Marketing 'Madness': Conceptualising service user/survivor biographies in a period of deinstitutionalisation (1975–2014)

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Abstract: This article aims to present the lived experiences of psychiatric service users/survivors who have experienced the transition from institutional care in the 1970s and 1980s to community care services in the 1990s and post-2000s. By using a biographical narrative approach the study compares service users' historical experiences with their contemporary experiences of community and residential care. Sixteen biographical narratives were analysed to explore how mental health services have changed over time, from the perspective of service users/survivors, their families and mental health practitioners. The study examines how the closure of NHS mental hospitals in the 1980s, which were replaced in the 1990s with new types of community and residential care services, has changed the lives of service users/survivors. Thus, the article presents these lived biographical experiences which, for the majority of service users/survivors, were defined by the process of trans-institutionalisation rather than de-institutionalisation, within a neoliberal context.

- This article presents empirical data on how institutionalisation has changed for service users/survivors in this study since the 1980s.

- The article explores the lives of service users/survivors through their biographical stories to conceptualise changing models of care from their perspectives.

- The findings discovered that most service users/survivors in this study were still living in an institutional environment where medication played a significant role in their lives.

- Therefore, the article asks the question: to what extent has the neoliberalisation of care impacted on the lives of service users/survivors in this study?

mad studies; trans-institutionalisation; neoliberalism; residential care; biographical experiences; mental illness

Introduction

To explore the impact that community care service has had on the lives of people with mental health problems, service users/survivors were recruited who had undergone a minimum of six months of treatment in a pre-1983 mental hospital, and who are still receiving support from contemporary care services. To supplement these experiences, the narratives of family members were collected to coincide with the stories of service users. In addition to these, mental health practitioners were also recruited who were employed within both the pre- and post-1983 mental health system. This study attempts to represent the biographical narratives of service users/survivors during the dramatic changes that took place in the 1980s and 1990s, which witnessed the end of long-term hospitalisation and led to the development of community care in the UK.

By discussing the differences in traditional and contemporary care archetypes during these very different time periods, the article aims to critically explore how service users/survivors conceptualise these changes. This article, however, presents evidence that the concept of deinstitutionalisation of mental health services may be misleading based on the biographical experiences of service users/survivors in this study. Although governments present the historical account of deinstitutionalisation, what seems to have occurred in the 1990s/2000s for service users/survivors in this study can be more accurately described as a period of trans-institutionalisation (Slovenko, 2003; Szasz, 2005). Therefore, this study presents a number of life histories that demonstrate that service users/survivors have been moved from large traditional mental hospitals to smaller privately run residential institutions, and although the care setting has changed, the process of institutionalisation has stayed relatively unchanged for individuals in this study.

The Psychiatrisation of Mental Distress

An ambition of contemporary psychiatry is to legitimise its status as a scientific discipline through the concept of empirical objectivity, where knowledge is produced independently of any social and cultural ideologies. From this viewpoint, behaviour can be objectified, and the experience of emotional variations, which result in mental distress, can be justified pathologically as a biological phenomenon (see LeFrancois *et al.*, 2013; Faulkner, 2017). This biomedical perspective dominates psychiatry's comprehension of mental 'illness', where mental distress results from an individual's '"faulty" brain physiology and "disordered" personalities"' (Beresford and Wilson, 2002: 542). Yet, alternative conceptualisations of mental distress have emerged, from the anti-psychiatry movement in the 1960s and the international Mad Pride movement in the 1970s (LeFrancois *et al.,* 2013; Lewis, 2017); these

movements have significantly influenced the emergence of Mad Studies as a contemporary academic field of study (see Menzies *et al.*, 2013). The connecting theme which brings Mad Pride activism and anti-psychiatry/Mad Studies disciplines together is the importance of service user/survivor voices, and their voices and experiences have become the vital force that facilitates the deconstruction of mental 'illness' as a pathological condition. As Menzies *et al.* (2013) suggest, the Mad Pride movement and the anti-psychiatry movement challenge psychiatry's definition of human behaviour, where morality is constructed from the binary concepts of 'healthy' and 'sick' (Kafai, 2013; Faulkner, 2017). Therefore, this service user/survivor perspective challenges what anti-psychiatry/Mad Studies refers to as the medicalisation of everyday life (Szasz, 2007; Menzies *et al.*, 2013).

