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**Article:**

# **To tell the right story: Functions of the personal user narrative in service user involvement**

by

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## **Abstract**

From the starting point of narrative ethnography, this article explores a specific kind of service user involvement in psychiatry: staff training activities in which patients and former patients are invited to “tell their stories”. A core feature of these stories is that they are based on the narrators’ self-perceived experience, and they all have a highly personal character. I call these stories *service user narratives*, and these are the topic of study in this article. The narratives’ disposition, content and functions are explored, as is the role played by the personal aspects of the stories. This article investigates two functions of the service user narrative: the narrative as a means (1) of creating alternative images of mental ill health, and (2) of enabling a critique of psychiatry. The context wherein the stories are told can be understood as containing an inherent power asymmetry, in which the narrators hold a subordinate position relative to the organization and its employees. Hence, the study explores how power structures affect and might be affected by the user narratives. It turns out that while the user narratives work as counter-narratives in some respects, questioning the dominant order, in other ways they maintain the current power balance within psychiatry. The personal features of the user narrative are vital to enabling the delivery of a critique—however, at the same time, the same personal features could also work to help maintain the narrator’s inferior position.

## **Keywords**

*Narrative, service user narrative, user narrative, function, service user involvement, user involvement, counter-narrative, power.*

## Introduction

In the last 20 years, service user involvement (or user involvement)<sup>1</sup> has become increasingly common in the political discourse and welfare practice in Sweden and elsewhere (Braye, 2000; Karlsson and Börjesson, 2011). However, user involvement is known to be an imprecise concept, resulting in many different activities with different aims depending on where and by whom it is implemented (Braye, 2000). While examining how user involvement was realized in psychiatry, I found that one common implementation was to invite current and former patients to “tell their stories”. Characteristic of the stories told was that they included a considerable number of personal references and intimate details. In many ways, they resembled life-story narratives (Polkinghorne, 1991), and I refer to them as *service user narratives* or *user narratives*. These narratives,<sup>2</sup> particularly their personal character, made me curious, and they are the topic of this article. More precisely, investigated here are such instances in which user narratives are consciously planned and used as a way to create service user involvement within psychiatry. What does telling these personal stories in this context achieve?

Ultimately, service user involvement entails the relationship between service users and practitioners; it is a relationship understood as one of the core dimensions of human service organizations (Hasenfeld, 2010). This relationship holds an inherent power asymmetry,<sup>3</sup> as the practitioner generally has an advantage in terms of power. This power asymmetry is characterized by, e.g. differences in educational level, class, societal positions and discretion, as well as by a mandate to distribute benefits, practice public authority and govern care (Hasenfeld, 2010; Lipsky, 2010). Concerning health care and the relationship

between clinicians and patients, Abrums (2004) has pointed out that this

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<sup>1</sup> The two terms are used synonymously in the text, and the concept of user involvement concerns using service users' knowledge, views and opinions in the formulation and execution of welfare services.

<sup>2</sup> Within different academic fields, the concept of narrative can have various meanings and refers to different things. In this article, I ascribe to the sociological use of the term, focusing on narrative as a way of constructing reality and identity.

<sup>3</sup> In the article, power is understood as a relational entity (cf. Foucault, 1987). All agents exercise power in accordance with their resources and knowledge; however I recognize the existence of structural power asymmetries between groups in which domination becomes a significant expression of power (cf. Fraser, 1989).

relationship is a “social relationship of control that supports the dominant order” (p. 188). Thus, in the context in which my narrators tell their stories, they have generally done so from a structurally subordinate position. It has been suggested that members of subordinate groups are especially well situated to raise critical questions concerning societal institutions assumed to serve the welfare of society (Harding, 1998). However, Agevall and Olofsson (2006) have argued that service users’ dependence on the service provider can prevent expressions of critique (cf. Möller, 1996). In many cases, the service users’ health or livelihood is directly dependent on the organization, and with no alternative service provider to turn to, a narrator may face severe personal costs if expressing a critique places her or him in conflict with the service provider (Agevall and Olofsson, 2006).

Lipsky (2010: 193 pp., 208) has claimed that a more balanced power relationship between users and practitioners is needed to improve service provision and to help avoid discriminatory and stigmatizing practices in human service organizations. Accordingly, some stakeholders argue that emancipation and the transformation of power relations is an important aim of user involvement (e.g. Braye, 2000; Ager and McPhail, 2008). Such a change would not necessarily imply dramatic transformations, but could merely mean that service users’ views are considered to a greater extent. However, research has shown that it can be difficult to create an influence for service users. Hodge (2005) has shown how power relations in psychiatry are actually reproduced through activities designed to create influence, while according to Stickley (2006), it is impossible to change power relations from within the organizational discourse. Hodge (2005) and Stickley (2006) both conclude that service user involvement in their studies seem to have as its main function legitimizing the organization, while real influence for the service users is rare. How then are the narrators and the service user narratives in my study affected by the power structures governing the psychiatric context (cf. *ibid.*), and can the narratives become a way of challenging the dominant order?

The following analysis is divided into three parts. First, I describe the user narratives more closely with regard to their creation, disposition, content and “emplotment” (Ricoeur, 1984). In the second part, I focus on two functions (Cortazzi, 2007)<sup>4</sup> of the narratives that became evident in my material—namely, user narratives (1) as a way to show alternative images of mental ill health, and (2) as a vehicle to enable a critique of psychiatry. In the final part, I explore how the power structures of psychiatry affect and might be affected by user narratives. Throughout the entire analysis, I pay special attention to the role played by the private nature of the stories.

