ant Lettinga, Petran Kockelkoren, Tiago Moreira, Jeannette Pols, Dirk Stemerding, Gerlinde Struhkamp, Lara Tauritz; the participants of the doctoral workshop Science, Medicine and Society in Paris in May 2001; the members of the Kolloquium Kultursoziologie at the University of Bielefeld; and the anonymous reviewers of this journal.
facts in laboratories has been described in detail. So, too, has the art of framing facts in such a way that they become transportable and comparable. Transportable so that what is asserted here can be mobilized as a fact elsewhere as well. And comparable so that once the facts about A and B are assembled, it can be established whether A is bigger, smaller, better, or worse than B, or vice versa. The requirement that they be transportable as well as comparable demands a lot from facts. They must be discrete and cast in terms that are unequivocal. This is possible only with the help of classification systems that differentiate in clear-cut ways between classes of entities, with measurement techniques that make it possible to evaluate signs and situations in a reproducible manner, and with modes of quantification and accounting that in close cooperation, turn differences into degrees (see Marks 1997; Timmermans and Berg 2003).

While all this has gradually been laid out, there has been a lot less attention to the ways in which knowledge works in situations that are complex, fuzzy, or both. There are, however, many of those. While a practice like that of writing scientific articles calls for the framing of transportable and comparable facts, neither transportability nor comparability is all that important in many other contexts. Not just those of bush hunters, smelling nondiscrete smells, hearing nondistinctive sounds, and otherwise using the nonverbal skills of their well-attuned bodies. Not just in premodern contexts. The practices in highly modern hospitals, equipped with fancy technology, where (at least so far) the task of helping a patient is more important than that of crafting facts, also depend on complex, fluid, and adaptable knowledge. While there are few terms to talk about this, the risk is that clinical work be termed an art.1 Where this happens, science and art are being opposed, and the first is either celebrated or criticized—while the second is deemed to be beyond words, so that nothing further can be said about it. Thus, it may be shielded from outside criticism. But it is also hard to defend.

In this article, we would like to contribute to the articulation of the fuzzy, complex, and adaptable style of knowing and acting that is crucial to clinical settings. For while it may well be that in the past, professionals have avoided such articulation to close their ranks, now this strategy is no longer working. The requirements of transportability and comparability are rapidly being imposed on clinical practices. The pressure is astounding. The clinical tradition is being squeezed by the laboratory tradition, and only the latter is ever called scientific. Finding words for clinical ways of knowing and acting is important—if only to be able to express what might be lost if it is discarded. But let us be clear: it is not our aim to defend the clinic in some frozen state, as if it were beyond doubt. Insofar as it can be saved, we would rather like to
contribute to its improvement. How might clinical ways of working be improved on their own terms? If we are to tackle that question, we need to find those terms. In this article, then, we will talk about clinical work by contrasting it with the laboratory tradition—while seeking the words to do so.²

Our case is that of rehabilitation programs for people with a physical disability.³ Rehabilitation programs seek to help people with disabilities to live their daily lives with an impaired body. Thus, curing a disease is not the issue. Instead, what is at stake is caring for a particular person with an impaired body interacting with particular surroundings. How can body and surroundings be attuned to each other in such a way that a person’s daily life becomes bearable—or even pleasant—despite an often seriously disturbing disability? To focus our analysis, we will concentrate on one of the more prominent ideals in rehabilitation programs: independence. What is independence? The laboratory tradition seeks to answer this question in a clear and distinct way so that it may operationalize and then measure “independence.” This should allow researchers to quantify how much independence a specific person has. More or less—that is the question. However, in the clinical tradition, independence appears to be a more intricate phenomenon. There are different kinds of independence, there is juggling between these, there are tensions, irreducibilities, and (often unpleasant) surprises. There is no single way forward, or backward for that matter. More or less is not all that important. Instead, in daily life with a disability, independence is something that is persistently tinkered with. To underline that we are dealing with clinical tinkering here, we call it “doctoring.” Doctoring, or so we will argue, is the mode of knowing and acting specific to the clinic.

**Independence Measured**

Let us start out by looking in some more detail at what independence comes to be in the laboratory tradition, that is to say, when it is being measured. Within physical rehabilitation, the independence strived after was by tradition of a physical kind. Can you move? Can you take care of your own body—eat, drink, dress, wash yourself? Cognition was included, too: can you talk to others in a comprehensible way? Can you remember what you need to? The people for whom rehabilitation centers were originally built were often partially paralyzed due to some form of neurological damage. They were soldiers wounded in combat and traffic victims. (Later, people who had suffered a cerebrovascular accident or who had multiple sclerosis were also admitted.) The damage done could not be reversed, but as bodies
are impressively adaptable, some of the skills these people had lost could be partially regained—if they were willing to put in a lot of effort and if a suitable treatment program was followed. Thus, people could become functionally independent again: able to function without too much help. The aim of the first training programs was invariably to treat basic skills such as eating, drinking, dressing, and grooming. People also learned to walk again or to move about in a wheelchair.