These service user-led approaches, which in psychiatric literature are often grouped together under the heading of the 'anti-psychiatry movements', have been to a certain degree rejected by contemporary psychiatry. An example of this can be seen in the writings of Semple and Smyth (2013) in the *Oxford Handbook of Psychiatry.* Semple and Smyth (2013) suggest that evidence from this perspective relies heavily on case study analysis, which they view as subjective and influenced by ideological perspectives on the political left. As in their critique, these theories are based on 'an association with half-baked political theory of the Marxist-Leninist strain' (2013: 24). As they state:

> Although the central arguments of the anti-psychiatry movement have largely
> been discredited in mainstream scientific literature, they have retained currency
> in some areas of the popular press, within some patient organizations, and in

certain religious cults. They are presented here for historical interest and so that
sources of modern-day advocates of these ideas can be identified.

<div align="right">(Semple and Smyth, 2013: 24)</div>

From Semple and Smyth's (2013) perspective, contemporary psychiatry is a scientific discipline and is apolitical. They do not seem to acknowledge its recent history being fundamentally linked to the rise of the new market economy (i.e. neoliberalism), which has transformed the political arena across Europe and the United States (Carney, 2008; Esposito and Perez, 2014). This idea of a market-based system as a form of democracy is central to UK politics of the late-20th and early-21st century. Neoliberalism advocates the concept of a small government and a deregulated market-based system, which can theoretically respond to the needs of individuals within society. This ideology has led to Conservative and Labour governments embedding this neoliberal approach into contemporary health and social services (Cummins, 2012), and at the heart of contemporary health care is the growing concern relating to mental health. Mental health services, which are dominated by psychiatry, receive 13.8% (£22.5 billion) of England's health budget, creating a significant market (DoH, 2010). As Szasz (2007) states, contemporary psychiatry has been significantly influenced by public health concerns, which are responded to by the pharmaceutical industry with its ever increasing objective to produce and market medications to the masses. The marketisation of mental health services reinforces a biomedical perspective, where mental distress is conceptualised as an 'illness' that can be treated with medication in the community or, if this fails, within a hospital or residential-based environment (Szasz, 2005; 2007; Shimrat, 2013; Esposito and Perez, 2014; Glasby and Tew, 2015).

From a neoliberal perspective, any individual diagnosed with a mental health condition becomes a consumer of health services (Carney, 2008). Since the 1980s we have seen the rise of new markets of medication and community care services (Esposito and Perez, 2014). These services range in nature from an increasing variety of medications, to large residential care units, to care packages designed to support people within their homes. Within contemporary mental health services psychiatrists and GPs become the gatekeepers, where individuals experiencing mental distress are transformed into consumers of mental health services. No matter how convincing the argument that psychiatry is apolitical, it is hard to deny the influence that neoliberalism, as an ideological perspective on the right, has had over the rise of psychiatry as an economic force since the 1980s (Esposito and Perez, 2014).

Neoliberalism and Mental Health Community Based Services

With the closing down of the mental hospitals after the Mental Health Act 1983, the emergence of neoliberalism has transformed the provision of mental health services in the UK (Beresford, 2012). The deregulated market system of neoliberalism, based on the idea that competition responds quickly and effectively to the ever-changing needs of service users/survivors, underpinned the new system of community care (Esposito and Perez, 2014). This ideological perspective implied that the market would improve standards and drive down costs. Mental health consumers would engage in successful treatments, thereby develop successful markets, and disengage from markets which were ineffective or even oppressive (Morrow, 2013; Esposito and Perez, 2014). In the UK this new health care market economy was fundamental to the development of services in the post-institutional care period. This led to charitable organisations being transformed into third-sector enterprises that positioned themselves as competitors for local authority/government funding. As hospitals were now

seen as ineffective when treating people with mental 'illness', the new community care revolution would instead treat/support patients in the community. Unfortunately, as Beresford (2012: 154) suggests, 'the replacement community-based provision was often inadequate, under-funded, of poor quality, and poorly coordinated'.

During this transition, psychiatry had a new role of administering an increasing toolkit of medication within the community, outside their traditional hospital environments (Beresford, 2012; Morrow, 2013; Esposito and Perez, 2014). Community care offered a new form of treatment for mental health service users/survivors, but a key problem emerged as there was a lack of market diversity with this system of health care. For this market-based system to be successful in mental health services, patients needed multiple options to be active consumers (Exworthy and Halford, 1999; Carney, 2008; Morrow, 2013). Although psychiatry has been significantly funded by the NHS, its belief in a singular pathological interpretation of mental distress (i.e. a biomedical model) does not offer diversity to the consumer. As psychiatry conceptualises mental distress as a biological 'illness', it in turn administers treatments drawing on an ever-growing arsenal of psychoactive/psychotropic medications, and has influence over the commissioning of social care living environments. Therefore, psychiatry increases new pharmaceutical and residential care markets, which medicate and house large numbers of people in the most cost-effective ways (Forrester-Jones *et al.*, 2002; Morrow, 2013; Esposito and Perez, 2014). This creates wealth for the pharmaceutical industries, and has led to the growth of residential care industries in the UK (Szasz, 2005).