### **Narratives and potential for emancipation**

In sociology, narratives are usually studied as a means whereby individuals create (social) reality through interaction; narratives are seen as a way of collectively making sense of, understanding and ascribing meaning to reality (e.g. Bruner, 1991; Sparkes and Smith, 2008). Complementarily, from a psychological or micro-sociological starting point, narratives are understood as a vital means by which individuals conceptualize the self and their identity (e.g. Polkinghorne, 1991; Battersby, 2006). In mental health care, the healing or health-promoting dimensions of narratives have been widely acknowledged, which is something exemplified by the practice of “narrative therapy” (see Morgan, 2000). It has also been argued that narratives promote understanding and learning (Greenhalgh and Hurwitz, 1999); thus, patients’ stories have been acknowledged as a fruitful tool in the education and training of mental health practitioners (Balen et al., 2010).

Even though life stories and narratives, as well as service user involvement, are objects of an extensive body of research, and although service users’ personal experiences are understood as a key component in user involvement (see Beresford and Croft, 2001), there is a limited amount of research investigating narratives within user involvement. The issue has been addressed in the field of

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<sup>4</sup> In the social sciences, the term *function* is best known in relation to the structural functionalist framework. I use the term *function*, however, as it is understood in ethnographic narrative analysis (see Cortazzi, 2007:387p). Hence, investigating the narrative functions in this article does not entail examining the effects of the narratives in relation to their intended outcome.

somatic health care by, e.g. Blickem and Priyadarashini (2007) and Hardy et al. (2007), and in palliative care by Cotterell et al. (2009). Here, the patient narratives are understood as possibilities for identifying areas for improvement of care or to promote patient-centred care, and the narratives are commonly gathered through interviews instead of being presented by patients in front of an audience. In mental health care, Lloyd and Carson (2012) have presented a user involvement model in which patient narratives are used as a base to create a “critical conversation” between users and practitioners, thereby allowing the practitioners to critically reflect upon their practice. In this research, however, the narratives themselves are rarely the main topic of inquiry; rather, the focus is on the activity of service user involvement or the specific opinions that the narratives express.

Among others, Banks-Wallace (1998) and Williams et al. (2003) have investigated the emancipatory dimensions of narratives. Focusing on storytelling among African American women, Banks-Wallace shows that narratives can be a way for marginalized groups to strengthen themselves and resist oppression. Investigating narratives as a way of empowering women in marginalized communities in New Zealand, Williams et al. (2003) conclude that “storytelling has re-emerged as a method with which people might begin to challenge dominant social discourses (and hence social structures) through their assertion of non-dominant cultural constructions, personal identities and world views in the public sphere” (p. 34). Such narratives can be understood as counter-narratives, attempts to challenge the dominant “truths” and discourses (i.e. the master narratives) in a given context by presenting alternative stories and views of reality (see Bamberg, 2004; Andrews, 2004). Counter-narratives give voice to perspectives that are seldom expressed and articulate experiences of oppression and discrimination (de los Reyes and Mulinari, 2005: 93, 130). While master narratives preserve existing power structures (Thommesen, 2010), the counter-narratives attempt to resist oppression and alter the power relations.

## **Method and empirical data**

### **The context of the narratives and the characteristics of narrators**

This article is based on field notes derived from participant observations conducted within the framework of my PhD project, while the organization in which the narratives were presented is a county-based psychiatric organization in one of Sweden's metropolitan areas. The organization provides care across the entire spectrum of mental health to both adults and minors in the form of out- and inpatient care, as well as compulsory care and forensic psychiatry. The organization has facilities throughout the county, and as a whole the organization employs approximately 3,000 people.

The narratives investigated were prepared, planned and carried out within this organization as intentional acts of service user involvement. More specifically, the narratives analysed constituted patient involvement in staff training. Sometimes, the narrators engaged in staff training in a delimited way, telling their stories and answering questions, whereas at other times patients were responsible for implementing the entire staff training module, thus allowing for further discussion and exercises based on the narrative. In those instances, patients continued to refer to their narratives to support their arguments. Access to the settings was primarily granted in contact with the employees and/or service users responsible for the specific staff training, people who I usually had no prior relationship with.

Within the material, I have identified a total of 10 user narratives told at different staff training events. The narratives are told by women and men, usually between the ages of 25 and 40, and most often from a middle-class background. Drawing on their narratives, some were relatively well-established citizens, whereas others lived a little more on the margin. However, none appeared as being excluded from society in the sense of lacking housing, financial means or social relationships. The narrators had a variety of experiences with mental ill health such as: self-harm, border line personality disorder, autism spectrum disorder, psychosis and schizophrenia, depression or bipolar disorder. The narrators' various experiences of mental health problems



and their social backgrounds did presumably affect their narratives and the way they told them. Yet, their narratives exhibited many similarities, and as narrators the individuals appeared as a quite homogenous group: well-mannered, well-articulated and dedicated to the task. In the analysis, I focus on the similarities between the narratives rather than the differences.

### **Conducting the analysis**

In the analysis, I initially focused on the 10 narratives as they were told as a compounded whole, typically at the beginning of the training module. However, given that the narration in many cases continued throughout the staff training sessions, I also included the field notes as a whole in the analysis. When analysing where and why user narratives were used, I also considered parts of the field notes recorded when patients, former patients, practitioners or managers discussed the matter of user narratives. All the field note extracts in the analysis have been translated from Swedish, and all names and in some cases specific details have been changed to ensure anonymity.

