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Submitted on 9 Nov 2005

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Biographical work and returning to employment following a spinal cord injury

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Abstract

The question of returning to work after the onset of severe impairment is inseparable from the biographical work that disabled people need to achieve. Qualitative analysis of interviews I carried out among people who had become paraplegic and among rehabilitation professionals offered the following insights:
- During a period extending beyond rehabilitation, interviewees were absorbed by the work of coming to terms with their impairment and delegated the question of occupation to the professionals. At a later date, some of them manage to recast their biographies and gain ownership of their occupations and activities for themselves. An open environment, which offers negotiable opportunities and space for relationships to form, encourages the development of biographical work.
- Nowadays, the question of exclusion would appear to dominate the domain of rehabilitation. The belief that prolonged inactivity engenders marginalisation has led professionals to develop a doctrine whereby they encourage their patients to plan for their professional activities from a very early stage. Struggling with different time demands (for example, lengthy administrative procedures, reduced rehabilitation time) professionals organise their work around a new time frame which conflicts with their expertise and is difficult to reconcile with the trajectories of disabled people.

Keywords: disability, rehabilitation, return to work, biographical work.

Introduction

The employment of disabled people is an important issue facing contemporary societies. This can be demonstrated by the fact that many
national governments have made recommendations and introduced legislation designed to encourage recruitment of the disabled workforce.

Yet affirmative action programmes are not sufficient to promote the employment of people living with severe motor impairments, most of whom remain on the fringes of the labour market. For example, studies carried out in different countries show an employment level of approximately 30% for people with spinal cord injuries (Athanassou et al. 1996, Conroy and McKenna 1998, Krause et al. 1999, Berkowitz et al. 1998, Tomassen et al., 2000). In France, a recent survey found a 20% employment level among people with tetraplegia of traumatic origin (Ravaud 2001).

While there are many studies seeking to answer the question of ‘why’ employment levels are low within this sector of society, there is a lack of studies that, in the domain of the employment of persons with motor impairments, examine the experiences of these people as players in their own lives, asking the question of ‘how’: how do disabled people deal with various structural and personal factors in order to manage their employment?

Medical sociology has widely examined the subjective and social experience of chronic illness. Numerous studies have shown that, far from confining themselves to the “sick role” described by Parsons (1951), people with chronic conditions actively negotiate their roles when interacting with healthcare professionals, manage illness and stigma in everyday life, try to regain continuity in their disrupted lives and sometimes become innovators by building new meanings and values (among others: Strauss and Glaser 1975, Bury 1982, William 1984, Charmaz and Paterniti, 1999, Charmaz, 2000, Pierret 2003). The experience of disability goes hand in hand with the loss of certain aspects of self and thus affects identity. The person begins a lengthy process whereby he/she will try to establish continuity between the various aspects of his/her past and present life (Corbin and Strauss 1988). This “unending work” of biography construction sometimes enables people to “transcend their losses, resolve their feelings about them, and emerge with a stronger more valued self” (Charmaz 1999: 72). We are then able to observe what Albrecht and Devlieger (1999) have described as “the disability paradox”, in reference to the high quality of life often reported by persons with serious and persistent disabilities, “against all odds” (see also Young and McNicoll 1998).

These publications are important because they have gone beyond the traditional biomedical model of illness, by restoring personal agency within the structural and interpersonal context of everyday actions, and demonstrating that the “process of healing requires much more than institutional medicine can offer” (Frank 1997). The rich theoretical framework built by these studies has applications which go beyond the simple realm of health. In particular, examination of biographical work can shed light on the way people with impairments attempt, during the course of their personal trajectories, to develop meaningful social activities that contribute towards a feeling of personal achievement. Indeed, illness and subsequent impairment often halts
the course of social activities which until then had been taken for granted. The planning, organisation and realisation of new activities are part of the biographical work of injured people.

In this article, we propose to analyse, from two different perspectives, the ways in which the question of returning to employment arises in relation to the biographical work of people with spinal cord injuries.

First, in the tradition of symbolic interactionism, we consider individuals as creative actors and we focus on the meanings people ascribe to their (inter)actions. Specifically, we consider our approach to follow that of Corbin and Strauss (1987, 1988) and Charmaz (1991, 1999) in their work on managing chronic illness. The concept of “biographical work”, borrowed from Corbin and Strauss (1987, 1988), is central to our work. Their empirical research has shown that illness is always placed in a biographical context. By calling into question the ability to perform the tasks usually associated with aspects of self-concept, illness breaks what they call the BBC chain which links the three major dimensions of biography: body, biographical time and conceptions of self. “BBC is defined as conceptions of self (identity), arising directly or indirectly through body as they evolve over the course of biographical time” (Corbin and Strauss 1987:253). Biographical work consists in “putting the BBC chain back together … This means that several changes must occur in body, self and biographical time. Old objects (including body and self) must be reconstituted or given new meaning. New objects must be sought and discovered” (Corbin and Strauss 1987: 264). Biographical work is not continuous, but is triggered by significant events, which become significant turning points when they “authorise thinking of one’s history in a different way and, at the same time, committing oneself to new ‘futures-to-come’” (Leclerc-Olive 1998). A reorganisation of this kind is possible due to the plasticity of the past, which, because of its unfathomable nature, lends itself to a diversity of never-finished readings, making it as hypothetical as the future (Mead 1980). Another perspective, found particularly in social constructionism, leads us to place activity associated with the construction of meaning within the dialectical relationship of individuals to society (Berger and Luckmann 1966). The social-historical context which envelops (inter)actions, while furnishing individuals with the tools necessary to develop their creative activities, defines their room for manoeuvre by limiting what it is possible to do (Ville and Paicheler 2000). This perspective is tantamount to considering biographies as social constructions at the interface of agency and structure. However, to the extent that they guide future projects and actions, they are no less a situated reality (Berger and Luckman 1966).

In the work presented here, the focus is on social activities rather than on the management of impairment. By studying the conditions in which occupational and integration projects emerge following a spinal cord injury, and the actions undertaken to adapt to them or modify their course, we hope to show how the question of the return to work is inseparable from people’s biographical work, the evolution of which is itself influenced by the broad
structural context of social policy and, more specifically, by rehabilitation practices.

The first section of this article concentrates on the rehabilitation phase. We look at how and within what context the question of whether to continue activities (work or training) or to redirect them (professional reclassification) takes place. In the second part of the article we examine the evolution of the return to employment, from the end of rehabilitation through to the research interview, positioning it within the person’s overall trajectory, i.e. in relation to the total organization of work done to manage the impairments (Corbin & Strauss 1988). We will see how activity management is inseparable from personal trajectories and from their temporality. Finally, in the third section we compare the experiences of the spinal cord injured people interviewed with the experiences of professionals in the field of rehabilitation. We show the logic which leads these professionals to organise their work within temporalities that are difficult to reconcile with those of the persons they are caring for.