While neoliberalism offers a radical solution to improve mental health services, there seems to be a key problem of how successful this ideology can be when applied to a health care

system, which is based on pseudo-markets (Exworthy and Halford, 1999). With the rise of these new markets, particularly the growth of residential care, Thomas Szasz (2005) has argued that the notion of deinstitutionalisation is misleading. From his perspective, what we are witnessing in the 21st century is the process of trans-institutionalisation, where service users/survivors have been moved from traditional NHS mental hospitals to the newly built and privately owned residential care units, underpinned by markets and profit. Therefore, the aim of this article is to explore how life has changed for service users/survivors with significant mental health problems over the past thirty years. Thus, it will examine how the experiences of deinstitutionalisation have impacted on the lived experiences of service users/survivors from their perspective in a community care setting.

Methodology

By comparing staff and service user/survivor experiences of long-term care, the study's intention is to comprehend changes in the contemporary care system for people diagnosed as having a mental health condition. This qualitative study analyses the biographical narratives of people with mental health conditions in an attempt to compare changes in care services, from confinement to contemporary support within a community setting, by using Bertaux's (2003) biographical interviewing technique. Semi-structured interviews lasting between thirty minutes and two hours were undertaken; this approach asks only a small number of focused questions relating to participants' life experiences. By limiting questions, this produces a biographical narrative that gives more control to the participant and restricts the interviewee from being drawn into a structured hierarchy (Wengraf, 2001). The importance of this form of interviewing is that participants were allowed to start their life story at any historic point they choose. This enabled them to speak freely about their position

in relation to the research issue raised. It also allowed participants to translate their own events, themes and meanings within their own biographies to produce a narrative form.

In total sixteen participants were interviewed, consisting of nine service users, three family members and four mental health practitioners. The study employed a snowball sample where information was sent out to local health and social care services in the North-East to facilitate recruitment. Hence, a number of social work/social care/nursing practitioners helped the research team promote the study to recruit service user/family volunteers. Service users/survivors were recruited who had experienced hospitalisation because of a diagnosed mental health condition. They had all experienced long-term hospitalisation between 1975 and 2014, which was defined in this study as a minimum period of six-months in hospital. All service users/survivors were still receiving support due to their long-term mental health conditions. The age of service users/survivors ranged from 55 to 71 years. All service users/survivors were from a white ethnic background, and more male service users/survivors (n = 6) were interviewed compared to females (n = 3). Although black and minority ethnic (BME) communities are overrepresented in mental health services in the UK, and people from these communities are more likely to be diagnosed with a significant mental health problem (Bradley, 2009), this was not reaffirmed in this study. It should be noted that the North-East of England has the lowest BME population in England, at 6% compared to the national average of 19% (ONS, 2011). When conducting the research the team observed that there was a visible lack of BME service users/survivors accessing mental health residential and community care services, and this may account for why no BME service users/survivors volunteered to take part in this study. However, the majority of service users/survivors were from traditional working-class backgrounds (n = 8), with one participant defining himself as middle-class.

The mental health practitioners had been employed within a mental hospital before or during the implementation of the Mental Health Act (1983). They had actively worked in health or social care services during the 1990s, and witnessed the transition of hospital-based care to community care services. With reference to the practitioner group, two female participants were from a white ethnic background and two male practitioners were from black/Asian ethnic minority communities. The majority of practitioners described growing up in a traditional working-class setting (n = 3), with one participant indicating that they were from a middle-class family. Finally, all family members who were included in the study had actively visited and/or had been part of supporting a close family member throughout their time as a service user. The age of family members ranged from 50 to 72 years. Two of the female family members were from a white ethnic background and one male family member was from a black ethnic minority community. All family members interviewed could be defined as growing up within a traditional working-class community. Interviews in the study took place in 2014–2016, in the North-East of England.

A phenomenological approach was used to interpret the biographical narratives of participants in this study (Kafai, 2013). This study presents participants' interpretations of their life events to situate the analysis from a service user/survivor perspective. By employing Daniel Bertaux's (2003) methodology to service users' biographical narratives the findings explored personal experiences of social change (Bertaux, 2003; Kafai, 2013). N-vivo was used to help organise the data in order to apply a thematic analysis to the research. However, this study has a number of limitations due to its small sample size, therefore the research does not claim to be representative of any group outside of the sample size. To protect the

identities of participants, pseudonyms are used to represent the narratives of participants throughout the findings section of this article. Full ethical approval was gained by the research team from the host university as well as through the relevant health and social care organisations before the research commenced.