The user narratives occurred “naturally” throughout my field studies (Silverman, 2007). This means that, in contrast to narrative interviews, when I was making participant observations life-story narrations took place without me evoking them. The situations in which the narrations were given allowed me to take notes close to the actual speech. In the main, the only thing going on in the room was the storytelling, as all other people present sat quietly, listening. Nevertheless, except where quotation marks denote, all narrative extracts presented are approximations of what was said and not verbatim transcriptions. Hence, the narrative extracts are derived from field notes and not from recordings, thereby making impossible a meticulous focus on frequency of words, choice of words, grammatical forms and so on. Instead, the “live” setting of my narratives offers a good opportunity to situate and understand each narrative in relation to the broader contextual setting in which it occurred, as well as to study the interpersonal relationships between narrator and audience (see Mishler, 1986). The analysis focuses on content and overall structure, rather than on details and specific forms (cf. Lieblich et al., 1998:13), and the

narratives in this case are the main object of study instead of a method used to investigate something else.

To investigate the function of the user narratives, then, homing in on the “whats” and “hows”, as well as the “whens” and “wheres” (Holstein and Gubrium, 2007) of the narratives, I have considered four narrative aspects. Given that the user narratives themselves are the main topic of this article, the most significant part of the analysis is devoted to exploring the *content* of the narratives. In practice, I have conducted this part of the analysis by looking for recurring themes or commonalities among the 10 narratives (cf. Lieblich et al., 1998). In addition to the content, I also investigated the *context* in which the user narratives appear. Do they appear in some specific settings?<sup>5</sup> How do the narratives relate to the surrounding context? In analysing the context, I also examined how the narratives were *received* by the audience, taking into account how the audience responded both during and after the narrations. As a researcher, I can be understood as a part of the audience, thus possibly affecting the narration. However, apart from presenting myself and my study at the beginning of each of the staff training activities, I did not actively interact with the narrator or the staff training participants during the sessions by raising questions or participating in the follow-up discussions. Lastly, what was *said* about the narratives is considered. In this respect, I take into account how different people in my material talked about and explained the use of user narratives. In its entirety, this approach can be compared to Cortazzi’s (2007) method for analysing narratives and their functions from an ethnographical starting point.

### **What’s the story?**

I begin the analysis by considering the shape and content of the user narratives. What kind of story is the user narrative?

### **Teaching the telling: How user narratives are directed by psychiatry**

Throughout the fieldwork, it became evident that the narrators themselves did not fully control their narratives. As chief of the activities, the organization ultimately determines when and where in the organization the user narratives

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<sup>5</sup> As previously mentioned, the narratives most commonly occurred in staff training activities.

are told. Concerning the content of the narratives, the narrators have a greater influence; when actually telling their narratives, they are in a position to decide what to say. Even so, by governing the situations in which the narratives are told, the organization is able to influence the content of the narratives as well. If, for example, the context of the narrative is a staff training activity concerning recovery from self-harm disorders, the narrator is expected and instructed to shape the narrative to suit the occasion.

Another way the organization influences the content of the user narratives is by educating the narrators. During my field studies, I followed a “communicator training” seminar: a two-day education session in which approximately 20 patients and former patients were trained to tell their stories in a psychiatric context. The training contained a great deal of teaching on rhetoric and pedagogy, and on how to structure and tell a story in general. Much time was devoted to practicing speaking in front of an audience, which aimed at boosting self-confidence, overcoming stage fright and enabling the narrators to speak more freely, although the content of the user narratives was also discussed during the education. For instance, it was understood that the narrations were expected to touch upon private matters; hence, teaching included making the narrators aware of what parts of their life they were comfortable sharing. It was repeatedly stressed that aspects of their stories that the narrators were not “finished processing” should not be brought up because this might lead to an uncontrolled expression of emotions. This part of the education was apparently aimed at protecting both the narrators and the organization from inconvenient situations that could presumably arise if the narrators were not properly prepared.

In the communicator training, the overt aim of telling one’s story was formulated as a way to: (1) improve treatment, (2) increase the quality of care, (3) point out shortcomings, and (4) challenge the existing view on mental ill health. As these goals imply, the organization is aware of and accepts the fact that the user narratives might present negative experiences of the organization. However, the tutors never talked about this as expressing critique. Instead, a user narrative

was formulated as giving the patient's "view", "experience" or "perspective"—something the organization could use to improve the quality of care. In an effort to control the negative aspects of the user narratives, the importance of "being positive" was repeatedly stressed during the education (cf. Hayward et al., 2005):

That is what this education is about, Sarah [one of the tutors] says: learning how to talk about this kind of [negative] experience, how to "spew them out" [referring to an expression used earlier] because there is nothing wrong with that, but what we have to learn is how to do it in a constructive way . . . to do it constructively so that the listeners do not just shut the door not wanting to listen, but instead to tell it in a way that actually gets the message through. (field notes)

Another tutor closed the entire training session with these words:

What I want you to carry with you from this education, regardless of where you are telling your story, is this: "be a role model", "be a good example" and always "focus on what has helped you". (field notes)

Another way in which the education directed the user narratives was by stressing the importance of always adjusting to the overt aim of the activity in which the narration takes place; to be a good narrator, one has to meet the expectations in that specific context. Since the overt aim is never to express critique, this kind of steering implicitly becomes yet another way to orient the narrators towards the more positive aspects of the narrative, towards the aims of "facilitating learning", "improving care" and "improving attitudes".