Most people in rehabilitation centers manage to regain some of the skills that were ever so ordinary to them before their bodies got damaged, but few are entirely successful. To gain a better insight into the extent of people’s impairments, rehabilitation centers started to list and lay out systematically what would otherwise have been scribbled down in a person’s file in no particular order. Assessments were designed. As an example, we present you here the instrument most widely used in North America (and, in translation, also in the Netherlands): the FIM™ instrument, used to measure functional independence (see Figure 1).

The FIM™ instrument allows a professional to register a person’s level of functional independence in eighteen performance categories. These are clustered in five areas: self-care, sphincter control, transfers, locomotion, and communication and social cognition. Behind each of the eighteen categories there are three boxes for noting the results at three moments of assessment. Thus, a linear time line is set up. It allows for a comparison of this person’s situation on admission, as and when discharge is due, and after a few months, when this person comes back to the center for follow-up. In the boxes, numbers are to be written. These numbers indicate the level of functioning for that particular skill. What these levels represent is printed on every single form so that there is no misunderstanding about it. Of course, a certain fluidity seeps in here—does this person’s “bladder management” require minimal assistance (which is the case when he or she is able to personally take on 75 percent or more of the task) or should it be scaled as requiring moderate assistance (the person does more than 50 percent of the task but less than 75 percent)? Distinctions such as this are not always as clear-cut as hoped for. However, overall, give and take a few points, the seven-level ordinal scale makes it possible to fairly consistently evaluate a person’s functional independence. FIM™ ratings range from a maximum of 126 points (complete independence) to a minimum of 18 (dependence in all areas evaluated). What results is an impression of the amount of care a person is going to need. First in the center, how much is there to rehabilitate, what seems feasible, and what seems out of the question? And then, at the time of discharge, the FIM™ instrument helps to see if the
Source: FIM™ is a trademark of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.
person will need to go into residential care or may be able live at home and, if so, what additional support might be needed. The second kind of comparison that the form helps to make is that between one person and his or her needs for care and another. Or as it is put in the publication from which we copied the form, “The FIM, for instance, predicts the approximate help in minutes per day that a person with a certain level of disability needs. It is a valid measure of physical assistance or substituted effort from one person to another” (Granger et al. 1996, 244).

The FIM™ instrument was designed as a tool to be used in the hospital. It helps to quantify functional independence, however difficult that may be, to facilitate comparability: comparability between one moment in a person’s rehabilitation trajectory and another, and comparability between the situations of different people in need. Currently, however, this scale is used for a third kind of comparability as well: comparability between treatments. To compare treatment programs, people’s results of FIM™ ratings are aggregated. The ratings of one person are added to those of another on the same treatment program. In the process, the ratings change from being information about a person to being information about the program in which that person is enrolled. Aggregates of FIM™ ratings are thus used as outcome indicators in research into the effectiveness and the efficiency of rehabilitation programs. Such research is meant to make rehabilitation evidence based, and the FIM™ instrument is made crucial to what counts as evidence. If one treatment program leads to a higher overall aggregated rating on the FIM™ instrument, it is more effective than the next. As Granger and his colleagues (1996) put it, “Improved FIM ratings indicate decreased support time and it follows that they have a relationship to the cost-effectiveness of the treatment program” (p. 244).

There is considerable criticism in the field on the use of independence scales such as the FIM™ instrument for program evaluation. The critics say that functional independence may well indicate the extent of a person’s dependence on others but say very little about the extent to which the person has a meaningful life after his or her rehabilitation. In response to such criticism, most program evaluations include what they call emotional, social, or vocational functioning in their studies. However, instruments that allow for the assessment of emotional, social, and vocational functioning are much less developed, and especially so for the people who happen to be the target groups of rehabilitation. So despite their limitations, measurement scales of functional independence such as the FIM™ instrument are ubiquitous in rehabilitation assessment. They have become the key instruments with which to measure disability and monitor progress, facilitate communication
between professionals about particular patients, establish the effectiveness of treatment programs, and make comparisons between these.

**More Help or Which Help**

Let us now move to the clinic. We move, more particularly, to a neurological ward for people with either spinal cord injuries or multiple sclerosis and to various homes of people who have been discharged from this ward.\(^8\) These are sites where fuzziness is prominent and where it is important to deal with complex situations—not to reduce them to a score so as to know about them but to deal with them so as to make daily life worth living. What immediately becomes apparent in clinical situations is that quantifying the degree of a person’s independence does not help very much when it comes to dealing with in/dependence on a daily basis. On the FIM\(^{TM}\) instrument, there is only one dimension: more or less. The highest score is for a person able to perform activities without using technology and without assistance of someone else. It gets lower if a person needs, first, a technical device and, then, the assistance of other people. From total independence, the score goes all the way “down” to total dependence. However, in the daily lives of people with disabilities, there are more relevant dimensions.