It should be noted that there were a number of intersectional relationships that emerged with reference to gender and social class, which shaped the narratives presented in the findings section. Although service users'/survivors' experiences of hospitalisation were similar, the two female service users/survivors still had contact with their families and received regular visits when in hospital or housed in residential care. This was not the case for any of the male participants in this study. Yet, the most significant intersectional relationship that impacted on service users'/survivors' lives related to their socio-economic status. The majority of the group described themselves as working-class, and experienced high levels of poverty and deprivation within their life stories. Hence, the narratives that follow are framed by these experiences of poverty and deprivation, which are interrelated with their experiences of disability.

Mental Hospitals and the Institutional 'Care' System

To conceptualise how life has changed for service users/survivors due to the community care movement, it is important to explore their experiences of care inside the historical NHS mental health hospitals. From a historical perspective, when examining institutional care within the mental hospitals during the 1970s and 1980s, no participant described their experience as positive. From a service user/survivor perspective, the fundamental issue they reported related to systems of medical control and periods of boredom. All of the service

users/survivors described experiencing very regimental systems of patient control during their time in hospital. Jack illustrates this by describing how every aspect of his daily life was controlled in the hospital regime. For Jack, all interactions and activities were controlled by nursing staff, including mealtimes, recreational times and rest times. Within his narrative he discusses sitting for long periods of time with other patients in a recreational room. As Jack states:

> You couldn't go to sleep on your bed then [during the day] because they used to lock the doors in a morning [at] ten o'clock and they used to open them at twelve o'clock when it was dinner time. Shutting again at two o'clock and then opened them at five to get ready for the night time. You had to be clean-shaven and stuff the likes of that.
>
> (Jack: service user/survivor)

As Jack illustrates, all choices were removed from his daily routines within the hospital. It was these regimental experiences of institutionalisation that were central to the memories of participants who were treated in the mental hospitals (see Goffman, 1961). Interestingly, service users/survivors very rarely described any relationships with medical staff during their earlier experiences of hospitalisation. Medical staff seemed to be described in the same way as the interior of the mental hospital. As Jude states:

> Yes. It was like a cocoon. I've always been like trapped in the building. It was the same in Stafford. I was like trapped in a building. I felt I was in a cocoon.
>
> (Jude: service user/survivor)

Like many service users/survivors, Jude describes being prescribed an increase in medication during his period of hospitalisation. Service users/survivors in general reported taking high levels of medication during these periods. Interestingly, all service users/survivors reported that it was difficult to recall key events and experiences during these periods, which may have been due to this increase in medication. For some service users/survivors it was during their first stay in hospital when they were initially prescribed psychoactive/psychotropic medications. As Jason indicates:

> Since I first went into hospital, yes, [because of this] I still take four tablets a day yeah. I'm on anti-psychotics.
>
> (Jason: service user/survivor)

For Jason, after being prescribed medication during his first stay in a mental hospital, it resulted in him being prescribed medication throughout his adult life. This was common for all service users, as once prescribed medications this seemed to result in long-term pharmaceutical treatments. To coincide with the narratives of service users, family members reported a number of concerns about the overuse of medication within mental hospitals, reporting that their relatives were highly medicated during these periods of detainment. Donna's family described extremely unpleasant memories during visiting times, both family members suggesting they noticed a recognisable increase of medication during her time in hospital. They both described her struggling to communicate with them during their visits:

She'd lost so much weight and she was fretting to be home. Crying when we went

and asking to come home all the time. So she didn't like it. Well I had said to my

mother, 'I think you best try and bring her back home'. … She'd had enough and

she looked absolutely dreadful and she wasn't herself.

(Gloria: family member)

Gloria and Pauline refer to how Donna's behaviour was significantly altered during these periods of hospitalisation. Donna's niece describes the hospital visits as extremely upsetting. They suggest that Donna's personality was completely transformed during her stays in hospital. Interestingly, none of the practitioners described mental hospitals as a particularly effective environment to 'treat' mental 'illnesses'. Johnny, a mental health nurse, describes mental hospitals as being dominated by a traditional medical ethos, which defined professional practice during this time period. He suggests that:

[t]here were very clear roles, yes, and it was very medically driven. There's no

getting away from that. Very medically driven and it's sad to say, I cannot recollect

an instance where there was any kind of psychotherapeutic interventions. I can't

recollect it.