These examples show that the organization directs the user narratives, and the power structure governing the situation becomes quite clear: the narrators are recruited (and trained!) by the organization to conduct activities following its requirements. Accordingly, this form of service user involvement is understood within the organization as a more controlled form, while in other kinds of service user involvement, the patients act more freely in relation to the organization.<sup>6</sup> In spite of this, it is assumed that the patients also benefit from the opportunity to

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<sup>6</sup> It should be noted that during the two-day communicator training seminar, a representative from the local network of patient organizations had the opportunity to speak, thus underscoring the importance of an uninfluenced patient perspective and encouraging the participants to join other kinds of activities to create a user influence as well.

present their narratives, and the patients indeed hope to gain something. As expressed during the training, the main motivation in becoming narrators was the opportunity to be listened to and to freely talk about the mistreatment they were sometimes exposed to. Thus, the dimension of personal vindication seems to be central. This personal motivation is then usually combined with an outspoken will to influence the organization to do better, thereby ensuring better treatment for future patients (a goal coinciding with that of the organization).

Leaving the training, typically in good spirits and with great aspirations regarding making a difference (an attitude characteristic of the entire training programme), the narrators are then registered on a list of available speakers that the organization can engage when needed.

### **A three-dimensional narrative**

With all its complexities, a person's life can never be narrated in its entirety; a specific life-story narration is one of many possible ways to present an account of one's life, and the narrative is always adapted to a specific context and purpose (McAdams, 1998:1138f; Bury, 2001:281). The user narratives investigated here naturally differ from one another, but they also share common characteristics. Together, they can indeed be seen as a specific kind of life-story narrative, typically consisting of a combination of three distinguishable aspects.

First, the user narratives contain elements of an "illness narrative" (see Frank, 1995; Hydén, 1997; Bury, 2001). This dimension of the narrative involves the narrator's focus on the mental ill health she or he has experienced. For example, narrators talk about how the ill health appeared, how they first discovered their problems and how they managed the consequences of their ill health. The following extract demonstrates this aspect of the user narrative:

The last time I had a psychotic episode was when I was going to Stockholm for work; my little kid was newborn at the time. Then it came again; it seems like I have an episode every time I have a child. The feelings are so strong, and it can be triggered by positive feelings, as well—not only by negative events. Sitting on the train, I was chatting with a friend on my computer, and apparently I became

weirder and weirder in my writing. I don't remember any of this, but it got so bad that my friend decided to alert the police, so they picked me up at the station. . . . I remember telling the policeman how sick he was in the car on our way to the psychiatric emergency room. Because that's how I feel when I'm in psychosis: I am well and everybody else—you're sick. (John's narrative)

Second, the user narratives contain dimensions of what could be called a *care narrative* (cf. Öhlén, 2001), which can concern positive experiences of care as well as experiences of misunderstanding, neglect or abuse (Halldórsdóttir and Hamrin, 1997; Skott, 2004). In this narrative element, the narrator gives an account of how she or he has experienced different therapeutic approaches and the treatment received from different practitioners. The following extract is an example of the care narrative dimension; Nadal talked about her time at a closed ward, and she highlighted both the positive and negative experiences of care:

I couldn't breathe; it's this feeling of total powerlessness—I was constantly crying. It was the same thing every time lying in the belt bed. And I felt so humiliated when the nurses just left the room, left me there all alone in the belt bed, even though it's against the law. Or sometimes they just sat there reading a paper, ignoring me completely. . . . However, I want to add that other times I was treated well during the belting. That's when the nurses held my hand, talking to me and telling me I wasn't alone. That felt good. Or when they help you to focus on just breathing, that made me calm. (Nadal's narrative)

Third, the user narratives also typically contain a distinct dimension of a regular life-story narrative (see Polkinghorne, 1991; Battersby, 2006), which is an individual's narration of her or his own past, present and future life. In the user narratives, these are the threads that do not connect to the individual's ill health or experience of care; instead, they are merely accounts of ordinary life interjected throughout the narrative. These extracts from different user narratives exemplify the regular life-story narrative dimension:

I like spending time with my family and my two cats, and I am also a creative person. (Nadal's narrative)

I studied to become a nurse, but realized that I wasn't really interested in that line of work. But the man I was living with was a

parasite; he was supposed to write a novel, and the only way for him to survive was at my expense, so I had to work *and* do all the housework. (Katrin's narrative)

In sum, the service user narrative contains elements of an illness narrative, a care narrative and a general life-story narrative fused into an integrated whole. The emphasis on one of the three aspects can vary in different narratives depending on the plot, but the user narratives in my material are characterized by the fact that they always contain, to some degree, all three aspects. As the extracts already quoted show, it is essential to an understanding of the user narratives to recognize that all three dimensions of the narrative are highly personal. The user narrative as a whole is a highly personal narrative, commonly containing intimate and private details. Even so, at the same time they are presumed to say something general about the subject at hand; therefore, they have a collective dimension (Hydén, 1997:59).

### **The emplotment: Learning, understanding, and change**

The plot of a narrative can be understood as the purpose of the story, and through emplotment the narrative is directed towards a given ending and becomes a coherent whole (Ricoeur, 1984; Polkinghorne, 1991). As suggested earlier, the organization governs the emplotment of the user narratives, and the narrators telling the stories—usually in an outspoken manner—supports the framing obtained by psychiatry. An examination of where the stories are told reveals that the structured use of user narratives in order to create service user involvement is basically exclusively connected to learning activities. The learning activities can target the general public or other patients and relatives (cf. Gemmae et al., 2012), but I focus here on instances when the learning is aimed at employees of health care organizations, typically through different kinds of staff training.<sup>7</sup> It is assumed within the organization that practitioners could learn about mental health and care from patients' stories (cf. Hayward et al., 2005). This learning is often spoken of in terms of an “enhanced understanding”, thus providing a perspective other than the clinical one—

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<sup>7</sup> In my experience, this is one of the most common ways, if not the most common way, of implementing user narratives in service user involvement.

namely, the patient's perspective (cf. Haeney et al., 2007; Hydén, 1997), which is articulated through the service user narratives.

