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Captured by Care: An Institutional Ethnography on the Work of Being in a Rehabilitation Process in Norway

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The Norwegian rehabilitation policies and new public management reforms share some features and are divided by others. The features that divide them are so contradictory that they create difficulties for people who are in a process of rehabilitation. Having studied the everyday life of people being in a process of rehabilitation, I argue that the continuous change in organizational structures in general makes the processes hard to endure for service users, specifically the reforms characterized by neo-liberalism, because they, to a large extent, contradict the holistic rehabilitation ideology. This further illuminates the paradox that the greater and more complicated the functional impairments are, the more work related to the rehabilitation process a person must do, and by extension, the greater the risk of deprivation.

Key words: rehabilitation, institutional ethnography, Norway, policies, public management, holistic rehabilitation

In Norway, the beginning of the millennium entailed a shift in policy of rehabilitation towards a more holistic approach inspired by Oliver's (1990) and others' social model of disability. This new policy diverged from the former more medically-based approach by arguing that persons in a process of rehabilitation need more than medical attention or repair in order to reach the goal of social participation in society. The means to reach this end was to strengthen the capacity of the service user herself, and to strengthen the cooperation between various actors in service production, making services more holistic and tailor-made for each individual service user.

This policy is part of new ideological trends putting the

individual at the center and holding up tailor-made services as an ideal in welfare states. This is inspired by the disability movement's focus on the needs and wishes of the persons themselves. Also, the New Public Management reforms that started in the early 1980s advocated the strengthening of the citizen as a user of services or as a customer. Service users are defined as customers in a market and should, therefore, be allowed to choose between various services.

The pro-business ideology, usually referred to as managerialism or New Public Management (NPM), swept over the western world from the beginning of the 1980s (Pollitt & Bouckaert, 2000), and Norway was no exception to this trend, although it was described as a reluctant reformer by observers (Christensen, 2006). Although NPM reforms focused on user-governance, other elements in the reforms contradict the holistic rehabilitation ideology. Examples of this are the focus on single administrative 'result service units' with separate budgeting and reporting, which are administrative arrangements that have made coordination of services even more difficult (Christensen, 2006). In Norway there has traditionally been strong legitimacy of the public sector, and the neoliberal reforms have not changed this picture in any substantial way. However, as I will argue in this article, the way public services are administered has changed, by establishing quasi-markets and making the system more businesslike. By ethnographically describing the difficulties faced by persons who are in a process of rehabilitation, I will illustrate how the NPM ideology collides with the holistic rehabilitation policy, making the everyday life of service users more difficult.

Background – The Field of Rehabilitation in Norway

In Norway the field of rehabilitation is centralized legally; however, the actual rehabilitation practice is the responsibility of the municipalities. In other words, the municipalities are important instruments of implementation of national rehabilitation policies. The political developments on the national level over the past 15 years have led to an expanded definition of rehabilitation and, in turn, led to an expansion of the field. The new rehabilitation policy, which has been adopted to varying degrees in municipalities and health authorities,

conceptualizes rehabilitation in relatively broad terms. Solvang and Slettebø (2012) summarize the change in focus as both a bureaucratic and social turning point that intends a move from seeing rehabilitation strictly as the training of physical functions to seeing it as tied to both training and to the adaptation of the environment. Participation is, therefore, the main goal of rehabilitation as an activity. I have elected to use the formal, statutory definition of the term as a starting point, as this definition can be seen to have resulted from the policy changes:

Habilitation and rehabilitation are time-limited, planned processes with clear goals and measures, where multiple actors collaborate to provide necessary assistance to the recipient's own efforts to achieve optimal functioning and coping skills, independence and participation in social settings and in society. (Ministry of Health and Care, 2001)

In other words, the definition does not detail who the actors can or should be; it is broad and open to multiple interpretations, and may, in the worst case scenario, even be overlooked. It encompasses multiple areas of life and, thus, involves a broad range of actors in health and the social sector.