(Johnny: Mental Health Nurse)

For Johnny, treatment equated to medication or restraint. He describes very little interaction between psychiatrists and patients, and most of the day-to-day activities and interactions were carried out by nursing staff. He also described his frustrations with the system as patients lived on wards for long periods of time. In his practice he defined 'treatment' as

consisting of medication or ECT. Most of the practitioners reported similar concerns with reference to the mental hospital system. Christopher, also a mental health nurse, described the different categories of patients living at the hospital. He states:

> You had long-stay, medium-stay, short-stay [wards]… The short-term people would come in with a diagnosis that would either get some intervention. They'd say for as long – up to a year …, or it could be just less than that…. So some people … [would] be helped quite quickly…. Medium-term people … seem[ed] to me to be the long-stay ward but was called the medium-stay ward because there was nowhere for them [patients] to go. So they'd been in maybe a couple of years…. The long-stay had been there, well … They'd come in and they were never coming home.
>
> (Christopher: mental health nurse)

All practitioners in this study imply that, for many patients, mental hospitals were less about treatment and cure, and more about a system of housing people experiencing long-term mental distress, away from their communities and society as a whole. As illustrated, all participants refer to aspects of institutionalisation alongside the use of medication during this period. Participants in this study emphasised key issues which led to changes in mental health policy (i.e. the Mental Health Act, 1983), resulting in the closure of long-term hospital-based care, to be replaced by the community care system.

From Hospitals to the Community

As a result of the Mental Health Act of 1983, the care for people with mental health issues was transferred from hospitals to a community care system, i.e. a process of deinstitutionalisation. In the late-1980s and 1990s the mass closure of mental hospitals led to the community care system being established in the UK. Although participants agreed that the closure of the mental hospital system was a positive move to improve care, they were also highly critical of the process of patients being moved into the community. William's story is somewhat representative of the narratives of service users/survivors within the study. William describes now he was suddenly moved from a mental hospital ward to the community. He recalls this move as being extremely stressful, which led him to feel suddenly isolated. William describes having no one to turn to for help within a community that felt alien to him. He states that:

> I was still mentally ill and I was not used to living on my own. So in the first week I was there full-time I wrote to my brother in Australia and said, I'm living in this house all by myself but how shall I manage? I don't know anything about cooking.'

> (William: service user/survivor)

When living in a mental hospital his daily routines and domestic duties were organised by nursing staff. As William had spent a long period of time in hospital he had not developed any basic life skills. Once living in the community he found it very difficult to adjust to life outside an institutional regime. Unfortunately, for William this had a negative impact on his mental health and he spent long periods of time on short-stay psychiatric wards. His inability to cope throughout the 1990s within the community led to him being placed in long-term residential care. This experience of leaving mental hospitals for the community was comparable for

seven out of nine service users/survivors in this study. For most service users/survivors, life in the community was short-lived and they were subsequently moved into new privately run residential care units, built to replace the mental hospitals. Only two service users/survivors managed to successfully adapt to living in the community; both Harry and Jack have successfully adjusted to living in the community with support from community care services. But even though they lived in the community, both also report long periods of social isolation. As Harry asserts:

> I struggle on my own …. I find it hard, but I can manage on my own but I would like to be in a home or something. I think like a residential home.
>
> (Harry: service user/survivor)

Interestingly, practitioners were also very critical about the closing down of the mental hospitals during the 1980s. Although Christopher is extremely critical of life inside the hospital wards, he also acknowledges how poorly the transition was managed by the NHS, and local authorities when closing hospitals and establishing the community care system. Confirming service user/survivor narratives, practitioners suggest that many people with severe mental health conditions were either moved into residential care homes or housed in small psychiatric units. Christopher reports that many service users never truly got access to the community. From a practitioner perspective, this process occurred too quickly and was underfunded. As Johnny states:

'I don't think it was ever funded properly [community care] … There needed to be that kind of half-way house first. … Not everybody will benefit from that because some of them have been institutionalised for yonks.'

(Johnny: mental health nurse)

Practitioners describe service users/survivors as often being abandoned in deprived communities around the North-East. Similar to William's experience, practitioners reported that for some ex-patients/survivors they had lived within hospital wards for long periods of time and were unable to cope in the community. In some cases, practitioners reported seeing ex-patients living homeless in Newcastle and Sunderland after the hospital closures of the 1980s/90s. Johnny reported that he would often go and speak with many of the patients he used to care for, and take them food and money. As Christopher explains:

What I think happened was as a consequence of [the mental hospital] closures, it was always predictable but it was terrible, it didn't need to happen. So many older people, or people who might have been in that medium to long stay, ended moving from a ward in a hospital to a small ward in the community. And those people that were short-stay, ended up eating out of bins. Because I remember about two years after I'd left the hospital seeing people on Wallsend Metro Station eating somebody else's leftover kebab from the night before out of bins and thinking, 'Actually in the hospital, at least they would have had somebody caring for them'.