Within the broader intention of fostering learning, it is possible to identify two main aims (plots) of the staff training activities, two purposes that the narratives are expected to fulfill: a change of attitude and a change of practice.<sup>8</sup>

The aim of changing attitudes is based on the belief that stigmatizing attitudes towards persons experiencing mental ill health exist among mental health professionals; this has been confirmed by, e.g. Hansson et al. (2013). These denigrating perceptions<sup>9</sup> of mental health patients are presumed to lead to poor treatment. Therefore, specific staff training modules focus entirely on enhancing caregivers' attitudes towards people with mental ill health, and on making the provided care more patient friendly. The assumption is that if positive attitudes become more common, this will lead to a change of practice and treatment as well. Thus, a change of attitude and a change of practice, the second overt aim, are coupled. However, the second aim can also stand on its own, which is the case when the staff training is aimed specifically at implementing a new treatment method. In these cases, the user narratives are used as "living evidence" of the advantages of the new method—a rhetorically strong story, since it is difficult to argue against a person's own experience.

### **Two functions of the service user narratives**

In my investigation of the service user narratives, two functions became evident. Regarding the ambition of changing attitudes, one function of the narratives was to provide an alternative picture of mental ill health, and concerning the ambition of changing practice, one function was to enable a critique of the organization. Through the analysis, it became evident that the personal character of the narratives was vital to both these functions.

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<sup>8</sup> It should be noted that I have not investigated whether attitudes or practice actually change as a result of the patients' narrations; therefore, I cannot say whether the user narratives in fact meet these expectations.

<sup>9</sup> Such attitudes include the idea that people with mental ill health are different, strange or even dangerous, unable of taking care of themselves and incapable of making informed decisions regarding their own lives or care.



### **An alternative picture of mental ill health**

When it comes to changing attitudes, the user narratives often focus on showing that people who experience mental ill health are “ordinary people”, or perhaps

different only in some limited aspect. They are people with the same value and dignity as everybody else and they are not dangerous or harmful, as the general understanding might claim. The narratives typically present patients as intelligible human beings leading lives that in most respects are “normal”. The following extracts demonstrate how this view is articulated:

Yes, I have a mental disorder, but there is so much more to me than that disorder—that’s what I want to communicate to you today.  
(Beatrice’s narrative)

A quarter of the entire population suffers some kind of mental ill health. This is nothing strange or unusual at all; still, people speak quietly about it. It shouldn’t have to be that way; people have to understand that the picture you get from the media isn’t true! (Katrin’s narrative)

In an analytical sense, the function of the narrative here is to provide an alternative and more positive picture of mental ill health—that is, a new or modified understanding of reality. When providing this alternative image, the regular life-story dimension of the user narrative becomes prominent. In the two following extracts, the narrators referred to their personal lives, showing that their lives are indeed “normal”.

I am also involved in local politics; for the moment I have taken a leave of absence from my regular job to work full time for my party.  
(John’s narrative)

At that time I started thinking of myself as a musician with a disability instead of a mental patient writing songs; it was a great feeling. At the same time my girlfriend and I moved in together. (Peter’s narrative)

In addition to such narrative references to ordinary life, some narrators also showed photos of their children, holidays or other private occasions to further illustrate their normality. Another very concrete way in which the patients painted this alternative picture is through the simple fact of actually standing there, in

front of the practitioners at the staff training, telling their stories in a clear and friendly manner and perhaps leading the entire staff training module. This action in all its concreteness reveals a capable and intelligible individual, contradicting the negative image of the incapable patient.

According to Bohn (2010:22), the phrase *cultural life script* “refers to the culturally shared representation of an idealized life”. The cultural life script is used as a frame of reference when narrating one’s own life story, and in Western societies events such as graduations, weddings and the birth of children are typical life script components (ibid.). To oppose the negative stereotype of mental ill health, the narrators pronouncedly oriented their stories towards the norms of the cultural life script, and the user narratives allow the narrators to reconceptualize themselves as human beings (cf. Frank, 1997) and moral subjects (Bury, 2001). However, people telling their life stories tend to give explanations for instances when their life deviates from the cultural life script (Bohn, 2010), and this fact became a considerable pitfall for the narrators in my study. In their attempts to conform their narratives to the cultural life script, the narrators repeatedly made efforts to explain missing life script events. In doing this, they often referred to their mental condition as the reason for their deviance. This extract, in which Peter talked about not making it through a residential collage for adult education (Swedish *folkhögskola*), is one example of this phenomenon:

Of course, this became a total disaster. You see, my kind of [mental] condition demands that I have my own space; I can’t have people around all the time—for example, I can’t live with someone I’m in a relationship with. I’ve had to come to terms with that. And this residential college was great fun, for sure, for as long as it lasted, but you were supposed to live together with other people, and I couldn’t handle that. (Peter’s narrative)

Hence, the narratives show that the narrators in some respects do in fact deviate from “normality” because of their mental conditions. Moreover, the single most prominent dimension of the user narratives is the illness narrative, and the narrators often tended to talk about the troubles of life and to single out what

makes people with mental ill health different from others. So even as the user narratives provide an alternative to the general denigratory understanding of people with mental ill health, often presenting the image of an intelligible, competent, well-mannered and friendly person, the narratives also continue to single out mental patients as being deviant in some respects.