Mr. Smith’s spinal cord was injured in a traffic accident a couple of years ago. He is wheelchair dependent and was discharged from the rehabilitation centre to return home, where he lives with his wife. Even though he is, and will stay, dependent on a wheelchair for moving from one place to another, Mr. Smith engages in walking exercises three times a week. If a so-called walkabout, a special kind of corset, fixes his paralyzed legs, he is able to walk from the bedroom to the living room and back. Mr. Smith: “I put on the walkabout myself, though it takes me a lot of effort. I call my wife to help me raise myself, but then I carry on alone. I walk all by myself. But I don’t want her to go too far away, I mean, just in case. I may always get spasms. So I like her to be around. Last week I did my walking while she was working in the front garden. She left the door open and she left the bathroom window open, so she could hear me. That was okay.”

Walking with disabled legs is tough, and Mr. Smith needs both a clever technological device and the assistance of his wife to be able to do so. But what kind of assistance does he need from his wife? Mrs. Smith gives him a lift up when he wants to get from a sitting to a standing position. And she is around. If one were to look at her, one might think, There’s Mrs. Smith; she’s working
in the garden. She does not support her husband with each step; he struggles with this for himself. Yet without her being around, Mr. Smith would not dare to do his walking exercises. Thus, he is dependent on her—to be able to walk—indeedently. This situation does not easily fit on a scale of more or less dependence, but that is not an issue for, understandably, Mr. Smith is not interested in comparison but in walking. He wants to keep his muscles exercised. And what matters to him in that context is not whether he needs help from his wife but what kind of help he needs. Giving a lift up and being around is a lot easier for Mrs. Smith to do and sustain three times a week than engaging in slow, painstaking, step-by-step assistance.

Rehabilitation researchers are not interested in what exactly carers do. They think it is fine to exclude such information from their assessments, for they deem it to be of secondary relevance only: “From the point of view of the carers, the main consideration is whether or not the patient needs any help; the precise nature of that help is often of secondary nature” (Wade 1997, 152). This, however, is not at all the “point of view of carers” that we came across in our fieldwork. Instead, professionals, home-carers, and patients put a lot of effort into talking about and experimenting with the details of the assistance—of devices and of people—that might work best. They were interested in not so much whether a person needs help but what kind of help exactly.

A physiotherapist: “We go into each aspect of an activity. How exactly is it done? What do you need to get it realized? If you want to walk, but you can’t put on the walkabout, it’s useless to try that. So you look for something else.”

People may walk in different ways, and assistance with this may take a variety of forms. Dependence is accepted as a matter of course in disabled living: the issue is to experiment with different modes of dependence that produce different types of independence.9 This is a qualitative rather than a quantitative matter.

Giving or asking for one kind of personal assistance is utterly different from giving or asking for another: being around is relatively easy to do, while giving step-by-step support to someone who can barely walk is a lot harder. Dependence on people comes in utterly different ways. The same is true for technological devices. They tend to give you not more or less of the same thing but different things. They do not allow for more or less dependence but make one kind of in/dependence or another.

Petra Brand usually sits in an electric wheelchair, but now she enters the physiotherapist’s room in a hand-pushed wheelchair. Carefully, she tries to
negotiate a bend. It takes her a lot of effort to push the left wheel while the right one is standing almost still. While she leans forward with her shoulders and trunk to increase the power in her arm, her left hand almost gets stuck between the door and the wheelchair. In her manual chair, Petra has difficulties getting over thresholds or doorsills, even small ones. Thus, when she has finally arrived, she is exhausted: “It took me almost ten minutes to move down from the ward to the physiotherapy gym. It’s exhausting and my shoulders hurt. With my electric wheelchair, it takes just a few minutes.” But in spite of pain and exhaustion, Petra seems happy: “It’s strange, but I feel less disabled in the manual wheelchair. An electric chair looks so . . . bad. It’s big and clumsy. When I’m having dinner with my family, for example, it makes me sit at a distance, a bit separated.”

In one way or another, Petra Brand needs a wheelchair for moving around. But there are important differences between “one way” and “another.” Her electric chair allows Petra to negotiate doorsills, rough terrain, and long distances without too much pain and exhaustion. But it is awkward in social interaction and makes her feel more disabled. It may get her far into town, but it limits her in the living room. In the living room, then, a manual chair is the better tool. It allows one to sit as close to the dinner table as the rest of the family. And while it is hard to move around in, it is also gratifying. So the question is not which chair helps Petra Brand most. Each chair has its own drawbacks and advantages, and the added value of these differs from one situation to another.10