Rehabilitation was introduced as an overarching concept as early as 1999 in a White Paper that stated that "everyone with an impaired functional capacity who need planned, complex and coordinated assistance to reach their goals" was in the target group. Since 2001, "persons with impaired functional capacity" has meant anyone with the "loss of, damage to or deficiencies in a body part or in one of the body's psychological, physiological or biological functions" (Ministry of Social Security and Health, 2001, p. #?). The definition of functional impairment is important to the field of rehabilitation because it defines the service recipients and service agencies that are to be part of the field.

In practice, the major changes that this new rehabilitation policy entailed were the mandating of individual service planning for people in a process of rehabilitation, of coordinating units of rehabilitation in the municipalities, and of planning the rehabilitation practice in the municipalities. The problem is that New Public Management reforms have slowly made

their impact on the municipality level, causing problems for the implementation of the holistic rehabilitation policy and the coordination of services around individuals, which I will demonstrate ethnographically in this article.

My Use of Institutional Ethnography

In my research I used the experiences of service users and service providers and their descriptions of the work that is performed to identify the institutional issues from their point of view by mapping how the work is performed in practice and how their work is connected with the work of others. I mapped rehabilitation processes by interviewing those involved. My interviews were conducted as conversations or, in other words, as unstructured interviews in which I asked the informants to describe the rehabilitation process from their point of view. As recommended by McCoy (2006), I encouraged them to talk in as much detail as possible about who is involved, the ways in which they were involved, who did what, who contacted whom and how, who initiated what and how it was done in practice. For example, if the informant talked about having had a meeting, I asked who initiated the meeting, what was the purpose of the meeting, who participated, which tasks were allocated to those in attendance, etc. In other words, instead of asking "How does your collaboration with agency x work?" I tried to map the procedures for collaboration in as much detail as possible by, for example, asking about a concrete course of events, or what DeVault and McCoy (2006, p. 39) call mapping institutional chains of action.

I interviewed service recipients twice over a period of one to two years. As mentioned, there were various reasons why they were in a rehabilitation process, but their diagnoses or functional impairments were not the focus of the study. Instead, the study focused on the collaboration that took place between service providers and service recipients; therefore, I also interviewed the service providers involved. The number of service providers involved and the extent to which they were involved varied from person to person, but each service recipient had extensive contact with service-providing agencies. Additionally, I interviewed next of kin in some instances.

After mapping the rehabilitation processes based in the service recipients' experiences, I next interviewed service

providers, who McCoy (2006) calls second-level informants, who had been involved in the recipients' processes to explicate and further develop the map. They represented many different professions, service providing agencies, and levels. In total, I conducted forty interviews lasting between 30 minutes and four hours. Additionally, I had access to some written documentation that in one way or another was used in connection with the rehabilitation processes.

The Work of Adjusting to Change

Entering the field of rehabilitation I had no experience with it neither as a service user, relative, nor service provider. My first impression from the meetings with the people who were in a process of rehabilitation, and in some cases their relatives, was that rehabilitation entails a lot of work from all actors involved. Smith's (2005, p. 229) generous notion of work as "anything people do that takes time, effort, and intent" opened my eyes to noticing the huge amount of work in which the service users and their relatives were engaged. The work that, according to them, took most of their time and effort was coordinating the services they received from various service providers.

When a person enters the system of rehabilitation in Norway on the municipality level, this usually is done through what is called a 'coordinating unit of rehabilitation.' This unit was established in 2001 in all municipalities in order to meet the problems of coordination in the field of rehabilitation. The administrators I interviewed who worked at these units reported that the establishment of the units had made it easier to get an overview of those who were in need of rehabilitation and made the inclusion processes fairer; however, another consequence was that the processes became more technical and impersonal. Previously, the service worker who was in touch with the service user decided whether a decision should be granted or not, whereas now the coordinating unit makes the decisions based on formal criteria. The problem is that the mandating of coordinating units coincided with the purchaser-provider split in many Norwegian municipalities, making the coordinating units more like decision-making offices than actual units with a coordinating function.