Before examining these three issues, the perspective used in this paper requires us to present a summary of the broader context of the rights of disabled people in France, in terms of benefits and assistance towards professional integration. This general context defines the structural parameters which may influence and shape actions and events, as well as the meanings ascribed to the latter by our respondents.

Aid available for disabled people in France

Faced with the difficulties of gaining access to employment, disabled people can receive two types of aid. Each type is based on a set procedure and a contradictory logic exists between them.

Since 1975, administrative recognition of a given level of disability which hinders the exercise of a professional activity can entitle a person to compensatory financial benefits which are calculated on the basis of the severity and cause of the disability. As an example, a permanent wheelchair user who has never worked, will usually1 (and in the absence of other resources) be entitled to two allowances (“for disabled adults” and “for third-party compensation”), the total of which, in January 2004, was about of 1300 euros per month2. Such benefits are subject to an income ceiling.

Furthermore, since 1987, if a company has 20 employees or more, a minimum of 6% of these employees should be registered disabled. Where this quota is not reached, the company must pay a contribution to the AGEFIPH3. This legislation was designed to encourage disabled access to sustained employment in ordinary work environments. To this end, and among other activities, this organisation finances a nationwide network offering assistance in occupational integration. In order to receive this aid, disabled applicants must request recognition as “disabled worker status” from a departmental (county) commission.

French employment law in favour of the employment of disabled people has had indirect effects on institutional practices. It is now easier to obtain disabled worker status; prior to the late 1980s, people with paraplegia were
generally considered to be “unfit for work”. Furthermore, some have recently been registered with disability levels lower than those usually awarded. Where this is the case, these people with paraplegia lose a part of their financial benefits. Finally, it might be said that the development of the occupational integration network is changing vocational rehabilitation practices in the direction of reinforcing normalisation through work.

A person who has become paraplegic therefore has to choose between two solutions: that of compensation for disabilities, or that of specific aid towards professional integration. More generally, he/she will have to make a life choice – to work or not to work – which takes into account his/her functional capacities, environmental obstacles, normative pressures and his/her own values and aspirations, factors which may well conflict with one another.

By offering people with severe disabilities the choice of whether or not to work, French legislation to some extent forces disabled people to be actors in their own personal trajectories. We felt this was an especially interesting context in which to examine the biographical work of these players.

Methods

We have used grounded theory (Glaser and Strauss 1967 ; Strauss et al. 1998), with the objective of developing a social constructionist analysis, as proposed by Charmaz (1990). Our broad research question was “How do people living with severe motor impairments (wheelchair users) manage (or not) to maintain a satisfactory level of social participation?”. Our first interviews led us to concentrate on the experience of spinal cord injured people. Their experiences seemed particularly relevant because of the length of time they had spent in rehabilitation centres and the interactions they had had with various professionals at these centres.

The focus then narrowed to the question of activities (occupational and other): when, how and by whom is this question brought up and under what conditions? What actors are present? What strategies do respondents put in place in the short and the long term in order to deal with them? In addition, the importance spinal cord injured people attach to their stay in a rehabilitation centre led us to conduct other interviews with professionals working at one of these centres.

Semi-structured in-depth interviews were carried out with 17 people with traumatic spinal cord injury and no cranial trauma, all of whom were wheelchair users of working age and living in an ordinary environment. The informants were contacted through different sources: 9 had taken part in another study and agreed to be recontacted, 2 were contacted through the French Federation for Disability and Sports, 2 via the disability associations press, 3 via a rehabilitation physician, and 1 through the social department of a disabled persons association.

Fourteen men and three women, with an average age of 38 (range 29-53 years) took part in the study. The average time since their injuries was 18
years (range 4-30). Table 1 provides socio-demographic information relating to the informants.

The interviews centred on activities before and after the injury, be they professional, training, volunteer or leisure. The purpose of the interviews was to trace changes in the course of these activities subsequent to the injury, and to examine the way in which the question of whether or not to take them up again, abandon them, redirect them or adapt them was raised, at different moments during individual trajectories. Both the structural and the interpersonal contexts of these changes, along with the players involved, were discussed. We also gathered general information, particularly with regard to the circumstances of the injury, how rehabilitation took place, medical complications, the family situation prior to and subsequent to the injury, and the resources available.

At the same time, five interviews were held with professionals (two rehabilitation physicians, an ergonomist in charge of employment, an occupational therapist and a psychologist) working at the largest rehabilitation centre in France, a pilot centre specialising in the treatment of spinal cord injured people. The aim of the interviews was for these professionals to describe their rehabilitation practices.

The interviews were recorded, transcribed and analysed in their entirety.

**Findings**

*The rehabilitation phase*

Following the acute phase of hospitalisation, rehabilitation lasted for an average of one year for interviewees questioned (range: 5 months to 2 years). This took place at a rehabilitation centre, and included a number of tasks which were appropriately structured and monitored by various professionals. The objective of rehabilitation is to achieve relative functional independence through (amongst other things) physiotherapy, sport and the acquisition of a disabled driver’s licence. Aid is not restricted to within the four walls of the rehabilitation centre; it generally includes fitting out the person’s home, and the organisation of a project of training, professional reclassification or a return to work.

After the trauma, most, if not all, of the activities engaged in prior to the injury are called into question. All of the respondents’ physical, psychological and emotional energy is focused upon an assessment of the damage that has been done to their bodies, the consequences of this damage and what needs to be done to regain autonomy. This initial work of recognising a damaged body is achieved through activities which are organised by the rehabilitation centre and whose main purpose is to improve functional performance. The interviewees reported being absorbed by this task, the highly structured nature of which helps them keep at bay any form of introspective analysis.
Table 1: Background of the informants

