A Diagnosis of Schizophrenia:
The Role of Service User Stories in Challenging Stigma

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Abstract

I reflect on how lived experiences that are derived from service user expert knowledge have the potential to confront stigmatization, which is encountered widely by people who have a diagnosis of schizophrenia. The implications of the political dimensions of the diagnosis are explored and the impact of stigma on those who have mental ill-health is discussed. The value of narrative research is highlighted, and the growing importance and increasing recognition of the validity of service user expert knowledge is considered. Using two stories to illustrate how professionals responded to me as a parent with a diagnosis of schizophrenia, I highlight the defensive practice I experienced and the assumptions about me as a person with mental ill-health. I reflect on how simultaneous feelings of power and powerlessness, accorded to my personal and professional status, are experienced in this context. This leads to consideration of the potential for service user expert knowledge, specifically in the context of narrative research, and how such knowledge expressed in stories and narratives can influence professional frameworks of practice. Schizophrenia is indeed a diagnosis of discrimination, but the presentation of service user expert knowledge through narrative research has the potential to overcome the experiences of stigmatization.

Keywords: mental ill-health, stigma, schizophrenia, narrative research, social inclusion

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I am a senior lecturer in social work, a researcher, and a service user with a diagnosis of schizophrenia. As a service user given this diagnosis, I have experienced unintended misunderstanding from peers and other academics (Fox, 2011) and unequal treatment from professionals involved in different aspects of my care (Fox, 2012). This article discusses the potential that stories told by experts-by-experience (Humpston, 2014; Hydén, 2008) have in confronting stigmatization of people who have a diagnosis of schizophrenia.

This article considers the nature of stigma and discrimination that arise from being labelled as a "schizophrenic" and addresses the wider context of this label as a political diagnosis of exclusion. The nature of practice, stigmatization, and professional negative stereotyping is explored through the presentation of two stories of "lived experience":[1] firstly my experiences as a mother-to-be and secondly my

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[1] The notion of lived experience refers to the way that symptoms of mental ill-health are experienced and described by service users themselves.

experiences as a mother with a diagnosis of schizophrenia. The validity of service user expert knowledge and its place in the wider context of mental health are addressed through a discussion of narrative research. Accordingly its potential role as an effective methodological framework to challenge stigmatization is highlighted. The nature of what constitutes authentic service user experience and knowledge is considered with discussion of the value placed on different types of knowledge. Alongside this, the tension that arises from being perceived as both an expert-by-experience and as a "schizophrenic" is explored with consideration of my corresponding personal and professional status as a service user, social worker, and social work academic.

Reflecting on the Nature of Stigmatization

Many people have limited understanding of the nature of schizophrenia and what it means for those who the experience this illness (Rethink, 2012). As a result of this ignorance people with schizophrenia may experience discrimination in housing opportunities, employment (Fox & Ramon, 2011), relationships, and in their daily life, due in part to society's fears of the "mentally ill" and the demonization of those with a diagnosis (Rethink, 2012; Royal College of Psychiatrists, 2009). Recently, on 4 March, 2013, on a U.K. radio discussion program, *PM*—a respected and high profile afternoon news program—the presenters reported on the case of Nicola Eddington, a service user with a diagnosis of schizophrenia, who killed a stranger as a result of her mental ill-health. The sensationalism and vilification that accompanied this discussion, focusing on the schizophrenic, was concerning. There was very little understanding of the categorization of schizophrenia, its symptoms, or of what it is like to experience such an illness (Rethink, 2012). More widely, the process of risk management is a complex and challenging area for many U.K. health and social care professionals as they manage the balance between risk aversion and effective risk-taking for people in recovery and their dependents.

The biomedical model arises from a traditional psychiatric model of care. It emphasizes the medical origin of mental health issues and places primacy on the expertise of the clinician in diagnosing and treating mental ill-health, predominantly with medication (Golightley, 2011; Pilgrim, 2009). Within this model, schizophrenia is described as a family of symptoms that persist for a specified length of time. Gelder, Gath, Mayou, & Cowen (1996, p. 246) described the acute stages of schizophrenia as characterized by the "positive" symptoms of "delusions, hallucinations, and interference with thinking"; patients may either recover directly from the acute phase or further deteriorate into chronic schizophrenia. The chronic symptoms of schizophrenia are "characterized by thought disorder and the negative symptoms of under-activity, lack of drive, social withdrawal, and emotional apathy" (p. 246).