Ellen is a single mom struggling with both psychiatric and somatic health problems. Her everyday life is filled with

appointments with various service providers, either concerning her or her children. She collected the written decisions she has gotten from various municipal service units over the last few years. The headings of these decisions show that the municipality rearranged their service units organizationally many times during that time period, and the names are constantly changing. Ellen states that it is difficult to know which service unit is in charge of what. The coordinating unit only dispatches applications and has no coordinating function. When I analyzed the documents produced in the rehabilitation process, one issue emerged very clearly. The different logos on the documents, as well as their senders, tended to change during the period in which an individual was in a rehabilitation process, though the same services or cases were being discussed in the documents. One of the reasons for this is that the names of the agencies often change as a result of organizational changes or attempted changes.

Cecilie is a young girl also struggling with both psychiatric and somatic health problems. She describes the process of being allocated a Labour and Welfare Administration case worker thus:

They have organized a new system for the cases. Now, it goes by the year you were born. Previously, it was by the alphabet. So this is the third case worker I have had. For the previous year, there was a different system. They change all the time and it all gets mixed up.

Her caseworker in the Labor and Welfare Administration confirms that she has changed case workers three times over the course of the year because the welfare administration had changed the criteria for being in a specific category. First, they changed the way they categorized the service recipients, from using the alphabet to using date of birth. Later, they reorganized the cases according to whether the individuals had an employer or not, because they believed that those who did not have an employer constituted a "special group." It is understandable that those who work within an institution want to specialize professionally, but the problem is that for those who must repeatedly relate to new case workers, this is very

exhausting. The things that appear to the system to be logical and to constitute organizational improvement, appear frustrating and disruptive for those who are subjected to the changes. Repeated changes of case workers ends up being a labor that must be performed by the service recipients, in that they must repeatedly talk about their situation to new people and they must create relationships with them. Øystein, a middle-aged man who has suffered from an accident where he broke his neck and was paralyzed, describes it like this: “you constantly have to repeat a story that is not specifically pleasant to repeat.”

The service recipients are not the only ones expressing dissatisfaction with the frequent reorganizations. Many of the service providers I interviewed also talked about their frustrations in this regard. Some talk about professional meetings in which professional questions are not prioritized due to the need to discuss issues related to organizational changes. Others expressed dissatisfaction about having to repeatedly relate to new constellations of service recipients and collaborators. According to the service providers, it takes time to build new collaborative relationships with service recipients and other service providers, and when these relationships are repeatedly broken, the processes must be started afresh. There is also a risk of reorganization becoming a task in and of itself, or a goal in itself, which takes attention away from the issues the organizations are actually tasked with solving.

Ruling relations are defined by Smith (2005, p. 227) as “objectified forms of consciousness and organization, constituted externally to particular people and places, creating and relying on textually based realities.” The informants’ stories clearly illustrate the problems that arise from the reorganization of structures in the municipal sector. The written decisions show that the number of service units the persons have to relate to has increased. All of the municipalities in which I conducted my interviews had, to varying degrees, rearranged their organizational structure several times in the last few years. For the service recipients I interviewed, the primary consequence of this was the number of appointments they had and the work they otherwise had to do, for example, to meet documentation requirements imposed by the different agencies. Thus the

fragmentation that the differentiation and professionalization of the welfare apparatus created has been further exacerbated by the flattening of municipal structures and the creation of units focused on results. The coordinating units that were mandated in order to cope with these problems merged with the purchaser-provider split, which made them useless for their primary mission, separating the service workers from the administrators, and, in consequence, making the rehabilitation practice more 'managerial.'

The Work of Being Present

Without me asking for it, Ellen showed me her filofax and the appointments she had in the coming week, which, according to her, was representative for a normal week in her life:

Monday: dentist appointment with her son, appointment with the psychiatric nurse in the municipality and meeting with a lawyer concerning a child custody case

Tuesday: appointment at the family center, appointment with the child protection services and a child psychiatrist

Wednesday: parent conference at school

Thursday: meeting with her GP and a meeting at her children's school

Friday: meeting with a case worker at the Labor and Welfare administration

In addition, she often had appointments at the hospital which was an hour away from where she lived. All these appointments took most of her time and strength, and as she said, "Even if I had managed to work, I wouldn't have had time for it." She describes the work of always having to follow up the written decisions this way, "You always have to push them (the service workers), always have to show that you are paying attention, now this date is coming up, nothing happens automatically, and there is no cooperation between them."