For people with a disability, the relevant question is rarely whether they need technical assistance. Whether you want it or not, you find yourself dependent on a wheelchair—or some other technical device.11 That is an irreducible fact. The crucial questions are, On which technical aid do you depend? Which one might be best for you? and What are their relative merits? Which activities will different devices help you to engage in and how will they do so, in which way, at what costs? Techniques tend to have a variety of consequences for the people using them: they interfere with people’s bodies and their social relations, they allow for some practical possibilities and not others, they interfere with one’s self-image, and finally, they cause the kind of problems (like pain and sores) that medicine tends to call “side effects.” Nothing is going to be perfect. So in the clinic, the question rarely is, Does this person need help or not? Instead, it is to figure out what, in practice, all things considered, might work best in a person’s specific situation. That is crucial to doctoring: the clinical way of working in situations that are not about more or less but about one thing or the other.
More Independent or Which Independence

Independence does not depend on a single skill but on a wide range of them. This is why the FIM™ instrument presents a list with no less than eighteen performance categories. All of these are scored separately. For your ability to transfer yourself from bed to wheelchair may well be worth a score of 5, while your problem-solving capabilities have gone down to 3. And so on. As measurement instruments go, the FIM™ instrument does not present a simple world but one in which eighteen categories are each scored on a 7-point scale. This allows for a differentiation between a great many “independence profiles.” Yet the independence this measurement instrument comes to assess is far simpler than the independence relevant to clinical practice. The reason for this is that the instrument defines all “core aspects” of independence a priori and then adds up the results in a linear scale. In clinical practice, by contrast, one person is not just more or less in/dependent than another. People are in/dependent in quite different ways.

After almost ten months of rehabilitation at the spinal cord unit (a unit for people with spinal cord injuries, mostly due to traffic accidents) Mrs. Van Dijk will return home, where she lives with her husband. She has been trained to groom and dress herself, and to transfer herself from a bed to a wheelchair without any help. She also plans to take up such household tasks as ironing, dusting, and preparing meals again. Mr. Van Dijk will not be obliged to do everything even if, according to Mrs. Van Dijk, he will certainly help where he can. He takes care of her devotedly. What Mr. Van Dijk has always done is managing the administrative affairs of their household. Extending that task, he now also organizes everything to do with his wife’s care: appointments and arrangements with care providers as well as phone calls with the insurance company, the wheelchair service, or other health-related institutions. Mrs. Van Dijk: “My husband is very good at that, he knows all the names of the people there and he can be very persistent.”

While Mrs. Van Dijk has put a lot of effort into learning to put on her own shoes again, she would not be able to fill in forms, make applications for refunds, or negotiate with wheelchair companies. This does not bother her in the least. It has never been her business to do such things, and unless something happens to her husband, it is unlikely to be so in the future. For other people, this is different. This should not surprise us: people tend to find some parts of their daily life more important than others, and this does not alter overnight when one gets a disease or has an accident. Unlike Mrs. Van Dijk, many do not care about ironing and dusting but definitely want to do
the management of their own lives. That “functional independence” is primarily defined in terms of bodily self-care, then, gives rise to criticism. Maybe measurement instruments should incorporate other priorities: “If a person can get dressed in 15 minutes with human assistance and then be off for a day of work, that person is more independent than the person who takes 2 hours to dress and remains homebound” (DeJong 1979, 444). But what is going on here? The priorities incorporated in measurement scales might indeed be shifted. Instead of privileging functional independence of a bodily kind, they might give more weight to social and economic independence. But it is also possible to say that here we hit on the limits of all quantification. Neither bodily self-care nor working is necessarily a true marker of “real” independence, of a larger quantity of it. Instead, independence may well differ not only in degree but also in kind.

In rehabilitation practice, this was realized a long time ago. Instead of striving after as much independence as possible, participants seek to find out which independence might best suit the situation of a specific person. As rehabilitation practitioners Barnes and Ward (2000) claimed, “It may be better for a young man to have a goal of opening a can of lager rather than making a cup of tea!” (p. 9). In practice, then, priorities are set. For even if someone might like to engage in all activities of daily life independently again, this is unlikely to be realistic. You have to learn to concentrate on doing one thing while letting go of another since you simply cannot do it all. Most disabled people cannot begin to dream about dressing in the morning, to go on to work after that, shop for groceries, and finally take care of their children. They are worn out after one of these activities; doing them all is out of the question. People who try even so overburden themselves and end up lying in bed for days afterward, unable to do anything at all. In living with a disability, “more” is not always “better.” While in measuring independence it makes sense to aggregate different abilities to the highest possible outcome, in daily life, aggregating the actual tasks (while doing them independently) may soon lead to collapse, and thus to total dependence.

To avoid collapse, people have to learn to compromise. To do what is most important, postpone what can wait, and let go what after all is not that crucial. To juggle between this, that, and the other. To work out what works best while accepting that sooner or later one inevitably fails and may only hope to learn from that. None of this is easy. And the most frustrating bit is that different aspects of independent living often clash.