### **A vehicle enabling critique**

As previously mentioned, the primary explicit purpose of the user narratives is never to deliver critique; instead, a typical plot is to lead to a change in practice. Although changing practice does not necessarily involve explicitly expressing a critique, any call for change usually implies that the current situation is in some way unsatisfactory. Accordingly, the patients indeed used their narratives as an opportunity to deliver their critique. These expressions of critique were permitted by the organization, but instead of using the term *critique*, organization representatives formulated this aspect of narration in terms of the patients' expressing their experiences or perspectives. Normally, however, expressing one's experience of care seems to entail a considerable amount of critique.

In seven of the 10 narratives studied here, critique constitutes an ample part of the narration, although the three remaining narratives contain only small amounts of critique. In these cases, the absence of critique reflects the fact that the narrators experienced the care they received as satisfactory. All 10 narratives share the ambition of effecting a change in practice, but while three narrators attempted to do this by using positive examples, thus enhancing the practitioners' understanding of mental ill health, the seven narrators considered in this section attempted to do this through use of critique. An analysis of the structure of these seven narratives with respect to the introduction, middle and end (see Hydén, 1997) fleshes out an ideal typical structure of the narratives.

The *introductory part* of a user narrative typically contains a fair amount of the regular life-story dimension, with patients usually sharing something about themselves and their background. Sometimes the stories reveal a difficult past characterized by multiple social problems, and sometimes they reflect a happy background. Regardless, this part of the narrative presents the narrator

her/himself. For example, Beatrice started her story by relating her past relationship with the father of her children:

He had his own business and worked a lot. I became pregnant early in our relationship, and wasn't sure I wanted to have the baby, but my family said that of course I should keep it and keep the relationship together. I soon felt a great loneliness in the relationship because the father wasn't around. I had to do everything: all the housework, raising the children, cleaning, laundry and so on. (Beatrice's narrative)

In their introductions, the narrators typically also discussed the expressions of their ill health a great deal, along with the difficulties their mental ill health (or the discriminatory view of mental ill health held by the general public) led to. David talked about growing up with Asperger's syndrome:

I always felt like I wasn't like everybody else in school. I only had one friend, a guy just like me. But I didn't really have any interest in the other children anyway. The teachers used to say that I was unintelligent. I got bad grades and had a hard time concentrating. Everybody except the chess teacher said I was stupid, so I started to believe that it was true. (David's narrative)

Such accounts seem to create sympathy for the narrator, and I could usually witness the audience carefully listening during this part of the narration, focusing on the narrator, nodding slowly in understanding or empathy, smiling at happy memories or shaking their heads and grimacing compassionately at accounts of difficult events. On the whole, the introduction seems to create a relationship between the narrator and the audience. According to Frank (2000), the relationship between narrator and listener is vital to the narrative, as it enables unity and understanding, and through the introduction the narrator becomes visible as a human being, usually in an exposed position, and thereby presumably more difficult to dismiss.

In the *middle* of the narrative, the illness and care dimensions are given the most space, and woven into this part of the narrative is a fair amount of critique directed towards the organization. This critique can involve anything from

relating outright mistreatment to remarking on odd routines within the organization and reporting how specific practitioners had talked to or treated patients badly. Johanna's account provides an example:

When the doctor asked me why I hadn't talked about my husband's assaults earlier, I said that I didn't dare, because my husband is a high-ranking psychiatrist himself, and I was afraid that he'd find out. The doctor didn't believe me and accused me of delusion and paranoia. His distrust made me angry, and I tried to leave, but the doctor pushed the alarm and guards forced me brutally to the belt bed, dragging me through the corridors and ignoring my explanations and tears. Usually you're belted lying on your back with your arms at your sides, but I was put on my belly with my arms on my back, lying in that position for several hours [she shows the position with her arms and body]. This has permanently damaged my shoulder and arm. (Johanna's narrative)

The critique put forward can be seen as creating an alternative picture of the organization, often implicitly understood as doing "good" (Hasenfeld, 2010:10), as well as a way of questioning the authority of the clinicians (cf. Abrums, 2004). Moreover, this part of a user narrative can be understood as a kind of emancipation from the care sometimes violently forced on patients. As demonstrated in the preceding extract, the critique is continually underpinned by personal accounts. Without the personal elements, the critique in this case could have been formulated something like this: "The doctor did not believe my words and accused me wrongfully of being paranoid and delusional. The guards did not listen to me and used excessive force that violated policy." However, the vivid personal descriptions seem to be a way of gaining support for one's statement, thereby making the statement more trustworthy and more difficult to contradict (cf. Gemmae et al., 2012).

In the *final part* of the narrative, positive experiences of recovery and care are common. The patients here discussed the ordinary life they now lead, being free from their mental ill health or having learned strategies to cope with the situation. Here the narrators also gave examples of when the organization had

indeed done well, helped them and been genuinely caring, and they relate positive encounters with professionals who have done their jobs well:

The turning point for me was when I met this nurse; she was really good. . . . When I told her that this was voluntary care and that I didn't want to do a supervised urine sample even if that was standard procedure, she listened to me and understood. She set aside the routines for me, and because of this a true discussion started; now we could really talk to each other. Later she fought for my sake, making sure that a proper ADHD evaluation was done, and it showed that I didn't have ADHD at all—I had Asperger's syndrome. . . . Later I received KBT treatment to learn strategies to manage difficult situations. The panic attacks disappeared after this, and I haven't had any need to contact a psychiatrist ever since. (David's narrative)

This positive ending serves to restore the audience's faith in the organization that had perhaps been damaged by the critique, and it could also relieve some of the hard feelings towards the narrator that might have arisen. This part of the narrative typically also answers the critique and resolves the plot, as the answers usually concern the narrator's view of how good care should be conducted. These answers become yet another way to infuse hope in the audience, and Chart 1 sketches the outlines of this ideal typical structure of the service user narrative:

<b>THE SERVICE USER NARRATIVE</b>		
<b><i>Introduction:</i></b> Create understanding, relationships and sympathy	<b><i>Middle:</i></b> Present critique and problems	<b><i>End:</i></b> Give positive examples and solutions, create ease and hope

**Chart 1**

Embedded in the service user narrative is often quite a voluminous and vast critique of the organization as expressed by the narrators and, more importantly, received by the audience without dispute. With its creation of relationship and sympathy, the introduction becomes a “seatbelt” for the audience, and the calming effects of the final part of the narration work as an “airbag”; together, they allow everyone involved (audience members and narrator) to walk away safe and sound from the “crash” of the critique. As shown earlier, this embedding of the likely provocative parts of the narrative is promoted by the organization through its communicator training. Thus, the organization actually provides the narrators with a tool to deliver critique, but simultaneously directs and governs the shape of that critique.

Here, it is revealed why the personal character of the user narrative is important to this function of the narrative: it plays a significant role in creating the circumstances (relationship, closeness, sympathy, ease, comfort, etc.) necessary to successfully express critique. After the narratives had been concluded, I commonly heard people in the audience saying to one another, “This has to change,” or “Something has to be done about this.” Likewise, the comments and questions after the narrations rarely challenged the narrators view; instead, they commonly were curious and positive in tone, as an understanding of the critique and a desire to change seem to have been created.

Looking at the overall disposition of the user narratives reveals the presented ideal typical structure in five of the seven narratives used to express critique. In the other two cases, the critique is more evenly distributed throughout the narratives. The ideal typical structure appears in these narratives as well, but there it recurs in smaller segments of the narratives, in which each bit of critique is embedded in fragments of personal experience and positive examples.

### **Power relations: Questioned and maintained**

Thus far in the analysis I have focused on describing the user narratives and some of their functions. Now I turn to a discussion of how the user narrative is

affected by the prevailing power structures governing psychiatry (cf. Stickley, 2006) and the possibility that user narratives might question this dominant order.

### **The service user narrative: A counter-narrative?**

If one applies the concepts of master narrative and counter-narrative, the user narratives presented throughout this analysis clearly exhibit some features of a counter-narrative. Turning to the first function presented earlier, the user narratives examined here in many aspects did exactly what one expects a counter-narrative to do: they presented an alternative image. If the societal master narrative of mental ill health views those living with ill health as deviant, low functioning, unpredictable and dangerous (Angermeyer and Dietrich, 2006), the user narrative attempts to establish a much more positive picture. Still, as demonstrated, to some extent the user narrative singles out people with mental ill health as in some ways deviant. On some occasions, the narrators also more directly reproduced the negative image of a dangerous mental patient, as in this extract:

After that I tried to start a new relationship with another woman, and then I became violent again in this relationship as well. That's how I react, and I got put in the closed ward again. . . . And I was very violent at the ward, "bang on psychotic" and "totally fucking crazy."  
(Peter's narrative)

Even if indeed they sometimes unconsciously reproduced the master narrative (cf. Thommesen, 2010) they wanted to challenge, generally the narrators in my study fundamentally rejected the master narrative of mental ill health. The user narrative worked as a quite clearly defined counter-narrative, presenting an alternative picture intended to replace the presumed false stereotypes perpetuated by mainstream society (cf. Abrums, 2004; Banks-Wallace, 1998).

Concerning the function of enabling critique, despite the element of critique they contain, the user narratives in this case actually run closer to the institutional master narrative. The master narrative at issue now is the institutional master narrative of psychiatry, which contains a picture of the good, genuinely caring organization (Hasenfeld, 2010), the belief in professional, clinical authority and knowledge (Stickley, 2006), the canonical diagnosis system as presented by



DSM-IV and conventional, clinically proven or “evidence-based” ways of conducting care and therapy. In relation to this master narrative, the user narratives indeed give voice to a perspective perhaps seldom expressed, particularly in the middle segment, which conveys the critique of the organization and in which the narrative questions the organization, articulating problems and experiences of oppression (cf. de los Reyes and Mulinari, 2005).

Hence, in this part the user narrative appears as a counter-narrative. However, in the last part of the user narrative, examples of good practice are repeatedly stressed, confirming and legitimizing established practice. Additionally, the changes of practice that the narrators argued for in the last part of their narratives confirm the current order because the practices suggested are commonly accepted forms of treatment and therapy—that is, they are situated well within the boundaries of the master narrative. The critique expressed in the user narrative therefore highlights that the organization does not attain (and sometimes falls very short of) the ideal standard of the master narrative, but in the end the user narrative aims at helping the organization to reach those standards (i.e. to become truly caring by means of conventional practice). Hence, while the user narrative more fundamentally rejects the master narrative on mental ill health, the narrators seem to share many of the overarching standards of the master narrative of psychiatry.

Another way that psychiatry’s master narrative governs the user narrative is through communicator training. Even if the training aids the narrators in many ways, at the same time it directs the ways that critique is expressed, and the importance of adding parts to the narration that confirm the organization as “good” is repeatedly stressed. In addition, by controlling the employment, the organization influences the structure and content of the user narrative. All in all, this steering contributes to orienting the user narratives towards the master narrative of psychiatry, and the counter-narrative is controlled to a large extent by the master narrative. And, as shown above, precisely the fact that the user narrative in vital aspects is complicit with the master narrative of psychiatry seems to be an important reason why it is possible to express critique without being dismissed; if the user narratives were too dissenting from the master

narrative, it is less likely that they would be taken into serious account within the organization.