The concept of schizophrenia has political status in that it places the social control of the patient with schizophrenia in the hands of professionals. It confers authority and power upon medical practitioners rather than assisting service users to improve their health experience. This political dimension, posited by Boyle (2002), is echoed in the history of care of people with schizophrenia. Bentall (2003) reflected on how a diagnosis of schizophrenia and subsequent treatment was imposed on

dissident citizens in the former U.S.S.R. in the 1980s as a method of political control and containment. Moreover, once a person has been given the diagnosis of schizophrenia it seems to become the overwhelming conceptualization of the person's health and well-being, as Walker (2006, p. 6) wrote:

> When we are talking about a person's thoughts and feelings we are essentially talking about their identity (which includes values, beliefs, memories, fears, and desires). This is not like something physically wrong with part of their body. A "disorder" of thought or feeling is a labeling of a person's identity. The labeling of subjective experience feeds on itself and perpetuates itself.

Thus, the disorder becomes part of their identity, and no longer a diagnosis that describes their symptoms, further underlining the nature of schizophrenia as a diagnosis of exclusion.

Similarly Boyle (2002) believed the conferment of a biological diagnosis of schizophrenia gives a form of comfort to the public, professionals, families, and service users. By giving a name to confusing and bizarre behaviour, professionals are claiming that they have some power to treat and cure that behaviour. However, receipt of a diagnosis of schizophrenia for many service users and their families is frightening and stigmatizing (Repper, Nolan, Grant, & Curran, 2008; Rethink, 2012), although many clinicians argue that when a patient accepts a diagnosis of schizophrenia, this is the start of their recovery because they are accepting and taking responsibility for the illness.

Yanos, Roe, Marcus, & Lysaker (2008, p. 1437) discussed how a sense of acceptance of the mental health diagnosis, when a service user aligns to that identity, can hinder rather than promote recovery because the service user "loses previously held or hoped for identities (self as student, self as worker, self as parent, and so on) and adopts stigmatizing views (self as dangerous, self as incompetent, and so on)." This sense of a worthless and pathological self is referred to as *internalized stigma*. This process of acceptance thus adds further disability to the mental health symptoms as it reflects society's low expectations of individuals with mental ill-health and underlines belief in their non-achievement. Self-stigmatization can seriously hinder the service user's journey of recovery, because even if they have opportunities to succeed, they no longer have the will or capacity to do so because of the feeling of inherent self-worthlessness. Internalized stigma can therefore affect the building of identity in recovery.

Stigma through diagnosis remains a corrosive and discriminatory experience for many people who use mental health services, as they are socially excluded from their communities (Royal College of Psychiatrists, 2009). Secker (2011) identified two elements of social exclusion: the first relating to the deprivation of rights as a member or a citizen of a particular group, community, society, or country; and the second relating to the lack of opportunity to participate in key functions or activities of society. Many people are excluded both from participating in society and from taking part in mainstream community activities.

The Validity of Storytelling as a Methodological Framework

U.K. mental health services seek to promote increased service user involvement in decision making about their care and treatment (Department of Health [DH], 2001, 2011) and offer increasing opportunities in the U.K. for service users with a mental health diagnosis to influence service development and monitoring (Mind, 2004) and to be involved in mental health research (Beeforth, Corilan, & Grayley, 1994; Rose, 2001). Alongside this practical implementation of empowering practice, increasing recognition has been placed on the value of storytelling by experts-by-experience and its role in illuminating the service user's perspective of receiving mental health services (Fox, 2012; Humpston, 2014). The methodological framework for the development of narrative research has been recently established (Hydén, 2008; Hydén & Brockmeier, 2008; Medved, Brockmeier, Morach, & Chartier-Courchene, 2013) and can be used increasingly to validate research that draws on individual experience.

Hydén (2008) described how he used narratives told by service users with a diagnosis of Alzheimer's disease to enable them to explore how their identity was formed and changed by the development of their illness. In a methodological discussion, he delineated between narratives as textual objects and narratives as part of a storytelling event. In the former example researchers may transcribe the content from an interview and focus on analyzing the content of the story to find new meaning from the discourse. In the latter, the focus is on the narrative as a story that takes into account to whom it is told (the audience), how it is performed, and in what context. This emphasizes the importance of how the *individual* makes meaning of their own experiences, rather than emphasizing how the *researcher* makes meaning of the service user's experiences. Hydén (2008, p. 56) noted: "If stories not only are thought of as representations of events it becomes possible to view stories and storytelling as social action: social states are … established, negotiated and changed through stories." He reflects on how the story influences both the service user's identity and their relationship with their social context.