Mr. Emerson arrives for an outpatient treatment of Marc Jansen, the occupational therapist of the neurology unit of the rehabilitation centre. Recently, he
went through a period of exacerbation of his multiple sclerosis: he was able to walk in the past, but now he needs a wheelchair to cover greater distances. He is still able to drive, but has difficulties lifting the wheelchair into his car. Marc Jansen gives some instructions about folding and lifting a wheelchair, and Mr. Emerson pushes a couple of buttons, folds the chair, and lifts the heavy wheels onto a table. When Mr. Emerson grows noticeably tired, Marc fetches a chair and Mr. Emerson is relieved to be able to sit down. Marc seems concerned: “You’re quickly exhausted and lifting this heavy stuff is very bad for your back.” Recently, Mr. Emerson has complained about back pain, and Marc says, “A good lifting technique is really important and you may put a small stool in the back of your car, which you can use when you are exhausted.” Mr. Emerson looks worried: “You know, this pain in my back will yet stop me from doing anything at all.”

Mr. Emerson lives alone. So far, he is able to independently engage in the necessary activities of daily life. Setting his own pace, he does the laundry, the shopping, and all the other tasks in his household. These jobs are tiring, but the more nagging problem is that when his back aches, he cannot do them at all. To spare his back, he should avoid lifting his wheelchair into his car. But he wants to drive so as to go out and meet other people. Housekeeping and driving clash, but Mr. Emerson is not prepared to easily give up on either. He tries to do both. The occupational therapist helps by giving instructions about lifting the wheelchair in a way that spares the back. He wonders about techniques that might give additional support and encourages Mr. Emerson to ask his physiotherapist about back-strengthening exercises.

Measurement instruments offer a comprehensive assessment of predefined activities. They assess each activity for everybody in the same way and, having mapped them on a single dimension, add the results together. Clinical practice, by contrast, does not aggregate but coordinates. How to best attune the various and varied activities relevant to daily life to each other? This is partly a matter of seeking the right tools and of adapting them to a person’s specific situation. It is partly a matter of finding out which are the more relevant activities to train. But the most challenging part of coordinating different ways of being independent is reconciling conflicting activities with one another—or setting up a priority between them. In the clinic, then, the aim of professionals and patients is not that the latter accumulates the ability to engage in as many predefined activities as possible. Rather, disabled people and professionals experimentally seek to fine-tune and balance various in/dependences in such a way that daily life becomes as good as it can be. Thus, clinical work is a matter of juggling between different kinds of in/dependence. Professionals, patients, and their carers all engage in this, yet
because of the fuzziness involved and the juggling nature of what is being done, we call it “doctoring.”

**Time Lines or Time Folds**

While the laboratory strives after metric knowledge, the clinic seeks to handle complex situations. Another crucial element to that difference is their respective configuration of time. Measurement techniques like the FIM™ instrument are used to monitor the development of a person’s functioning. The form is filled in at subsequent moments during a patient’s trajectory: at admission, at discharge, and after some months of follow-up. Thus, a time line is brought into play. Then and now. Now and later. On this time line, improvement and deterioration of a person’s condition may be mapped. This can be useful in a hospital for it creates an overview: an overall impression of where things are going. The use of the FIM™ instrument as “evidence” of the effectiveness (or lack thereof) of treatment programs depends on this linearity, for effectiveness is defined as improvement in the course of a given time.

But in clinical practice, when it comes to handling life with a disability, time is not linear at all.¹⁴ Things do not necessarily move in a single direction, since improvements and deteriorations are often intertwined.

Hans Faber is in his forties and lives with his wife and their 14-year-old daughter. His spinal cord was injured in a traffic accident many years ago and he is paralyzed from his stomach downwards. In the years following his spinal cord injury, the symptoms most annoying and difficult to handle were the spasms he had in his limbs. He recounts, “I used to lie in bed or take a shower and then—wham!—my legs would fly into the air. I had to strap them to the wheelchair, for it also happened at work. I would be helping a customer and suddenly my legs would just shoot up without warning. That was just so awkward. And to safely drive a car, I had to strap my legs as well.” The spasms decreased when, four years ago, Hans had a small pump implanted in his body that slowly releases medication. His muscles became weak. This made life less eventful in a welcome way. However, recently Hans has developed pressure sores. He had to be admitted to the spinal cord unit. There he tells about the possible cause of the breakdown of his skin: “I never had that before. It’s likely to be related to this pump, to the medication. The doctor I see here says that it’s good to have some spasms, because if your muscle tone falls away, your blood circulation gets bad. This increases the risk of sores. And since I got the pump, my muscles have no tone.”
Hans Faber’s spasms were awkward in working, dangerous in driving, and unpleasant when he was taking a shower. To be rid of them was an improvement. But it led to weak muscles, diminished blood flow, and a fragile skin. Pressure sores do not easily heal, and Hans Faber ended up in the hospital. There, he has to have operations and weeks of bed rest. That clearly is a deterioration. Earlier, we saw that different elements of daily life with a disability may clash. The extra complication in Hans Faber’s case is that they do not clash at one particular moment. Instead, something that is good at one point turns out to be bad later on. How to deal with such complexity? In this particular case, the dose of Hans Faber’s medication was brought down, and he got back some of his spasms. He had to fasten his legs again, but as he kept some medication, the movements were not so violent as before. He also learned to do exercises to actively contract and then relax his muscles. As his muscles became more active, the blood flow to his skin also improved. The hope was that, thus, further pressure sores would stay away. A compromise was crafted.