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Cause of injury*</th>
<th>Age at time of injury</th>
<th>Employment status (at time of injury)</th>
<th>Employment status (at time of study)</th>
<th>Other activities (at time of study)</th>
<th>Marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antoine</td>
<td>32</td>
<td>TI</td>
<td>17</td>
<td>Apprentice</td>
<td>Full-time</td>
<td>None</td>
<td>Couple</td>
</tr>
<tr>
<td>Bertrand</td>
<td>38</td>
<td>TI</td>
<td>20</td>
<td>Student</td>
<td>Part-time</td>
<td>Going out</td>
<td>Single</td>
</tr>
<tr>
<td>Catherine</td>
<td>31</td>
<td>TI</td>
<td>19</td>
<td>Student</td>
<td>Part-time</td>
<td>Housekeeping, baby</td>
<td>Couple, 1 child</td>
</tr>
<tr>
<td>Christophe</td>
<td>33</td>
<td>TI</td>
<td>29</td>
<td>Labourer</td>
<td>In training</td>
<td>Music</td>
<td>Single</td>
</tr>
<tr>
<td>Claire</td>
<td>43</td>
<td>TI</td>
<td>15</td>
<td>Student</td>
<td>Unemployed</td>
<td>Voluntary, reading</td>
<td>Separated</td>
</tr>
<tr>
<td>Eric</td>
<td>50</td>
<td>TI</td>
<td>30</td>
<td>Engineer</td>
<td>Full-time</td>
<td>None</td>
<td>Couple</td>
</tr>
<tr>
<td>Gérôme</td>
<td>45</td>
<td>TI</td>
<td>20</td>
<td>Student</td>
<td>Unemployed</td>
<td>Oenology, fishing</td>
<td>Couple</td>
</tr>
<tr>
<td>Gilbert</td>
<td>39</td>
<td>TI**</td>
<td>18</td>
<td>Electrician</td>
<td>Unemployed</td>
<td>None</td>
<td>Separated</td>
</tr>
<tr>
<td>Gilles</td>
<td>33</td>
<td>WI</td>
<td>25</td>
<td>Mechanic</td>
<td>Unemployed</td>
<td>Sport (competition)</td>
<td>Couple</td>
</tr>
<tr>
<td>Julie</td>
<td>31</td>
<td>TI</td>
<td>15</td>
<td>Student</td>
<td>Part-time</td>
<td>Painting, sculpture</td>
<td>Separated, 1 child</td>
</tr>
<tr>
<td>Laurent</td>
<td>29</td>
<td>TI**</td>
<td>20</td>
<td>Student</td>
<td>Full-time</td>
<td>Computing</td>
<td>Single</td>
</tr>
<tr>
<td>Pascal</td>
<td>43</td>
<td>TI</td>
<td>21</td>
<td>Mechanic</td>
<td>Unemployed</td>
<td>Voluntary, house husband</td>
<td>Couple, 2 children</td>
</tr>
<tr>
<td>Paul</td>
<td>44</td>
<td>WI</td>
<td>22</td>
<td>Roofer</td>
<td>Unemployed</td>
<td>Voluntary, Town Council</td>
<td>Couple, 1 child</td>
</tr>
<tr>
<td>Renaud</td>
<td>34</td>
<td>TI</td>
<td>4</td>
<td>Student</td>
<td>Part-time</td>
<td>Cooking</td>
<td>Couple</td>
</tr>
<tr>
<td>Serge</td>
<td>50</td>
<td>WI</td>
<td>30</td>
<td>Stable lad</td>
<td>Unemployed</td>
<td>Sport (competition)</td>
<td>Single</td>
</tr>
<tr>
<td>Vincent</td>
<td>37</td>
<td>SI</td>
<td>22</td>
<td>Labourer</td>
<td>Full-time</td>
<td>None</td>
<td>Single</td>
</tr>
<tr>
<td>Yves</td>
<td>40</td>
<td>TI</td>
<td>17</td>
<td>Student</td>
<td>Part-time</td>
<td>Voluntary, Town Council</td>
<td>Couple, 2 children</td>
</tr>
</tbody>
</table>

*TI = traffic injury, WI = work injury, SI = sports injury

**The traffic injury took place on the way to work, and for legislative purposes is therefore considered to be a work injury
“When you’re there [at the rehabilitation centre], you are involved in everyday stuff, and it’s only later that you have time to think […] You do what has to be done, what you can do, you go through loads of phases, but its only afterwards that you can theorise a little. At the time it’s just physical, everyday, material constraints, um … that’s all it is…” (Bertrand).

Within the context of total immersion in a highly problematic experience, it is rare for someone who has just become paraplegic to think about future activities. Only one of the interviewees said that he had taken it upon himself to do what was necessary for appropriate occupational training.

In the vast majority of cases it is the rehabilitation professionals who broach the subject of returning to work during time spent at the centre. They make suggestions which, where possible, correspond with previous work activity, i.e. returning to their studies (for the younger people not yet in the job market) or returning to former employers (for those already in work).

The extent to which these suggestions are structured depends upon the centre’s capacity to offer concrete solutions.

Ten interviewees underwent their rehabilitation in a pilot centre for treating spinal cord injured patients. In addition to the smooth running of the various stages of functional rehabilitation, this facility offers various types of general and professional training. It runs in conjunction with an adapted teaching establishment which has a majority intake of disabled students - but also teaches able-bodied students – and proposes timetables to suit rehabilitation treatments. The seven other informants were rehabilitated in smaller provincial centres which were less specialised and which did not have the same capacities for developing integration projects. Occupational integration suggestions tended to be less structured in the smaller centres (such as continuing studies via correspondence courses, or occupational training in a single field – accountancy). For nine of the informants still at school at the time of the injury, the integration project recommended pursuing their studies. For three others, the focus was on reintegrating into the company which had employed them at the time of the injury. Another interviewee was offered training. Finally, three interviewees who had been working as manual labourers received no proposals for occupational integration, reintegration or training.

Going with the flow or giving up: The most frequent strategy adopted by the interviewees was that of “going with the flow”, i.e. delegating (at least for the time being) the question of occupational integration to the professionals.

Most of the time this delegation had taken the form of passive acceptance of the integration project developed by the professional team. In the interviews, this project was described as being “outside” the person, coming from undefined players (“they” or “everyone” are terms used to designate one or more of the rehabilitation staff), and not contested or discussed.
“They [the professionals in the rehabilitation centre] told me ‘you have to think about the future’. So they thought a bit on my behalf. Because I was in industrial design, they sent me to B., in a professional rehabilitation centre. Everyone was saying ‘have to do that’. Back then, I pretty much let myself go. I had no idea, I really didn’t know very much (Gérôme).

Acceptance – after delegating to the professionals – of the integration project was frequently considered as being taken for granted (“I was brought up to work”). Interviewees suggested that continuing with their occupation meant remaining in the norm. At this early stage of personal trajectories, where the interviewees are constantly aware of their disabilities and the consequences of them, this attitude allows them to maintain the illusion that life is continuing as before.

“You are so low after an accident, you’re just shattered! Your only aim is to be like everyone else. I had to work, all my mates were working. I wanted to be like everyone else” (Gérôme).

Above and beyond mere acceptance, delegation sometimes takes the form of a contract whereby the professional has the role of “comeback initiator” (Corbin and Strauss 1988), in developing the initial project which will help the person return to a satisfactory life, within relevant functional limits. Antoine, for example, took up the challenge set by his rehabilitation doctor, and returned to the general studies he had abandoned prior to his injury, in order to take up an apprenticeship.

“I got someone who was very kind and very competent, a doctor who laid his cards on the table and it’s true that that is pretty rare. He came to see me and he said ‘listen, I’m ready to give it a go if you are. You’ll be with people who have been disabled for a few years and who are completely autonomous, so if you want to be like them you’ll have to work at it, but you can do it, I know you can do it!’”.

However, the suggestions for integration projects made by rehabilitation professionals can be off-target, especially when they are poorly structured. People absorbed in dealing with their disabilities are often not able to be open to new ideas. This was the case for two students who decided to “give up” their studies.

“I didn’t know if I wanted to live or die … so business school was the last of my worries” (Bertrand).