Terje is a middle-aged man who has suffered from a stroke, and is therefore in a process of rehabilitation. His wife

describes the feeling of always having to be home when the home care services are there and of coping with the large amount of service workers:

So many different people are walking in and out of our home. Terje is in the bathroom and suddenly a person he hasn't met before comes in. It's terrible, we don't have any private life at all. This is a public arena really.

She explains that they have had up to 30 different service providers in their home during one single month. Similar to Campbell's (2008) description of the case in Canada, home care services have been made more managerial in Norway and have been labeled 'stop- watch services,' pointing to the limited time the service workers have with each client.

The Work of Proving You're Deserving

The coordinating units make decisions regarding the services to which a person is entitled. Thorbjørn is a young man who has suffered from a stroke, which caused a need for rehabilitation. During the last year he has received eight written decisions on services to which he is entitled. The written decisions clearly show that they are formulated a certain way in order to warrant a particular form of action. The documents are written in the second person, although it is clear that the decisions are not written for the person. For example: "you have a minor learning disability," or "you are being fed by a tube" or "you need help going to the bathroom." Clearly these statements are not written for Thorbjørn, but still the decisions are written in a personal "you" form. The written decisions often have a duration of six months to a year, and then a new application must be filled out. The case officer I interviewed about this said, "since the reason why Thorbjørn receives services is that he has a minor learning disability, it makes no sense that he has to fill out these applications for eight different services each year."

This is a case of what Smith (2005, p. 116) calls institutional categories that need to be filled in order to fit institutional procedures. The decisions have to be written in a certain way in order to warrant that the service recipient is actually entitled to

the services. The service workers have to write that Thorbjørn has 'a minor learning disability' in order for him to receive the services needed. Even so, the services only last for one year, and then he has to apply again. It may be argued that these decisions are written in a way that objectifies the service recipient and may be perceived as humiliating. The purchaser-provider split has made documentation more important, and the application procedures have become more complicated and more standardized, leaving less room for individual adjustment and the use of professional discretion.

Some of the service recipients I interviewed were frustrated by how difficult it is to get admission to rehabilitation institutions. The wait is generally a year or longer, although this varies from institution to institution. A physiotherapist at a municipal rehabilitation institution talked about the relationship the institution had to the coordinating unit of rehabilitation. She said the rehabilitation institution had a list of the service recipients who had been there and who they thought would benefit from returning. Those not on the list were unlikely to be given a place again if they applied for one. Service recipients must contact the decision-making office to apply to return to the rehabilitation institution:

We have a list (laughs) ... so regardless of what the service recipient says, we make up our mind about the benefits we think they have had from their stay. They may want to come back though we do not think there is any point to that. Then we have a dialogue with the granting office and ... now I should be a bit careful, but most likely they will be rejected. Probably. Because there is quite a lot of pressure on this unit, so that getting someone who is not motivated or who just has a room here ... then someone else who needs [the place] may as well get it. But then there are some who we think will benefit from returning. They will be put on a list where they get to stay here a specific number of times per year.

Representatives of the rehabilitation institution and the coordinating unit meet once a week to discuss whether those who have applied for a place there should be offered one. The coordinating unit has an overview of the entire municipality, and

their recommendation determines the outcome. Interviewing people working at the coordinating unit reveals that there is a reason why they have to prioritize the way they do. Actually, managerial reforms require municipalities to pay a daily fee to hospitals (that are state owned) if they do not manage to receive patients who have been cleared for discharge. Therefore, they use the rehabilitation institution as a substitute to care homes. These management relationships (Smith, 2005) are not visible to the people affected by them. People who are in a process of rehabilitation are probably not aware of the fact that whether they will get a place in a rehabilitation institution in the future depends on the effort and willpower they expend in training their functional abilities.