A compromise was crafted for the moment. What this particular course of action will lead to—for better and worse—cannot be predicted. And that is an irreducible difficulty of coordinating conflicting activities over different moments in time: problems later on may occur, but then again, they may not. You do not know, you cannot tell. There are often good reasons to do things in the present, not particularly to improve your present situation but to make life easier at some later moment. Thus, it often makes sense to fold the future into the now, to make it relevant to what you do. But how much sense this makes is necessarily uncertain. Thus, you may spend a lot of energy on your exercises, but if you then indeed do not develop sores, you cannot be sure whether this is due to your exercises. Maybe you would also have been fine if you had never bothered. You do not know. For researchers, it may be possible to investigate the effects of such activities as training on large numbers of patients. Thus, the past of some people (those who contributed to the research) can be used as a promised future for others (those who have to shape their treatments now). But for everyone in a clinical situation, the odds are just odds. Individually, you never know what does it. And if somehow you get into trouble, you may always reconstruct this as the result of mistakes (your own, those of your caretakers) in the past. Or not.

The uncertainties involved make tinkering with and balancing of potential events even more difficult than immediate ones.

Mrs. Breeveld has been wheelchair dependent for more than ten years, but the last couple of years the severe pain in her lower back has been particularly
disabling. Mrs. Breeveld: “I would like to go out more often and do more. But I can’t if I’m in too much pain. Sometimes I’m in so much pain that I need help with getting dressed, but usually I manage.” When asked what she does to relieve the pain, she says, “I’ve got medication, but it has all these side effects and I keep on needing higher doses. So I try to change positions as often as I can. I sit in my wheelchair for a while and when that hurts too much I go and lie down, or move to an easy chair with cushions in my back.” “Do you move yourself from the wheelchair to the chair?” “Yes. But each transfer is hard. I’ve just had surgery in my right wrist. And maybe I should spare my arms, because since I can’t use my legs, I use my arms a lot. The transfers overtaxes my arms, it does them no good. But what can I do? It’s not great to stay endlessly in my wheelchair either.”

Nobody can predict how bad it is for Mrs. Breeveld to use her arms to move from chair to bed and back again. May that prevent her from using them at all in a few years, months even? Might skipping one transfer each day make a difference to her arms? Nobody knows for sure. And in a case like this, it is not even possible for researchers to figure out the odds. Mrs. Breeveld does not belong to a large enough population of people similarly troubled, and the specificities of her situation are quite idiosyncratic. What is more, a controlled intervention is all but impossible to design. Nor might it be easily implemented: if it hurts Mrs. Breeveld so much to stay in her wheelchair all day, then why would she be prepared to do so for weeks on end for the benefit of some research project? There is no recourse to certainty or to the promise thereof. The balancing acts of the clinic involve a lot of unknowns. And not only are the facts blanks; the values of various courses of action cannot be meaningfully compared either. What is worse, pain in your back or the risk that soon you will be hardly able to use your arms? Put like that, the question makes little sense.16

You do one thing, not the other. But you cannot decide what to do in a calculating way.17 For however much you want to take the future into account, you cannot count on it. The future enters into the clinical present in fuzzy mode. It may be called a risk, but it is not amenable to “risk assessment.” Thus, instead of taming the future by making calculations, rehabilitation practitioners “doctor.” They experiment each day again while drawing on past experiences. Professionals mobilize what they have learned from the experiences of other patients (whom they worked with earlier or about whom they have been reading). Thus, a physical therapist may train Mrs. Breeveld to use transfer techniques that are likely to be the least damaging for her arms, all the while attentive to early signs of physical strain and prepared to adapt the technique if need be. But Mrs. Breeveld, like most people
concerned, also keeps on experimenting: she is attentive to what happens to her pain if she stays in her wheelchair and what if she stays in bed (even if that is boring). She tries to find positions that reduce the pain, and she seeks activities that she can do despite it. Thus, the clinical work of doctoring does not live toward a far-away future that will unfold in a linear way. Instead, it folds the future’s presently relevant uncertainties into the now. Another source of fuzziness, adding complexity to what needs to be doctored with.

Conclusions

Used as one technique among others, the FIM™ instrument may serve clinical work. It allows professionals to gain a quick overview of the outlines of the condition of a particular person compared to others or compared to that same person’s condition a few weeks or months earlier. How much rehabilitation, or support in daily life back home, will this person need overall? Has, overall, this person’s independence improved or deteriorated? The FIM™ ratings are helpful in staff meetings; they help professionals to communicate about the allocation of treatment. However, hands-on work in the clinic, where the treatment is actually done, involves a lot more. Let us summarize how “independence” differs between the laboratory tradition and the clinical tradition.