Medved et al. (2013) described narrative research undertaken with North American Aboriginal women about their experience of cardiovascular disease. They argued that narrative format gives insight into "the narrative fabric of self-understanding and identity negotiation" because it allows them to understand their "overall life under complex social and cultural conditions." Medved et al. (2013) noted how the women "bind together individual and collective memories; they localize personal histories in cultural traditions and interweave everyday experiences with the social weave of gossips, legends and myths." The individual narratives that people tell have the potential to capture the way the person locates their place in their social context (Medved et al., 2013), and narratives offer an understanding of how they negotiate their place in and their influence on the world around them (Hydén, 2008; Medved et al., 2013). This methodological stance places precedence on representing the individual lived experience of service users rather than of researchers or service providers.

The Stories

In the next section, two stories of personal experience relate my interactions as a mother-to-be and as a parent with a diagnosis of schizophrenia with professional services. It describes my negative experiences of professional engagement arising from concerns about the increased likelihood that parents with a mental illness diagnosis (including schizophrenia) might abuse their children (Falcov, 1996; Taylor et al., 1991). This experience occurred despite an emphasis in the U.K. mental health system (DH, 2001, 2002, 2011) that places precedence on the need to work in partnership with service users and carers, to increase their choices in receiving treatment, to offer opportunities for personalized services, and to enable their greater empowerment.

First Story

The first story relates my experiences as a mother-to-be in receipt of over-zealous and defensive practice from maternity services, despite the involvement of competent and respectful mental health services.

When I was three months pregnant, I met with my psychiatrist—a professional who had been involved in my care for more than 15 years—in order to agree on a management plan to monitor my mental health that included fortnightly visits from a community psychiatric nurse (CPN) in the latter stages of pregnancy. The CPN was a sensitive professional, aware of my needs as a professional worker and academic, and respectful of my ability to monitor and self-manage my own mental health. During my pregnancy my mental health was excellent and I was a happy and optimistic mother-to-be still working on my PhD thesis.

At 36 weeks pregnant, I received a letter from the hospital safeguarding midwife for vulnerable adults and children at risk, "inviting" me to a meeting of people involved in my care. The community midwife, health visitor, safeguarding midwife, and CPN attended. I informed the conveners of my concern at receiving a letter summoning me to a meeting, with no explanation and no warning. This concern was noted. The maternity service practitioners "recommended" that I stay in hospital for at least 48 hours following my baby's birth and that there be daily monitoring of her health and well-being for up to four weeks after. I felt cognizant of the power that professionals have to intervene in people's lives, and the need to be a compliant patient, combined with the relative lack of power that I possessed as a service user. I felt little sense of control or authority over my own life and that of my baby.

New motherhood is a time of discovery and apprehension as the new parents get to know the baby, and begin to see themselves as a family unit, rather than a couple. It was, however, made more difficult by a seeming presumption that I wouldn't be able to cope, although understandably, this support would have been very helpful if I had experienced any difficulties; and historically many women stayed longer in hospital and were monitored more closely than current practice usually allows today.

I found the constant visiting to be intrusive and over-zealous, although individual health visitors were thoughtful, caring, and respectful. We found we coped very well and soon had a rhythm to our care as we got to know our little daughter. I, however, found the experience of enforced contact with midwives and health visitors disempowering, alienating, deskilling in my role as a mother, frustrating, and upsetting. The negativity I experienced was based on the presumptions of my potential for failure and the lack of choice I felt in accepting the enhanced support, rather than on the individual actions of the midwives and health visitors, who were supportive and considerate.

When health and social care professionals in the U.K. seek to safeguard service users and their dependents, their process of risk assessment may lead them to draw on their past experiences, or research evidence (Falcov, 1996; Taylor et al., 1991), or even stereotyped perceptions about the behaviour of people who are given specific diagnoses (Goffman, 1963). This may lead them to attribute potential actions to the diagnostic category that a person is given—rather than focusing on the individual person and their needs and strengths (Rapp & Goscha, 2012); indeed many people do not fulfil the criteria associated with their diagnostic label, although a small minority may. More widely the process of labelling is an inaccurate science which in itself may be negative and stigmatizing (Goffman, 1963), often leading to a false correlation between the perceived stereotypes about people with a diagnosis and their real actions. This confirms the problems associated with undertaking a risk assessment based on a person's diagnostic category.