The Work of Fitting Into Categories

Everyone I interviewed has received services from the Norwegian welfare administration in one way or another. Harald is a middle-aged man in a process of rehabilitation due to having suffered from a stroke. His wife looked at her husband's individual plan during one of the interviews, and she laughed when she read: "Wants to return to work." She did not think this was a realistic goal at all, but also did not feel that she could raise the issue during joint meetings with the service providers in charge of her husband's rehabilitation process. She did not want to take away her husband's dreams, and also she felt that suggesting that this goal was unrealistic would be like saying, "Now we'd like to go on permanent disability benefits." In order to remain in the category in which they had been placed, she could not suggest that the goal ought to be changed. If the goal of returning to work was to be changed, her husband would need to move to another of the welfare administration's categories. Neither of them wanted the husband to be in the alternative category, because the permanent disability benefits would be lower than his temporary disability benefits. Thus, the welfare administration's system for categorizing benefit requirements got in the way of renewing the individual plan and making it more realistic.

The welfare administration uses different forms of benefits depending on an individual's functional ability and how likely the administration perceives the individual will be able to return to work. At the time this study was conducted, these

forms of benefits included medical rehabilitation allowance, occupational rehabilitation allowance, time-limited disability benefit (which has since been replaced by work assessment allowance), and permanent disability pensions. I was told by the caseworker of the young woman mentioned earlier, Cecilie, that they had assessed her case in such a way that a rehabilitation allowance was the best alternative at the time. She was too ill to be placed on what the case worker called an “occupational rehabilitation track,” and she was also too young for this type of benefit. The case worker had discussed this with a representative of the welfare administration, and they had agreed that it was too soon to think of occupational rehabilitation. The benefits the service recipient was to receive were nevertheless assessed on an ongoing basis, and Cecilie described the participants in the individual plan group thus:

Cecilie: There is a case worker from the Labour and Welfare Administration who is only called in when there is some financial matter, then they call this person, or if there is some major change in my mental health, right, then this person comes in.

Janne: That’s when the Labour and Welfare Administration comes in?

Cecilie: Yes, because sometimes we have to take a break in the treatment for a bit or something like that and then they have to know if we need to take break in the treatment and stop the progress.

Janne: Why?

Cecilie: I get medical rehabilitation allowance and you get that while under treatment. And they want to be informed about everything that happens, because then they know what the status of the illness is, so then they know whether the person is well enough that the rehabilitation can end or is so ill that they go on disability ... that’s what I have been told.

This segment of the interview shows that Cecilie has understood the situation to be such that it is financially preferable

for her illness to remain classified as it currently is. If she takes a turn for the worse, she may move to permanent disability, which neither she nor the welfare administration wants. If she improves too much, she may lose her medical rehabilitation allowance. In other words, she must strike a balance between different managerial logics to maintain the benefits she receives, which in turn makes it possible for her to complete her education. Mäkitalo and Säljö (2002, p. 166) point out that this is a large part of the work that is done in the employment office: to “monitor” and move people between the existing categories. Järvinen and Mik-Meyer (2003) point out that one of the paradoxes of social work is that the service providers are to both provide services and at the same time assume a monitoring function. The Norwegian Labour and Welfare Administration is especially prone to this double function because it contributes to individual rehabilitation processes and at the same time guards the state coffers. On the one hand, they are to ensure that the individuals enter paid work, or at the very least meaningful activity. On the other hand, they must ensure that the individuals do not receive more than the law entitles them to with regard to financial benefits. The service providers who work in the Labour and Welfare Administration, thus, relate to a variety of texts and objectives. The texts arguably frame what shall and can happen in and between institutions (Smith, 2005).

Discussion

People who are in a rehabilitation process experience their everyday lives as fragmented, planned, and directed according to the schedules of the service providers. This means that their daily lives are directed by systemic issues to which they must adapt. Their everyday lives must be planned according to the appointments they have with service providers. They must get up when the homecare service arrives in the morning, they must stay at home when the homecare service returns later in the day, or they must see their children off in time to make their appointment with the welfare authorities. In many ways, these appointments become what they *do* with their lives, because they do not have the time or energy to do much else.