### **The private: Enabling and prevailing**

Throughout the analysis it is clear that the user narratives become a way for the less powerful party in a psychiatric situation to give voice to her or his self-understanding and to critical comments on psychiatric treatment.<sup>10</sup> In such an expression, reference to personal experience is a key tool that enables the narrators to be heard. In general, a patient has limited opportunities to influence the organization, and participating in staff training, and being invited to tell one's story, provides such an opportunity. Here, the organizations allows the patients to convey their critique, and in return the patients agree to participate in staff training, accepting the larger employment of the user narratives as determined by the organization, including the sharing of very personal experiences. In general, the patients involved do not seem to mind the arrangement or to be bothered by sharing their personal accounts;<sup>10</sup> they generally believe in the worth of the activities and hope to influence the practitioners, feeling that they are making an important contribution.

Nevertheless, different conditions must be met in order for the various actors to speak and be listened to. For the patients, their knowledge and perception of psychiatric care in isolation is simply not enough; they must include private aspects in their narratives in order to be heard. On the other hand, the professionals never have to share such private experiences (cf. Hodge, 2005; Lalander, 2012). It is a common feature in a situation of power imbalance that the views of the dominant group are taken for granted as true without need for justification (Mattsson, 2010). The following extract makes evident that the man asking a question after Beatrice's narration requested personal accounts from Beatrice, while his own argument rests solely on its own strength:

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<sup>10</sup> One reason for this could be that the narration of one's personal life story is an extremely common and integrated part of psychiatric treatment. Thus, telling one's life story appears entirely normal to the patients because that is what one *does* as a psychiatric patient. To the extent that this is true, the user narratives can also be understood as underpinning the logic of psychiatric practice in general.

My question concerns what you said earlier about your obsessive thoughts [Beatrice had graphically described severe obsessive thoughts about killing herself or her child]. When you say that they are completely gone . . . ? [doubt in his voice, leaning forward with his elbows on the table]. Can you elaborate on that? You know, a certain amount of obsessive thoughts are fully natural. Women usually get a little angry when I say this [easygoing tone of voice, smiling], but the fact is that most mothers have these kinds of thoughts: “What if I were to push the pram out in front of the car? What if I dropped the baby off the ledge?” These obsessive thoughts are not supposed to last longer than two or three seconds; if they do, they become dangerous. (Beatrice’s narrative)

It was quite common that questions succeeding the narrations, like in this case, concerned the narrators as individuals or their experience of mental ill health,

rather than the psychiatric organization or the treatment (even if such questions were also asked). Moreover, the repeated retelling of the service user narrative, with its typical focus on mental ill health and troublesome personal experiences, continues to produce the picture and identity of the narrators as different and in need of sympathy and care, thereby reestablishing their inferior position (cf. Järvinen and Mik-Meyer, 2003; Lalander, 2012). From this perspective, the telling of user narratives can be seen as a manifestation and recreation of the power imbalances between patients and practitioners (cf. Hodge, 2005:173p).

Taking patients’ views, experiences and critiques into account, as well as allowing patients’ narratives to occupy time and space in staff training, can be seen as vital steps toward changing the power relations in psychiatry. In many respects, the user narratives provide a positive and nuanced picture of people suffering mental ill health, while also giving voice to experiences of oppression; such alternative stories and narratives are a way to resist subjugation and to create change (Williams et al., 2003; Andrews, 2004; de los Reyes and Mulinari, 2005). In contrast, if the user narratives are too heavily controlled and directed by the organization they might lose their emancipating and countering power. As this analysis has shown, the presentation of user narratives continues to single out mental patients as deviant, and in some respects the narratives reproduce

the structural power imbalance between patients and practitioners. It is largely the private character of the narratives that risks maintaining the power relation. Perhaps then, the ideal practice would be to limit the personal aspects of the narratives, focusing instead on the organizational problems they highlight. But such attempts would encounter difficulties, because these personal attributes (today at least) seem vital for the patient to be heard and for enabling the delivery of critique.

### **Summary**

The service user narrative consists of a blending of three types of personal narrative: illness-, care- and life-story narratives. These three dimensions are woven together in a whole by an emplotment that follows the purpose of the narration as determined by the organization. The overt purpose of using service user narratives as an act of user involvement in staff training is to facilitate learning, to change attitudes and to change practice. The foregoing study analyses two functions of the narratives that became evident in the material: (1) to create alternative images of mental ill health, and (2) to enable a critique of psychiatry. In the user narrative, the two important things in enabling the delivery of critique seem to be the private character of the narratives and the closeness to the master narrative of psychiatry. In some respects, the user narratives challenge the dominant order within psychiatry, but in other respects the user narratives continue to uphold current positions and power structures.

This article has certain implications for practice. If utilizing service user narratives as a way to accomplish user involvement, one should remain vigilant of the preservation risk whereby narrations serve to retain service users in a disadvantageous position or role. It should therefore be carefully thought through as to how the narrations are used and what kinds of narratives are requested. It would be beneficial to try and focus on the service users' factual reflections about the organization and the treatment provided, rather than on the intimate, personal dimensions of the narratives. Furthermore, if the narratives are meant to generate substantial change in practice, rather than maintain current patterns, it seems important to allow service users to formulate their narratives as independently as possible.

In this article I have concentrated on a few specific functions of the user narratives. Other functions, such as functions for the individual narrator, should be further investigated. In addition, depending on the varying social characteristics and mental health history of the narrators, differences in the narratives and their functions could advantageously be investigated further. Lastly, my analysis draws on quite a small and specific sample, and further research on the functions of user narratives within staff training, as well as within service user involvement in general, is needed—not least regarding how to use user narratives in a way that changes (instead of maintaining) stigmatizing attitudes, the inferior position of patients and poor practice.

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