(Christopher: mental health nurse)

As Johnny and Christopher both suggest, the initial problem that service users/survivors were confronted with was 'a lack of skills' because of long-term institutionalisation. Once patients left the hospitals they were rendered 'vulnerable' when entering communities because of a lack of services. As Christopher discusse,d the central idea underpinning the community care movement was that local people would support ex-patients/survivors into their communities. In this study, participants indicated that in reality local people often excluded and stigmatised ex-patients/survivors, rather than accepting them into their communities. From a practitioner's perspective, both of these issues resulted in service users/survivors experiencing social alienation after leaving mental hospitals for the community.

In this study, it was during the 1990s where the initial failures of community care services were revealed. As both service users/survivors and practitioners illustrate, there was a lack of funding and support in the community once the mental hospitals were closed. These narratives seem to indicate fundamental failures with the neoliberal approach adopted by the Conservative and New Labour governments during this period. Service users/survivors in this study found themselves in a quasi-marketplace, which not only was underfunded, but also seemed to lack choice, and lack the fundamental services they required to live in the community.

Residential Care and Hospitalisation

Within contemporary social care there is a general consensus that over the past 30 years we have witnessed the deinstitutionalisation of mental health services (Glasby and Tew, 2015; Hudson, 2016). When exploring how participants' lives have changed after

deinstitutionalisation, and the implementation of the NHS and Community Care Act (1990), the majority of service users/survivors in this study were living in privately run residential care homes. Both service users/survivors and care practitioners described very mixed experiences of working and living in different residential care units. From a service user/survivor perspective, attitudes concerning living in residential care were mixed. An example of this can be seen in Faye's narrative when describing living conditions in her residential care home. Faye's experiences of residential care are somewhat different to other service users/survivors, as she describes living in residential care as a somewhat negative experience. For Faye, life in residential care is conceptualised as isolating. She states:

> I just think it is just an awful isolated place.… It is like set back in a world of its own reality.
>
> (Faye: service user/survivor)

Interestingly, Faye has more interactions with the outside world compared with other service users/survivors, due to contact with her family. Family members often visit and take her for days out. Yet, for other service users, contact with the outside world seems to be far more limited compared with Faye's experiences. Jude's narrative is more comparable to other service users/survivors in this study. He reports experiencing intimidation and restraints in a previous residential care unit, but now describes having a good relationship with staff in comfortable living conditions. For Jude his positive relationships were primarily with care staff. He reports not having visitors as his family were now deceased, and reveals that he no longer leaves the residential care home. As Jude states:

I've enjoyed meeting people. There's a nurse here called Jeff who's really nice. You'd like Jeff.… [Although] I don't go out much. No. No. No. I'd like to get out a bit more in the sunshine. I'd like to go out a bit more but I don't actually get out much you know.

(Jude: service user/survivor)

For Jude, he acknowledges that his daily routine consists of either sitting in the corridor or in the TV area between mealtimes. Similar to Jude's narrative, a number of service users/survivors no longer have family members who visit them, or take them out of their residential homes. Yet, paradoxically, the majority of this group described their current residential care home as a positive living environment. This could partly be explained because service users/survivors described having many positive relationships with some of the care staff (as referred to earlier, this was not the case when living in the pre-1983 mental hospitals). An example of this can be seen in the number of participants who reported being part of a service user committee, which is designed to feedback to staff on living conditions. This gave service users/survivors a feeling of ownership within their residential care homes. As William reports:

I'm the Chairman of the Residents Committee.… I go round before the meeting… and ask each resident if there's anything they want discussing at the meeting. Some do, some don't. If they do, I note it on my reporter's notebook and then draw up an agenda. [The current manager] sits in at the meeting.… In the past, managers have not attended the meeting but have got the minutes and have not acted upon them.