First, outcome scales give a quantitative, one-dimensional assessment of independence. That fits their primary aim. They were made to get some indication of the amount of care a disabled person might require; the nature of this care was to be further established in the course of providing care. It was no part of the assessment. In clinical rehabilitation, by contrast, the nature of the care people need is more important than its quantity. Rehabilitation professionals, people with disabilities, and their carers at home have to deal with qualitatively different chains of in/dependency. By training, they seek to adapt a person’s disabled body to some tasks of daily life. They also try to find a technology that might best suit a specific person’s (bodily as well as social) situation. A lot depends on the carers, who may be willing and able (or not) to carry tools, give a hand, make phone calls, and so on. Gradually, a specific configuration of dependences and independences emerges from the network (of techniques, skills, bodies) that ensues. Thus, whereas independence measures assess whether a person is dependent, rehabilitation participants face the question of how this dependence may be doctored with.

Second, in measurement scales, independence is measured in a priori established dimensions. Equal weight is attached to all the dimensions. In the
FIM™ instrument, the subscores of the eighteen categories are measured and aggregated to a sum total. In clinical practice, by contrast, the various ways in which a person is in/dependent are not added up but coordinated in some other way. In each specific person’s case, different modes of in/dependence are differently attended to. Some are left aside as not particularly relevant; others get a lot of attention. Since it tends to be impossible to work on all aspects of independence, rehabilitation professionals welcome personal preferences when it comes to establishing workable goals. But this does not mean such preferences rule: in practice, different modes of independent living often clash. Dressing in the morning may be so exhausting that it takes up the energy one might have used to work. Seeking to drive may reduce a person’s ability to do household tasks. In such situations, one cannot have it all, and one mode of independence is privileged over the other, or alternatively, some compromise is crafted. Overall, the point is not to strive after a maximum sum total on the scale as a whole. Instead, professionals and disabled people seek to establish and secure a few kinds of independence, carefully adjusted to the disabled person’s specific situation. What matters most is daily life.

Third, outcome scales monitor the linear development of a person’s independence by comparing overall scores at different points in time. By contrast, in rehabilitation practice, time does not present itself in a linear manner. Instead, it folds. What happened earlier remains relevant later on. Interventions done a while ago, to improve some aspect of one’s life relevant at that moment, may have unexpected effects in the present. They may now rob people of most of their hard-gained independences. Thus, possible future effects of what is undertaken at present have somehow to be included in what one does or tries to do right now. But since these “future effects” are uncertain, the best way to handle them is not calculation. Instead, tensions between what is relevant for the present and what might become important later on are handled experimentally. Drawing on personal and other people’s experiences, they are doctored with. In this, no solution is for once and all: times keep on changing.

The FIM™ instrument and other independence measures were designed to serve clinical practice, and as long as they are just one of the instruments professionals draw on, they may indeed be useful tools. However, if in evaluation studies they must give an indication of the contributions of a rehabilitation program to a person’s independence in day-to-day life, then they are of limited value. And furthermore, if they are used in effectiveness research to provide evidence for or against a treatment program, things may get out of hand, for these tools fail to pick up clinical specificity. Good clinical work attunes to the complex particularities of a specific patient in his...
or her specific circumstances. Doctoring does not meet needs that may be accurately defined (to then be counted, one style fits all, the more the better) but attunes to each person’s particular preferences and needs. It does not seek total control, for that simply cannot be achieved. Instead, it creatively deals with insecurities. To many, the term “doctoring” does not sound too good. Here, we wanted to show that the fuzziness and complexity inherent in it do not imply that bad things are being done. Doctoring fits the situation in the clinic and that of the people who come there to seek help.

In actual practice, not all clinical work lives up to what one might hope for. It is by no means perfect, and it has its own problems, many in kind. There are mistakes and faults and failures. There are irreducible difficulties and others that deserve to be tackled. But while “evidence-based practice” is presented as a way to improve the clinic, it does not work out that way. Laboratory-type knowledge about the effects of well-delineated interventions on well-determined parameters may be a useful resource for making decisions about the interventions concerned. But in the practice of rehabilitation, “well-delineated” and “well-determined” imply, as the case of the FIM™ instrument illustrates, gross reductions of what is relevant to clinical practice and to daily life with a disability. Thus, imposing the standards of the laboratory on clinical work as a whole is a tragic mistake. For if doctoring is assessed with quantitative, one-dimensional, linear scales, something is missed. And if the outcomes of the assessments are taken to be evidence and become policy instruments, the creativity of clinical work not only will be misjudged but also risks being eroded.

Notes

1. In the medical field, a difference between “science” and “art” is evoked time and again (see Schlich 2007). The terminology of “laboratory” and “clinic” that we mobilize here builds on Canguilhem ([1963] 1989). Presently, laboratories are no longer confined within walls: health care is becoming one big virtual laboratory (see also Latour 1988). The role of industry is crucial to that; here we leave out this further complication, but see Healy (2002) and Sunder Rajan (2006). For the fuzziness of “the lab” itself, see Singleton and Michael (1993). And for studying fuzziness and complexities see Law (2004).