The first part of our analysis shows that during the period following injury, the broken body occupies the entire field of experience. Within the institution, with its daily routine of specific tasks, the patients work at regaining control of...
their bodies. They are not able to consider any rebuilding with regard to their occupation, and can often do no more than delegate the problem to the professionals or put it off until a later date: “because the focus is on the illness, or disability, biographical concerns are temporarily relegated to secondary status” (Corbin and Strauss 1988: 174).

On leaving the rehabilitation centre, in cases where our interviewees immediately took up an occupation based on the project developed by the centre professionals, we sought to examine whether or not the interviewees were able to fully gain ownership of this occupation activity. Where interviewees returned home with no integration project, we looked at how the question of an occupation emerges, at a given moment in their personal trajectories and how the interviewees dealt with this situation.

Integration projects after the rehabilitation centre

Among interviewees who immediately took up an occupation on leaving the centre, three outcomes were identified: 1/ at a given moment in their personal trajectory, the occupation project is called into question and rejected; this is clearly part of the interviewees’ biographical work; 2/ the occupation project is pursued and never questioned; 3/ the interviewee takes ownership of the occupation project and becomes an active actor in his/her own activity trajectory. I will now discuss each of these possible outcomes in turn.

Becoming someone else, changing one’s life: Where interviewees delegated responsibility to the rehabilitation professionals and accepted a project which corresponded with a position held in the period prior to the injury, in some cases the question of occupation/activity was to re-emerge at a later date and lead to a radical change in occupational project. In their interviews, these respondents justified this repositioning as resulting from the abandonment of meanings that had previously been taken for granted, or as a result of an adherence to new values, a change of attitude regarding their biography, or even a new identity. Interviewees talked about time as an essential condition for this change, and also the impact of relationships – discussions with companions “who have already been through it”. Their interviews illustrate a shared quality of meaning which is mutually constructed, that is, through interactions whose results are negotiated (Leclerc-Olive 1998). Doubts about the initial project thus reveal the evolution in the interviewees’ biographical work, during which the injury and its consequences are not only accepted, but are sometimes even interpreted as an opportunity for change – a “rebirth”. At this stage, experience of the disability is incorporated into the biography. A significant event or moment can often be cited as a positive turning point, in the sense that it dismantles assumptions about self and social relationships that had been taken for granted (Charmaz, 1999). Turning points presuppose reappraisals of self, as illustrated in the following excerpts:
“I’ve changed since then [rehabilitation]! At B. [vocational rehabilitation centre], I met a lot of different people who opened my eyes. Because before that, I wasn’t worth much, I was just a yob who just wanted to mess around, and they gave me a whole load of interesting ideas. But that’s because in hospitals and centres you’ve got a lot of time, you know! I think it’s a shame for those who go straight back home after the rehabilitation centre. They whine about their handicaps because they’re stuck in the past. […] I’ve had two lives, one before and one after. It’s completely different! I’m living a different life and it’s very interesting. But it took me three or four years to do. You need time, it doesn’t just happen in one go! (Gérôme).

“In fact, somewhere along the line I decided to take control of my life, to change, because since I was a child my life has always been a real mess […] It’s a second chance, yeah, it’s a new life, it’s true, because you’re starting from scratch. You have to change, you can’t stay like before, your state of mind changes. Okay, it didn’t happen overnight, you have to get out, see things, and talk with people.” (Christophe)

In this way, in the late 1970s, after having returned to their studies in a professional training centre, Claire and Gérôme decided to “live without working”; for them, this choice was a life project and they considered it to be an “opportunity”. They had both been injured by third parties, and they were granted benefits which enabled them to live comfortably. They are currently engaged in cultural activities and defend a lifestyle where human relationships and conviviality are very important.

Christophe, whose experience of disability is far more recent, is a member of the occupational integration network. At first he accepted the part-time job that had been organised for him. Yet he was to give it up after two weeks.

“It was nothing more than a job to keep you busy, but I’m not someone who gets bored, I don’t have time to get bored […] Looking back, I was scared, it frightened me, I just didn’t want to go back to the same old work routine […] I don’t think I could have stood it … you know, I wouldn’t be where I am, maybe I’d have committed suicide […] Because I know that if I’d stayed there I’d never have been able to leave and I’d have spent years there”.

At the time of our interview, Christophe was trying to develop his own project. During his two years of rehabilitation, he had begun to learn music. He wanted to run music classes for children, but his “integration advisor” did not take this suggestion seriously. His relationship with the institution did not allow for the sharing or negotiation of meanings. The resulting confrontation was a negative significant event associated with feelings of anger and anxiety. Christophe nevertheless incorporated it into his future life.
“He (the integration advisor) thought I didn’t want to do anything, to just profit from my pension and take it easy, but I want to make him understand too that in music, I move forward and in what I do I move forward and I keep in contact with him because, in a few years when I’ll have a BETEP (a diploma) in music, I’ll go back and make him shut up.”

“Staying in the past”: an impossible future: In some cases a passively accepted project had been continued without ever being questioned; the interviewee had accepted and been able to maintain the rehabilitation professionals’ employment proposition. The fact that the question of occupation had not been re-examined since the end of rehabilitation can be explained within the overall context of peoples’ trajectories. The interviews demonstrate how hard it is to give meaning to one’s biography after an injury. There are frequent references to a past which is finished, with negative comparisons between the present and the period prior to the event. Day-to-day management of the disability always seems to dominate experience – including professional experience – and to generate a feeling of frustration.

“I’m less mobile, I’m certainly less effective … I would certainly have had a different career, I’d certainly have done something more interesting […] I force myself to come here, I force myself to go out. It is time consuming, it requires effort, and I think that with this sort of disability you are better off with something regular […] I wasn’t like that before. I think I had more freedom. Whereas now, if you like, I force myself to keep up a certain rhythm during the week so that I can be more effective all the time […]. It’s a constraint, it’s pretty hard. There’s not much fun in it.” (Eric)

The difficulty of linking past and present and of building a new identity which incorporates disability also hinders any projection into the future. Indeed, the substance of a biography is a result of the joint construction of both the past and the future (Ricœur 1983). Thus, the impossibility of reconciling past and present forces one to limit the extent of the future, the past having become unavailable as a resource in biographical work (Leclerc-Olive 1998). Professional activity can therefore help one to mask this negative experience by bringing a more positive working identity to the forefront.

“In fact your whole world has collapsed in one go and you no longer have access to very much, so you can’t say ‘I’ll go on this or that trip’, that you are going to do this or that, because in any case your physical situation won’t allow it, it’s all completely out of the question, so, you know, there aren’t many projects available for the future. […] I think that a job for someone who’s disabled is a way of feeling a bit better about yourself, of feeling that you serve some purpose in society, so … When I’m at work I
don’t think about anything other than my job, and it’s sure that if you have a lot of time to think dark thoughts, well, it’s … Ultimately, if you don’t think about it, you no longer remember you’re disabled. [...] The only project is that of being able to carry on working. My aim, in fact, is to keep at it and make it through to the end!” (Vincent)

As soon as they had finished their rehabilitation (respectively 6 and 10 months after their injuries), Vincent and Eric went back to the companies which had formerly employed them. Both work full time and neither have any other regular activities. Despite the time since their injuries, their biographical work would appear to be suspended.