Although William is very positive about these meetings, he acknowledges that it is only his recent care manager who has made changes to the quality of care based on residents' feedback. Unfortunately, when exploring the impact of these committees on improvements in care quality, all participants struggled to give any concrete examples of significant changes within their residential homes. Yet, these service user committees could be interpreted as a system of 'disciplinary power', as any issues/problems were required to be fed back to the care manager through these service user committees. If service users/survivors displayed behaviours that were viewed as disruptive then these behaviours were interpreted as symptomatic of their mental 'illnesses', rather than frustrations with living conditions/care. Service users/survivors would also conceptualise their own disruptive behaviours as being associated with their mental 'illness', and discussed how these would often lead to periods of hospitalisation. William makes reference to how he decided to change his behaviour to prevent him from being admitted again to a psychiatric hospital. As he states:

> Well I've spent most of the time since I was first in [a psychiatric hospital] feeling sorry for myself. I'm mentally ill and angry and all that kind of thing, but there was a point on the [psychiatric] ward that I said to myself, 'If you don't behave yourself William, you're going to be here for years'. So I made a point of behaving myself, doing whatever was required by the staff, befriending the staff, befriending people.

(William: service user/survivor)

For William this was a conscious decision to participate with the hospital regime in order to be returned to his residential home. Interestingly, all service users/survivors described their experience of hospitalisation as being incredibly negative. This was also the case for the two participants living in the community, as they had spent significant periods of time on short-stay psychiatric wards. However, these negative experiences did not relate to any form of staff violence. When discussing bullying or intimidating behaviour by staff the entire group stated that this very rarely happened in contemporary hospital care. Service users/survivors felt that this type of behaviour was far more likely to be instigated by other service users than members of staff on psychiatric wards. As Harry suggests:

> People [are] chaotic and I suppose they must get periods of time where there's people in where it does get very chaotic or too many on the ward. And over the last few years there's been too many on the ward. They've had to put people up in Northumberland and god knows where. It's funny. To me, I'm just glad I haven't gone back in ... It'll be very noisy and you're around angry people, people with drug problems, drink problems as well. So I'm glad at the minute I've kept out of it for years. The last two experiences have been pretty much like that one. It's been chaotic.
>
> (Harry: service user/survivor)

Although experiences of physical violence were not observed within the contemporary care system, a number of participants briefly discussed observing other service users being restrained within hospitals and in residential care units. These experiences seem to have been somewhat normalised within their narratives, and were often described as happening to other

people. Although service users/survivors generally reported improvements in care, some similarities could be made between mental hospitals and residential care homes due to the use of medication as a form of treatment. Service users/survivors described very little change with reference to medication during their time in both institutional environments. From a service user's perspective, receiving treatment using psycho-pharmaceutical medications was standard practice within the mental hospitals, and this was still the case within psychiatric or residential care units. As Jack states:

> They put us on Prozac and it was no good. It didn't work and it agitated everything. It made us itchy, hot and everything. I had a bad reaction to it. They took us off that. Put us on something else. I think in the nineties they put us on a few things. Nowt would seem to work. And I went in hospital and Dr Gibson put us on venlafaxine. That worked. I was on that 2002–2003 I think and they've put us on Reboxetine which I've been on ten or eleven years.
>
> (Jack: service user/survivor)

For service users/survivors, they had been taking some form of medication since they first entered a mental hospital. Although their medication had changed over a 30 year period, the entire group expected to be on some form of medication throughout their entire lives. Medication was a constant throughout their biographical narratives. From a practitioner's perspective, working in care during the 1990s and early-2000s led to a shift in attitudes of staff, and a number of practitioners reported being optimistic during this time period. One care manager called Joanne describes how they attempted to encourage service users/survivors to leave their residential care homes during this time. Her team set up service

user committees, so residents could have a say in the running of the care unit as a service. Joanne describes attempting to bring the community into the residential home, by setting up fetes and garden parties to encourage communities to become more accepting of service users/survivors housed in this unit. At the end of the 2000s her residential care home was closed and she started working in a newer and larger residential care unit. It is during this period of time that practitioners become far more critical of residential care. From Joanne's perspective, this is when her feelings of optimism start to change, and she becomes very critical of new larger types of residential care:

> First impressions were a big home. It was a big massive home. A Sixty bedder. I done my first shift was on the floor and I was shadowing members of staff and I can always remember just thinking it didn't feel homely.
>
> (Joanne: care manager)

For Joanne, working in larger residential units meant far less interaction with service users. Although this unit was a lot larger than her previous care home, there were far fewer staff. She also notes that there were far more cases of disruptive and violent behaviour within this particular unit. On her first day she was introduced to the concept of restraining service users. As she states, 'I never realised when I applied for the job that there was going to be restraint involved…. I thought it was horrific.' For Joanne this was something which had not been part of her professional practice before working in this unit. Although initially restraints were extremely shocking to witness, she discusses how her attitudes changed overtime due to the level of violence that she witnessed by service users at this home. She reports that it was not uncommon in this particular residential care home for service users to attack members of

staff. For Joanne, after starting working in the larger residential care units she finally decided to change her professional role and move away from frontline care.