3. The examples that we mobilize come from an ethnographic study done in a rehabilitation center for people with severe physical disabilities done by Rita Struhkamp. Between 2000 and
2003, Struhkamp observed the daily routines on a neurological ward for people with spinal cord injuries or multiple sclerosis and held interviews with professionals and disabled people, some of whom she later visited in their own home environments. The original field notes and interviews were all in Dutch and have here been translated and adapted to a written format. All names are fictitious. First and last names are used according to the customs on the ward.

4. The FIM™ instrument is a more elaborate version of one of the oldest ratings for functional independence, the Barthel Index, which measures performance ability in mobility, self-care, and continence (Mahony and Barthel 1965). Both the Barthel Index and the FIM™ instrument have well-established psychometric qualities, such as reliability, validity, and precision (Kelly-Hayes 1996). However, these assessment tools have more problems than we can attend to here. For example, the Barthel Index measures muscle strength, which creates tensions when it is used to evaluate treatment programs that seek to avoid spasms (Lettinga and Mol 1999).

5. For discussion within the field, see Wade (1997) and Christiansen and Ottenbacher (1998). For recent examples of effectiveness studies in neurological rehabilitation, see Patti et al. (2003) and Macciocchi et al. (2004). For examples of recent program evaluations in rehabilitation, see Cifu et al. (2003) and Chen et al. (2002).

6. Most rehabilitation scholars refer to the International Classification of Functioning, Disability and Health (World Health Organization 2001) as the conceptual basis of rehabilitation assessment. The International Classification of Functioning, Disability and Health seeks to classify problems at the level of activities and participation rather than at the level of bodily functions and structures. See, for comments, Van Dijk (2001). For an analysis of disease classifications, see Bowker and Star (1999).

7. This kind of comment is, in critical mode, also found in the literature of the field itself. The main point of the criticism is that the repertoire of behaviors required to lead a meaningful life differs substantively from the “functional independence” measured by the scales used (Keith and Lipsey 1993).

8. While “the laboratory” is not confined to actual labs, “the clinic” does not stay within the walls of the hospital. A lot of “clinical work” is done in ordinary homes by patients or disabled people and their carers (see Willems 2000).

9. For coexisting enactments of disease, see also Mol (2002). For the coexistence of different modes of giving birth, see Akrich and Pasveer (2000), and for intertwined as well as diverging “blood pressures” during a brain operation, see Moreira (2006).

10. For the details of the mutual adaptation between person and wheelchair see Winance (2006).

11. Not only people with disabilities rely on technology in day-to-day living; everyone does. As Donna Haraway (1991) famously stated, “We’re all cyborgs!” But we are cyborgs differently; see also the analysis of what speaking aids make im/possible for people with speech disabilities (Moser and Law 2003).

12. For the ways in which rehabilitation teams try to tailor rehabilitation programs toward individual preferences, see Struhkamp (2004). For an example of failed coordination in the case of alcoholic liver disease, see Law and Singleton (2003).

13. Living with disability or disease usually entails juggling with limited energy (Charmaz 1991).

14. For nonlinear time in clinical practice, see Moreira (2004).

15. Uncertainty and risk are often discussed in the context of prevention and genetics (see, e.g., Nelis 2000). However, genetics may not be so exceptional: juggling with uncertain futures is a part of living with most chronic diseases.
16. For the difficulties that come with balancing incomparable entities in living with a disability, see Struhkamp (2005).

17. This rhymes with ways in which pregnant women who have to decide about prenatal testing rather than calculating probabilities and risks draw on a range of moral and social experiences (Rapp 1998).

References


**Rita Struhkamp** received her PhD at the University of Twente, the Netherlands, with her thesis “Dealing with Disability: Inquiries into a Clinical Craft.” She has published in various journals, among which are *Cultural Studies, Health Care Analysis*, and *Medicine, Health Care and Philosophy*. She now works at the Department of Research Policy at Erasmus Medical Center, University Medical Center Rotterdam, the Netherlands.

**Annemarie Mol** is a Socrates Professor of Political Philosophy at the University of Twente as well as a senior research fellow. Her current project is Good Food, Good Information (paid for by the Netherlands Organization of Scientific Research). She coedited, with John Law, *Complexities: Social Studies of Knowledge Practices* (2002, Duke University Press) and published *The Body Multiple: Ontology in Medical Practice* (2003, Duke University Press), *De logica van het zorgen* (2006, Van Gennep), and many articles.

**Tsjalling Swierstra** works as an associate professor in the philosophy department of the University of Twente, the Netherlands. He has published articles and books on the ethics of new and emerging science and technologies. He is currently working on a book about medical (bio)technology and moral change.