One might wonder if a quick return to one’s professional activity in the same context as the one prior to the injury is an obstacle to biographical work. Being faced with the same places, the same people and the same tasks can only serve to highlight what has been definitively lost, without offering any opportunity to develop new performances. Such a context would not appear to favour the possibility of using the past as a resource, which is a vital stage both in giving meaning to one’s biography and in developing a project for a satisfactory life.

Taking ownership of an occupational project: For some of the interviewees, it had been possible to move to a position of control over the proposed activity and to gradually make it their own, without necessarily calling into question the initial project suggested by the professionals. This evolution is demonstrated by the replacement, as the interviews unfolded, of “someone” and “they” (referring to the professionals) by “I”, who then becomes the main actor.

Three of the youngest interviewees, attending school at the time of their injuries, returned to their studies with the intention of finding future employment. Although they had had different types of training, there were many similarities in their trajectories. All three had achieved the qualifications they were aiming for, and moved on to actively looking for work. All three encountered the same types of obstacles (inappropriate suggestions and refusals which were implicitly or explicitly related to their disabilities), persevered and finally found salaried jobs in large companies. Finally, all three reported that they were very happy with their professional situation, and were able to identify projects for the future.

The interviews contained numerous examples of adjustments made in response to contextual events. Renaud, for example, had had to leave his home region in order to find work. Later on, repeated urinary complications forced him to work part time for a few months – something which he ultimately decided was “very pleasant”. A few years later, when he was living with a partner, he noticed that their combined income was over the ceiling entitling him to benefits. He had no hesitation in reducing his working hours - “I earn more by working part time than if I worked full time”.

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The three young people managed the domain of their occupations/activities by navigating between constraints and aspirations. The adjustments - made possible by both financial resources and their ability to adapt to the changing context – are part of a personal trajectory which has successfully integrated the experience of disability. Turning points, related to significant events or periods, may be identified in the interviews. Antoine, for instance, suddenly discovered the person he had become through acknowledging the attitudes of others when, after having obtained his baccalaureate degree, he left the institutional environment to attend business school. This revelation encouraged him to continue his studies. He described this confrontation with “the able-bodied world”.

“Living every day with able-bodied people was a bit like being the symbol of someone with a pretty strong character, someone who had a strong will to live, a strong desire to have fun. It was like, how can I explain it, not envy because you can’t be envious of my physical condition, maybe a little bit like admiration of a state of mind like mine. And it’s true that the people I met often said ‘in fact we keep forgetting you’re in a wheelchair because you give off something superior’, and from that point on a lot of things happened, I mean like relationships which were much deeper; […] It wasn’t so much the studies that I enjoyed, it was the environment, I guess it was the life around all that, the relationships you could have with people.”

Mainly as a result of his interpersonal skills, Antoine found a job without having to go through the integration network. At the time of the study he was a manager for a large company.

However, the interviews do not always allow us to pinpoint turning points in personal trajectories. This may be the case when biographical work unfolds in an implicit manner, without any conflicting features. This is probably true of Renaud, whose injury occurred when he was four years old, and whose trajectory has been built around disability.

The three young respondents did their rehabilitation at the pilot centre, and two of them continued their studies in a suitably adapted academic establishment which works in conjunction with the centre. The structured supervision at the centre and the open environment of the general studies programme are undoubtedly conditions which favour the positive development of personal trajectories, especially given that these studies are organised in such a way as to suit the individual needs of those concerned. All three passed their exams between 1984 and 1992 - i.e. in a general context of economic crisis and of a return to working values, and a more specific context of early encouragement towards the occupational integration of people with paraplegia. These factors may have influenced the strategies used by the interviewees.

As these examples illustrate, integration projects organised early on by rehabilitation professionals can be questioned by a disabled person and
subsequently abandoned, adopted as a person’s own, or never be called into doubt. This management of the sphere of activities is inseparable from personal trajectory management as a whole. It is part of – and a reflection of – the biographical work of people for whom temporality (which varies from one person to another) is an essential dimension. Furthermore, as we have seen, the context surrounding personal trajectories is also an important dimension of biographical work. Indeed, time and context are closely linked.

Let us now move on to the case of those who do not return to their previous occupations after leaving the rehabilitation centre, either because the professionals did not offer suggestions, because their suggestions were refused, or because a re-integration project rapidly ended in failure.

Leaving the rehabilitation centre without an integration project

Several interviewees mentioned a transitory period after returning home; although they give this stage different names, it is characterised by the expression of a certain disquiet, a lack of reference points and boredom. The interviews covering this period are full of negative feelings. Yves talks of “a two-year blank” during which he “was fed up with everything”. For Gilles, this time “in brackets” corresponded to his return to the Antilles, which he had left in order to undergo his rehabilitation in metropolitan France, where he had “stayed one year, one whole year being helped”.

Once again, the interviews show that the phase of personal trajectories during which people assess lost abilities and come to terms with a broken body continues beyond the rehabilitation centre in a manner that may be even more intense once one is removed from an institution generally perceived as reassuring.

“For two years after leaving F. [rehabilitation centre], I was a little …, I was feeling a bit low […] the return to civilian life as one calls it, is tough. Because despite what you learn at the centre, how to deal with pavements and all that, after that you’re all alone in, in a town, you’re worried about quite a few things, there’s people looking at you and all that, it all affects you. I pretty much panicked!” (Pascal)

This may be the reason why several interviewees felt the need to be closer to a community of disabled people through a sporting activity or by joining a disabled people’s organisation or association. Whatever the case, during this “halfway” period the biographical work continues, without assistance, in a context which seems harder to live with, and where the informants have to deal with other people’s attitudes. Even if at this stage they are not available to develop an occupational project, the question is bound to arise at some time during their personal trajectories; it can take three forms: 1/ the external form of an opportunity to be seized; 2/ the internal form of a desire to put an end to an unsatisfactory period of inactivity; 3/ finally, the question of return to work may be purely, simply and definitively rejected.
**Seizing the opportunity**: A member of the network of relationships makes a work proposal at a point in the personal trajectory where the person concerned has come to terms with his/her disabilities, has given direction to his/her biography, and is ready for the experience. It is no longer a case of delegating to a professional, but of “seizing the opportunity”. Just like the students mentioned above, the interviewees do not necessarily realise the value of the work they have achieved, which makes them ready to develop an occupational project. They tend to describe their evolution as a combination of circumstances, an opportunity. Hence Bertrand, who had not wished to continue his business studies after rehabilitation, accepted a job offered by a very close friend a few years later.