While there was a general consensus that social care had improved over the past thirty years, all service users/survivors and practitioners were extremely critical of the larger privately run institutions of care. Interestingly, Christopher suggests that there has been very little change in the practice of care, particularly in these new types of residential units. He is far more critical than other practitioners in this study. For Christopher, when comparing professional practice in residential care with that of the historic mental hospitals, he suggests that:

> It's just shit.… They [service users] are just now in the same kind of shitty plastic chairs but in [a residential care unit]. They'll never get out. … We [health professionals] have just moved them to somewhere else. We haven't done anything with their lives.
>
> (Christopher: mental health nurse)

From Christopher's perspective, society has replaced the old state institutions with new private institutions, which we now refer to as residential care homes. He suggests that the living conditions within these institutions have not symbolically changed. Christopher implies that the same structured daily activities, regimental systems of control and institutionalising processes are still in place. From his perspective, the most significant change which has taken place is that the care system has de-professionalised its care staff and is now a privatised service. It is in this narrative where we can view Szasz's (2005) concept of trans-institutionalisation (also see Slovenko, 2003) emerging from Christopher's professional

experiences.

Conclusion

The aim of this study was to analyse the biographical narratives of service users/survivors to conceptualise how their lives had changed from a system of institutional care to one of community care. Due to the nature and sample size of this study, no direct conclusions can be drawn from the experiences of a small number of service users/survivors; however, a number of questions emerge from these experiences. The first is the issue of community care being significantly underfunded (Beresford, 2012). In this study, historically a large number of service users/survivors were housed for long periods of time within mental hospitals. Treatments were dominated by psychoactive/psychotropic medications, and living conditions were defined by an institutional regime. In the late-80s and early-90s, once these institutions were closed, service users/survivors were relocated into communities in the North-East of England. For the vast majority of individuals after deinstitutionalisation had occurred, these participants struggled to adapt to life in the community. By examining the narratives of these service users, it becomes apparent that there was very little support offered to them once they were moved into the community. Only two service users/survivors managed to adapt to a community setting, with the remainder being placed into residential care. It seems apparent that community care was systematically underfunded (Beresford, 2012), which impacted negatively on the lives of service users/survivors in this study. Within the service user/survivor narratives we can see that the neoliberalisation of services resulted in change, but this change was significantly affected by economic cost rather than issues of equality and social justice (Beresford, 2012; Esposito and Perez, 2014).

Yet, the principal question raised by this study relates to the concept of deinstitutionalisation. Although contemporary psychiatry refers to the dismantling of mental hospitals through the process of deinstitutionalisation (Semple and Smyth, 2013; Glasby and Tew, 2015), there seems to be evidence in this study that there is still the spectre of the old hospitals in the current care system. In this study, the long-term housing of economically deprived mental health patients is no longer delivered by the hospital, but is now provided by a privately run residential care system. Based on the majority of service user/survivor experiences, the marketisation of mental health services seems not to have led to the deinstitutionalisation of care, but has resulted in the process of trans-institutionalisation, where service users/survivors have simply been moved from state-owned to privately run care units (Slovenko, 2003; Szasz, 2005). What this study seems to illustrate is that, for people with severe mental health issues, community care may not mean independent living, but institutional housing situated within a community setting. As these institutions grow in size, and house an increasing number of service users/survivors, we need to ask the question: are we seeing history repeating itself?

To conclude, this article suggests that it is vital to engage in alternative critical approaches of psychiatric services, particularly from the emerging field of Mad Studies (LeFrancois *et al.*, 2013; Beresford and Russo, 2016; Faulkner, 2017). Disciplines such as Disability Studies and Mad Studies, where disabled/service user/survivor experiences are fundamental in exposing hidden inequalities, can offer us an alternative perspective in order to challenge the 'medicalisation of everyday life' (see Szasz, 2007; LeFrancois *et al.*, 2013; Faulkner, 2017). Therefore, in this study, although many of the old mental hospitals have now been

transformed into luxury apartments (Hornstein, 2017), we should not make the assumption that the old model of institutional care has been completely eradicated. If we walk around any urban community it may be surprising to count how many residential care homes there are. Unfortunately, for service users/survivors in this study, life in residential care, although an improvement to hospital care, seemed surprisingly similar to the institutionalised experiences reminiscent of the classic work of Erving Goffman (1961).

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