I recorded my experiences and set out my considered opinion of best practice in an article published in Fox (2012). I sent a copy of the published article to the safeguarding midwife for adults and vulnerable children who had represented the maternity services that offered me care. The midwife responded positively and informed me that she had chosen to undertake a Master's dissertation about the experiences of maternity care for mothers-to-be with a mental health diagnosis. She asked me if she could refer to my article in her work and if I would be willing to share my story as an expert witness in her studies, requests to which I agreed. I felt that my experiences had been heard and had influenced practice.

Second Story

When my daughter was one year old and I had only recently returned to work, I attended training focusing on strategies to ensure that children were safeguarded in research processes. The training session was facilitated by a social worker who had experience of working with abused children. The social worker began to talk about the importance of safeguarding children when working with parents who were deemed to display risk factors. I reminded the social worker of the need to work in partnership with parents rather than against them, and that sometimes social workers were experienced as over-zealous. I reminded her that sometimes professionals drew on their experiences of professional engagement, which could be informed by negative stereotyping. I did not use a language of confrontation, but used the language of experience expressed in respectful and thoughtful ways. The facilitator

was very sure of her own professional power and her own position in working with mothers who she perceived to be "risky."

To my horror, the facilitator suggested that I should consider leaving the training, as she believed I was unable to participate constructively in the session and would disrupt it due to my own negative experiences. I was completely flabbergasted, as I did not believe that I had challenged her confrontationally or aggressively; I was maybe a little emotional this was the furthest I had been from my daughter and she had only just begun nursery. I reminded her that I was a professional and had travelled specifically to attend the course. She then reconsidered her position and "allowed" me to stay.

I felt humiliated and disempowered by her reaction, and felt my professionalism was undermined. I fed this back to her at the lunch break in a one-to-one conversation. She reported that carers had disrupted her training in the past and she felt she had responded to me by "allowing" me to stay. She seemed unaware of the humiliation I had felt—in front of other colleagues—and felt secure in her power. This experience rekindled my commitment to writing the article in Fox (2012), and reminded me of the importance of recognizing and valuing service user and carer experience.

The Role of Storytelling in Challenging Stigma and Discrimination

These two stories of service user and professional engagement suggest two different experiences: The former provides an example of a professional who is willing to engage with service user experience and develop practice accordingly, despite an initial focus on defensive practice; and the latter provides an example of a professional, confident in her own sense of professional power and unable to engage with experiences that challenge her professional view of reality. I experienced little control or power in both contexts and my experiences of disempowerment and frustration are palpable as the stories unfold. The reactions to me are based predominantly on my service user status, instead of my professional identity as an academic, researcher, and qualified and registered social worker, although I intervened in a less personalized and more theoretical way based on my professional status and practice wisdom. The diagnosis of exclusion, however, dominated the professional management of my care and treatment.

In these encounters I experience both a sense of powerlessness from being in receipt of services and being perceived as a service user, and a sense of power as an academic and practitioner. Despite the very obvious experience of powerlessness as a service user subject to professional control and to negative stereotyping from a trainer, there is a seemingly contradictory sense of power conveyed through being perceived as an expert-by-experience. For example, some people with a mental health diagnosis who use their experience to challenge negative stereotypes can develop a positive sense of self through accepting rather than rejecting their mental health diagnosis. Davidson (2003) has referred to this process as living "beyond the diagnosis" in which the service user not only leads a good quality of life through effective symptom management, but uses their disability as part of their wider expertise-by-experience to inform their participation in research, improving mental

health services, or training other service users (Fox, 2011, 2012) or writing stories to confront stigma (Hydén, 2008). Hydén (2008, p. 56) noted storytelling for those with an illness "is a challenge, but also an opportunity to actually master, maintain and often transform their identities." This process of living beyond the disability (Davidson, 2003) as exemplified in the process of storytelling (Hydén, 2008) embraces the growth of identity and a personal reconciliation to the mental health condition through the journey of mental health recovery (Spaniol, Wewiorski, Gagne, & Anthony, 2002).

My process of living beyond my own mental health diagnosis has been made possible through my professional development, which has equipped me with the skills to analyze, write, and reflect on practice experience (Payne[2] & Brandon, 2002). This opportunity is, however, alien to the experiences of many who have a diagnosis of schizophrenia and who, as described earlier in the article, often internalize the negative stereotypes accorded to this condition (Yanos et al., 2008). The combination of my professional and personal status that allows me to combat stigma and discrimination is indeed a privileged position and is a form of protest which may be less available to other service users and carers.