“I didn’t particularly think ‘am I going to work, am I not going to work?’. [...] A series of circumstances just made it happen. He [the friend] found himself with a big client and he couldn’t cope with all the accounting on his own, so he asked me if I was interested. I didn’t know anything about that, so I did some accountancy lessons with the father of another friend, and one thing led to another. I went from accounting to computing, and then we started a company together, that’s just the way things happened, one after the other.” (Bertrand)

Bertrand’s family and friends were very supportive. When he started his company, his brother sent him some clients. At the time of the interview, Bertrand was a part-time employee with a monthly salary of 3,800 euros and spent the rest of his time working freelance, which allowed him to spend one week per month at his house in the country.

**Turning the page**: Several informants describe how, after the difficult period following their return home, they wanted to “react”. After his “two-year blank”, Yves said to himself:

“You’re fed up because you’re not doing anything, so get on with it, do something about it!”

Various projects with different activities (competitive sports, further education, associative or elective responsibilities, professional activity) can then take shape, once again revealing the evolution of people’s biographical work. The trajectories described in the interviews are usually sinuous, marked with numerous adjustments between structural constraints (the dysfunction of specialty services in particular), physiological constraints (medical complications), aspirations regarding other valued areas of life (parenthood, involvement in a disabled people’s organisation and the strong values linked to employment. These successive adjustments can, though not without difficulty and recourse to aid (benefits, paid training courses), lead to an innovative
“customised” range of activities which suit the informant’s life choices. Julie’s story illustrates the progressive construction of occupations/activities.

Five years after her injury, her assessment of events is fairly negative.

“I really lacked confidence in myself when I realised that after five years, in fact, I should never have … I ought to have continued my studies … I really had the impression that I had totally wasted my time, and so I felt useless.”

Her analysis of the past enabled her to bounce back. She decided to bring her studies up to the level of her peers, and then she looked for work. She felt she needed the recognition which corresponds with productive activity. She obtained a CES as a secretary, and worked extremely hard in the hope that she would be taken on permanently. After more than a year, she learned that “in her case” she could “remain a CES employee for five years”. This negative outcome provoked feelings of discouragement during which she felt used and refused the renewal of her contract. After a time, she became involved in volunteer work which she found “very satisfying”. During this period she turned down several “totally insecure” and “never interesting” CES offers, but did not give up her search for employment. At the time of her interview, Julie had obtained an open-ended contract with a small company where she works 12 hours per week, with the possibility of choosing her working hours; this allows her to see her physiotherapist and to look after her daughter. She does not wish to work longer hours. She has also stopped her voluntary work (because she “no longer feels the need to do it”) and does painting and sculpture. Her benefits enable Julie to make decisions in her own time (i.e. to refuse insecure and/or uninteresting jobs).

Occupations/activities can be at the very heart of the biographical process, and the progressive and complex “knitting together” of this area of existence may be linked to all other areas. After a somewhat chaotic period, the fight for accessibility which Yves had begun as a volunteer in an disabled people’s organisation also became the purpose of his freelance activity as an ergonomics consultant. This interest was born of his experience of disability and is now at the heart of his various occupations (both remunerative and voluntary), giving meaning and coherency to his entire biography.

Fleeing the constraints of a job requiring few qualifications: Finally, two interviewees had decided to ignore the question of occupational integration when it was raised by social services upon their return home. This refusal was justified by their desire to live freely, “from day to day” and “without constraints”. But in these two cases, it was more a reflection of a pragmatic option than a philosophical one. The interviewees concerned – both manual labourers with few qualifications – made a decision to live off their benefits. They do not reject work per se, but rather the type of work they are likely to be offered, feeling it to be limiting, uninteresting and poorly paid. Their leisure
activities show they have come to terms with their disabilities, achieved satisfactory autonomy and even acquired new skills and accomplishments. Gilbert enjoys do-it-yourself projects and rides his motorbike, equipped with a sidecar in which he puts his wheelchair. Serge does athletics at competition level. Furthermore, their personal trajectories are not limited by an impossible future. Every year, they each go on holiday with their friends to faraway places.

Without the help of professionals and with limited resources each interviewee has managed to create his own activities. These are not structured as a life project but as default activities, a reaction to the only realistic alternative to a job requiring limited qualifications. The respondents are nevertheless the actors of their own personal trajectories, which, even if they might appear marginal compared to the standards of social integration, still provide a certain satisfaction with life.

“You might find it odd, but I think I may be happier like this than if I were able-bodied, because there are things I’d never have done as an able-bodied person, which I have been able to do and which I will certainly continue to do [...] Travelling for example, I couldn’t do that because I was always at work, so... » (Serge).

Even where they do not return to an occupation immediately after rehabilitation, the question of occupational integration is raised further along the personal trajectory – several times for some people – and interviewees have varying solutions which range from occupational integration to voluntary work and leisure activities or a combination of the two.

Whether it takes the form of an opportunity which has been taken or a desire to turn the page, the return to an occupation/activity after a difficult period reflects a favourable evolution in interviewees’ biographical work. They are now the main actors, finding, - in their personal network and via the support of disabled people’s organisations (especially sports) – opportunities which allow them to adjust their activities according to their limits and desires. While social benefits are a necessary condition for achieving this level of organisation, the services assisting professional integration are rarely called upon, and indeed often considered to be incompetent.

Analysis of the interviews with people with spinal cord injuries shows that the question of returning to work cannot be dissociated from personal trajectories as a whole. Whether or not they take up occupations again on leaving the rehabilitation centre, they still continue biographical work, which may take several years and which only they can do. This presupposes going through several stages: assessing the limitations imposed by the disabilities, accepting the consequences for their lives as a whole, inventing new performances and thus regaining a certain level of control over the body. This work of “coming to terms” (Corbin and Strauss 1988) leaves little place for the question of restarting or rearranging previous occupations. Certain events or
periods correspond to turning points, which prompt a review of the past in the light of the present. People are thus able to regain a sense of integrity (“reconstituting identity”) and are able to build new life projects which include their occupations (“recasting biography”, Corbin and Strauss 1988).

This temporality in biographical work calls into question the recent evolution in professional practices. We observed an increasingly urgent desire on the part of rehabilitation teams to reconcile functional and vocational rehabilitation as a way to encourage occupational integration. As they say themselves, such a stance – which involves “inducing occupational integration early on during the acute phase of rehabilitation” – requires encouragement to develop an occupational project as early as the first few weeks following the trauma (Tremblay 97). Yet, as we have seen, the rehabilitation phase, which is a crucial moment in the care of paraplegic people, is too brief to correspond with the biographical time needed to come to terms with a disability. In order to better understand the structural context and the room for negotiation which surround the question of taking up occupational activities again, it seems important to us to examine the reasons and conditions behind the emergence of this reorientation in practice, along with the possible effect it may have on the manner in which the biographical work of spinal cord injured people unfolds.

Using interviews with rehabilitation professionals from the pilot centre treating spinal cord injuries, we attempted to understand the rationale behind these new practices. We will illustrate how this logic, combined with constraints on work organisation, has led professionals to instigate a new doctrine which would appear to conflict with their professional expertise and which pushes their work into a temporality that is not easily compatible with the experiences of the spinal cord injured.