It is also a paradox that the service agencies produce so many appointments and meetings that they make the actual purpose of the rehabilitation processes—enabling the recipients to participate socially and in society at large—more difficult. Thus, there is a conflict between the agencies' requirements regarding appointments and other everyday activities. The issue is located in the conflict between everyday life and interactions with service agencies. Everyday life is fragmented as a result of the work that being in a rehabilitation process entails.

Many service workers find that the work they perform in relation to the rehabilitation processes has no purpose and seems endless. They see this as a circle in which documents must be obtained and submitted, though they do not quite know why. It is a kind of Sisyphean work, endless and useless. The work is often complicated, and many of the participants feel like they do not have the competence required to perform it. They find the work exhausting because there are so many uncertainties involved. What is the goal of the work they are doing? Will the work ever end? Many find the feeling of being in a constant battle to be a burden. These are the main characteristics that emerge from the experiences of my main informants regarding the process of rehabilitation: it is a lot of work; it is difficult work that comes with a lot of responsibility; it is emotionally exhausting; it is sometimes humiliating work that the informants find stigmatizing; and the purpose of the work is often unclear.

These issues are related, are partly co-produced, and are mutually reinforced. The more fragmented a process is, the more work required of the involved parties. In other words, the individuals who are facing the most difficulty (many services and a lack of direction) are also subject to the most stressful work. It is a paradox that the greater and more complicated the functional impairments are, the more work related to the rehabilitation process a person must do, and by extension, the greater the risk of deprivation.

As I have shown in this article, a lot of the work that has to be done is connected to managerial reforms making the system more administratively complex and (contrary to the intentions) more bureaucratic. The frequency of organizational changes has grown significantly in Norway during the past 20 to 30 years. Røvik (2007) explains this in terms of both the

demand and supply of new organizational recipes having increased rapidly during this period.

Reforms tend to lead to changes in the organizations that make them less stable for service providers and users alike. Attempts to implement changes in the organization lead to changes in categories, that in turn lead to reorganization of the service providers in charge of the rehabilitation processes. For the informants in this study, the reforms are felt through changes that make their everyday lives more unstable. For the users of the services, the changes result in a constant turnover of the service providers they must relate to, which in turn makes their everyday lives more fragmented. Additionally, the planning of the rehabilitation processes is made more difficult when service providers are constantly being replaced. Though arguably the changes in organizational structures rarely cause changes in goal achievement or changed patterns within the organization (Brunsson & Olsen, 1993), the changes do impact the individuals that are both within and outside of the organizations and who must relate to the changed structures in one way or another.

The managerial reforms are manifested in the informants' everyday lives in that they must relate to a large number of units that do not have any formal points of contact for collaboration. The managerial reforms produced so-called "result units" that were to "manage themselves" to a greater extent. Through the reforms, more responsibility was to be delegated to unit managers, which in turn was to make municipal bodies more efficient. This process, however, does not include considerations of service recipients who require services from different units and who need these units to interact. The municipalities needed to categorize the services in the different units and allocate responsibility for a service area to each of them. However, reality is not divided into these categories, and these reorganizations, therefore, make the everyday lives of people receiving services from the different units more difficult.

Conclusion

The new public management of municipalities has intervened into the holistic rehabilitation ideology, turning it into a less fortunate blend for service recipients in the field of

rehabilitation in Norway. It can be concluded that the system's need for change leads to the abandonment of service recipients' and service providers' need for stability. In terms of the problems the rehabilitation field has faced, these have tended to be solved as organizational problems. Seen through the lens of institutional ethnography and the informants' points of view, the solution to the problems are to be found in the opportunity to see the service providers as negotiating structures that acknowledge that there is a discrepancy between the complexities of everyday life and the system's ability to capture this complexity. Instead, the system is constantly changing the structures according to the latest organizational fashions.

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