The development of frameworks that promote service user and carer involvement in all aspects of mental health development, provision, and service delivery builds on the notion of expertise-by-experience and the value of service user knowledge. This starts to shift the balance of power from practitioners and service providers to service users themselves. Narrative forms of research told by experts-by-experience (Hydén, 2008; Medved et al., 2013), alongside involvement in training (Levin, 2004), research (Ramon, 2003), and service development (Rose, 2001) have the potential to challenge practitioners' professional framework and reconnect them with experience, conveying power and value to service user knowledge. An emphasis on service user experience demands a different approach from professionals.

More specifically in this article, narrative approaches to research offer an opportunity to confront and challenge negative stereotyping. Indeed articles grounded in lived experience are based upon an alternative methodological framework to traditional models and focus on recognizing the validity of user knowledge (Glasby & Beresford, 2006; Uhm, Liabo, Stewart, Rees, & Oliver, 2012). Glasby and Beresford (2006) looked at the current demand for evidence-based practice in both U.K. and international health and social care research and argued that evidence-based research needs to include, but should not be placed above, the learned knowledge of practitioners and the knowledge of service users. Glasby and Beresford (2006) believed that service user and professional knowledge can be just as valid as academic research dominated by belief in the physical sciences and the medical approach.

The validity of service user expert knowledge in the form of narrative research and in informing practice is, however, questioned in some academic circles

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[2] My maiden name.

(Harrison, 2002). Some researchers express concerns that people who regularly use their knowledge of their disability to inform research and practice are disconnected from the reality of their authentic lived experience (Harrison, 2002) and have become "professionalized." This debate raises wider concerns about the validity of user knowledge (Fox, 2007, 2008) and prompts questions such as, "Who is an authentic service user?" and, "Can narratives of service user experience be informed by theory yet still be authentic?" As I write and reflect on my experiences in this article my experience is no less authentic because of my knowledge and expertise, and no more professionalized because of my capacity for reflection; instead, my dual identity as service user and researcher adds layers of understanding to the story and makes it relevant to practice.

These stories present both authentic lived experience and explore the nature of professional practice. The duality inherent in these stories allows professionals to access the real feelings of frustration and disempowerment that I encountered, but enables them to link this lived experience to their theoretical professional frameworks. Moreover, if I were merely challenging as a service user, would the professionals respond to my challenge or would they dismiss me as troublesome and difficult? Does the language of academia allow them to consider the validity of my interpretations?

The strength of narrative research and storytelling is that it celebrates the perspective of the teller, not necessarily placing precedence on the perspective of the researcher (Hydén, 2008). As a person with a number of hats, I draw on the experiences I have and combine these perspectives in the story I tell. Narrative research embraces the identity and perspective of the storyteller and validates my experience as an expert. And although practitioners may feel the need to promote the safety of children of a parent with schizophrenia; or facilitators of group training may feel that sensitive discussions may be disrupted by the report of negative personal experience from service users and carers; the emphasis on expertise-by-experience with a focus on the strengths approach (Rapp & Goscha, 2012) requires professionals to build a relationship of mutual trust and respect. This reinforces the validity of narrative research and celebrates the perspective of service users as they seek to challenge negative stigmatization.

Conclusion

This article has considered how negative stereotyping and stigmatization persist in the mind of many health professionals and are still very present in practice today, as they impact on a service user's involvement in their care and treatment and their relationships with practitioners. The two stories that I have analyzed illuminate the challenging nature of practice, which expresses the rhetoric of partnership working but is more often strongly risk averse. The promising developments of narrative approaches to research show the potential of service user expert knowledge to influence and change practice and refocus attention on the value of service user experience. The paradigm that supports narrative research (Hydén, 2008; Medved et al., 2013) demands a different approach from professionals, trainers, and other researchers, one based on mutual respect that leaves room for difference and "otherness" to be valued and supported.

Excluding service users and carers from training sessions because they may "disrupt" sensitive discussion because of personal stakes, or working from a deficits model because of a label of schizophrenia, are no longer acceptable in a world that recognizes the validity of service user expert experience. The recognition of the importance of expertise-by-experience demands instead a kind of practice and research that acknowledges lived expert knowledge, values its validity, and allows it to challenge traditional forms of negative stigmatization and stereotyping.

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