Professional work and biographical work: temporalities which are difficult to reconcile

We interviewed all five members of a team which had been created with the purpose of instigating early occupational integration. Amongst other things, funding from the AGEFIPH allowed the recruitment of an ergonomist responsible for employment, in return for ensuring a certain number of professional reclassifications and placements. At the time of the study this action was deemed effective and was being generally extended to other centres.

“Patient time” defines the stages of rehabilitation: The interviews demonstrate the considerable knowledge the professionals possess regarding patients’ experiences; they have been applying this knowledge to their practices for some considerable time, and this has enabled them to codify chronologically the different stages of their work.

Their first task is to assist in what they refer to as “mourning” or “apprenticeship of paraplegia”, a phase which involves becoming aware of functions which have been lost and of those preserved, and which, according
to one rehabilitation doctor, can last “between six months and six years”. The role of the professionals is to provide information on the pathology and its consequences, and to enable the “patients” to achieve a certain level of autonomy through physiotherapy.

It is only after completion of the above phase that the so-called “return to social life” – i.e. returning home - can be envisaged. Amongst other things, this second phase involves assessing the way(s) in which the home needs to be refitted. This takes place in partnership with the “patient” and his/her family in line with the evolution of functional rehabilitation. Within the chronology of rehabilitation, return to work is the last stage.

“At first they say ‘it [work] is not my problem. For the time being there are more important things’. They are in a phase where they need to become aware of their bodies, of their image of their bodies, and so they are really not in a frame of mind where they can think about working […] There’s family and personal life, and all the uncertainties regarding their bodies which come before any occupation, at least for the first four or five months. They don’t feel like talking about professional questions. It is rare for anyone to take steps, to meet the ergonomist” (Psychologist).

“Juggling” with different times, or the rhetoric of time as a “factor of non-integration”: The professionals’ awareness of the incompressible nature of biographical time conflicts with a feeling of increasing urgency that reflects a negative perception of the effect time can have on succeeding in one’s occupational integration. In a general context of economic crisis, time is seen as a major “factor for non-integration”.

“I worked for a while in a professional training centre. Back then, the people who came were sometimes coming seven years after their injury. So on top of the sequels to their injury, they were divorced, alcoholic, drug-addicted, without any family, broke. They were totally washed out and I found it completely crazy to have kept them waiting so long before helping them with their occupational integration” (rehabilitation doctor).

In encouraging a patient to develop an integration project, professionals want to break away from what they sometimes consider as a “wait-and-see” or even “miserabilist” attitude - found in certain rehabilitation centres – towards paraplegic patients for whom it is felt that not very much can be done.

“Very early on we can say to them ‘you’re not finished, there are solutions […], you can have a place in society. Even if you can’t do the same job, you can change professions” (rehabilitation doctor)

For the most part, their work is nevertheless restricted to the period of rehabilitation, after which the patients “disappear into thin air”. Yet this
period – which now tends to be shorter and shorter – is barely sufficient to set up the administrative procedures which are required to ensure the entitlements of the patients (e.g. recognition of disabled worker status, financial aid for a return to work or for professional reclassification). Time is therefore “saved” by encouraging the patients to think about occupational integration at a very early stage.

“When you are trying to get things going and you don’t want to waste two years, you have to juggle! We manage, but the deadlines are often very tight. [...] We try to mobilise all of the networks, the company doctors, the human resources departments and the doctors here, so as to give them the maximum amount of resources with which to get a job under proper conditions. [...] But all that requires planning. It’s a real case of specific aid, and if all the steps are taken at the right time, there’s every chance of success [...] At the very least if people don’t succeed their integration, it gives them far more chance of avoiding dropping out” (ergonomist).

The professionals do their best to ensure that the time needed to complete the procedures coincides with the time in rehabilitation, so that everything is ready when the patients leave the centre. In the same way, when working towards employment, they tend to favour what they refer to as “sustained employment”, i.e. a return to the same employer as before. They believe this to be the most realistic solution, and in any case it is certainly the fastest. The theory that the passage of time contributes to the non-integration of disabled persons is thus reinforced by the belief in a psychological factor wherein sustained employment creates continuity after the injury, making the experience less painful.

“You’ve already got the disability to deal with. Then there’s the change in context or the change in everyday life, so if you have a change in professional life on top of that, it’s a lot to cope with. So where we can, we try to keep the person in the same job as before.” (rehabilitation doctor)

Professionals find themselves facing conflicting temporalities: there is the “biographical time” of people with spinal cord injury, the stages of which have been known for some time, and which define the chronology of tasks to be accomplished. There is also time which, as the professionals perceive it, pushes the patient into marginalisation and exclusion. Finally, two institutionally determined times operate, the first of which – too short and constantly being reduced – is rehabilitation, which increasingly does not allow for the various stages of their professional work to be followed; the second of which – too long – is the increasingly complex process of administrative procedures which forces rehabilitation professionals to rush the scheduling of their actions. In this maze of constraints, and in the broader context of an
employment crisis, the noose tightens. Helping people develop a new life project tends to be reduced to merely getting them (back) into employment. The restrictive context of their practice does not allow professionals to envisage other alternatives for patients such as voluntary work or participation in disabled people’s organisation.

“I’m on my own in this job, and that’s not the aim of the job. There are a lot of people, and you need to do acrobatics to deal with all the files; I’m already doing overtime non-stop, so if on top of that they tell me ‘to deal with people looking for associative or leisure activities’, it’s another job altogether! It’s not the same network, I’m not familiar with it, and it also requires a lot more time.” (ergonomist)

Nowadays, the question of exclusion dominates rehabilitation practices. Occupational integration is no longer done for reasons related to the social utility and positive recognition of work – an attitude which was at the forefront of rehabilitation practice for a considerable time; it is now perceived as a way of avoiding the negative effects of professional inactivity. We therefore see the emergence of a new doctrine whose aim is to examine at the earliest date possible the question of the return to work, thus ignoring personal temporalities.

The professionals dismiss the tension between their own temporalities and those of the patients by implicitly considering that there are two parallel logics which do not interfere with one another. Should they meet, it is to the benefit of the patient, at a moment when they are ready to look at the question of return to work. Everything seems to happen as if the professionals’ work of vocational rehabilitation were invisible to the patients, but with a delayed action, which takes the form of an opportunity to be seized at the appropriate time.

“Even if we think it is too soon [to examine the question of professional integration] and there are six months between the time he [the patient] leaves and the time he starts work again, it doesn’t matter, it will be at his own pace” (ergonomist).

“Even if he tells us to drop dead, somewhere along the line it has sunk in, and one day it will resurface. They’ve got it in their heads and they’ll be able to use it when the time comes” (rehabilitation doctor).

Conclusion
The transposition of the concept of biographical work into the question of the return to work after spinal cord injury is important for two reasons.
Firstly, the diversity of occupation/activities trajectories constructed by our interviewees and analysed through the concept of biographical work – that is
in relation to revisions of past meanings considered self evident at the time, the discovery of new values and new images of self – enables us to break with the ingrained notion that there can be no true integration without productive work activity. Indeed, some trajectories reveal to us original life styles where satisfying social participation is accomplished in ways other than that of working full time, with, occasionally, quite sophisticated combinations. Secondly, and in spite of similar clinical and institutional conditions (the consequences of paraplegia and a systematic stay in a rehabilitation centre), we have seen that the specific conditions which surround the experience of the interviewees have certain variations (for example, length of stay in the rehabilitation centre, ability of the centre to propose a realistic project for integration, interactions with the professionals). Relating these variations to biographical work allows us to uncover conditions both favourable and unfavourable to its evolution. More generally, focusing on biographical work shows that the management of occupations/activities is not a direct result of the experience of paraplegia, any more than it is of affirmative action and rehabilitation practices; rather, it should be understood in light of the dialectical relationship between agency and structure.

In addition, our work raises two main questions which open up perspectives for future research. The first question is that of the driving force behind the new doctrine of early readjustment. It concerns the reality of a process which may be propelling paraplegic people from professional inactivity towards marginalisation and exclusion. We did not observe this process in our study, but this assessment suggests the limits of our research, due to its small size and the non-representativeness of the sample of interviewees. It would appear that the method by which we chose to constitute our sample did not enable us to reach the most disadvantaged, those for whom resources are most lacking. It is therefore possible we missed the marginalized persons mentioned by the professionals.

We should nevertheless qualify this problem. The professionals probably do not have any better access than we did to a representative population of paraplegic people. Very few of the latter contact professionals for assistance in occupational integration (Flin-Chavernac, 2002), either because they do not wish to work, or because they have already achieved integration via their own networks or associations. Those who do contact specialist services almost certainly encounter greater difficulties. Whatever the case, studies of populations which are larger and more representative of spinal cord injured people as a whole would allow the reality of exclusion phenomena and their consequences within this population (such as alcoholism and drug addiction) to be assessed.

The second question concerns the lack of conflict - implicitly presumed by the professionals – between the patients’ biographical work and the professionals’ own rehabilitation practices. The experience of spinal cord injured people, as found in our analysis, would appear to disprove this premise. As we have seen, people submerged in the work of “coming to
terms” with disabilities tend to delegate responsibility to the professionals and to passively agree to any suggestions made during rehabilitation. The resulting situation obviously affects the course of personal trajectories. The question therefore concerns the consequences of this conflict between early occupational integration and biographical work. Answering this question involves concentrating – prior to the question of a return to work – on the biographical work which goes with the experience of paraplegia, and on revealing the positive or negative conditions for its progress.

As we have seen, time is a vital factor in biographical work. It is indirectly provided by the granting of benefits, which, for a certain period and when sufficient, remove the need to work. The vast majority of interviewees in this study have used this type of resource. Benefits gave most of them the valuable time they needed for the biographical process, and enabled some of them to develop an occupational project which was both suitable and satisfying, despite numerous constraints.

A space for interaction which favours contacts between people who have similar experiences can be provided, not only by institutions but also to a large extent by associations which can usefully take over from the professionals after rehabilitation. By offering a forum for discussion and exchange, such a context facilitates the questioning of values deemed to be self-evident, and the development of new meanings. For Gill (1997), community togetherness is a vital stage in the process towards real social integration where differences are respected. Marcellini et al. (2000) observe the same process in sports activities for people with disabilities.

The setting up of unrestricted activity projects could be one of the objectives of aiding disabled people to achieve integration. These could offer different options negotiated at any time during the course of personal trajectories when the evolution of biographical work allows the field of experiences to be broadened. A return to one’s studies meets these conditions, especially if adaptations are possible. Becoming involved in properly structured voluntary work or in local government can also be an effective way to temporise and to gradually adapt to a structured environment, with a view to productive integration at a later date.

On the other hand, the early return to one’s previous job – which recently became the AGEFIPH’s prime objective – offers none of these conditions. Generally speaking, and for all of us, the job market is a more closed environment than that of education or of disabled people’s organisations. Even where prospects for career development do exist, they often depend upon employee mobility and are therefore limited as far as wheelchair users are concerned. Furthermore, the generally unavoidable refitting of the premises and work station are additional constraints which tend to render the context less flexible and to restrict the scope of feasible alternatives. For all of the above reasons, it would seem that the solution of returning to one’s previous job – especially when it is not long after the injury – can be an obstacle to change and to the favourable evolution of personal trajectories. Further
research is needed to achieve a better understanding of the effects of sustained employment on the way in which biographical work unfolds.

More generally, early encouragement to achieve occupational integration, ignoring individual temporalities, and potentially limiting the number of opportunities and relationships available, is likely to restrict the development of biographical work. It is also likely to increase the pressures towards normalisation, and the cost to the individuals concerned can be considerable (Davis 1972, Philips 1985, Ville and Ravaud 1994). Finally, it is likely to reduce the way in which paraplegic people are assisted in the objective of occupational integration, neglecting those people who were active prior to their injury, but whose former jobs are incompatible with their disability, and those who, in the light of their experiences of disability, have revised their attitudes to life, and have opted for integration through something other than work.

Instead of examining the question of a return to work as an end in itself, a change of perspective is needed which encourages the biographical process, in order to avoid these pitfalls. The primary objective of aiding disabled people would therefore be to improve the conditions surrounding biographical work, and might usefully bring together both rehabilitation professionals and voluntary workers from disabled people’s organisations, which is particularly rich and well-structured in the area of disability in France.

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Acknowledgements

This research was made possible by funding from the Association des Paralysés de France (Convention APF n°9705). I would like to thank all the participants for the rich and colourful material they provided, Isabelle Baszanger and Jean-François Ravaud for their precious advice and Christopher Hinton and Jon Cook for their help in translation.

Notes

1 Decisions to grant allowances are taken at departmental (county) level, and local differences have been observed.

2 For information, the Minimum Wage for a full-time job in France is 912 euros per month, after tax and contributions; the “Revenu Minimum d’Insertion” (minimum insertion income) is 411 euros.

3 “Association pour la Gestion du Fonds pour l’Insertion Professionnelle des Personnes Handicapées (association for the management of funds for the professional integration of disabled people)
“Contrat Emploi Solidarité”: employment solidarity contract; a part-time employment contract for a period which may not exceed one year. Exceptions may however be made, in particular regarding disabled people.

Interviews were also carried out with professionals working in small provincial rehabilitation centres. A comparison shows quite contrasting practices whose description here is beyond the scope of this paper (Ville 1999). Using interviews carried out in the pilot centre, we wished to show the new orientation of practices within the context of economic crisis and the enhanced value of work, and the attempts on the part of professionals to integrate them into their knowledge base and justify them. These five interviews do not, of course, represent a large body of material and it would be useful to carry out complementary studies among new teams financed by the AGEFIPH, which have since been created in several other centres.

References


