Friends and family: Regulation and Relationships on the locked ward

Abstract

This ethnographic project explored the lives of women with learning disabilities in three locked wards. I found that aspects of women's lives were regulated by the service, in particular, this applied to relationships with family outside the unit, and peer relationships inside the unit. The women in this study valued these relationships, but they were treated with ambivalence by the service. Success in future community integration and accessing community resources can be dependent on the nature and quality of relationships with others, therefore, services should acknowledge that service-users need to forge relationships of their own choosing.

Introduction

Friends and family can offer support throughout life (Northway, 2015). For people with learning disabilities, families are very important; they help with stressful times and can offer an extraordinary amount of assistance in daily life (Goldberg et al., 2003, Roffman, 2000, Rolph et al., 2006, Tuffrey-Wijne et al., 2009). Good family relationships are described as enhancing self-image, resilience and caring skills (Walmsley, 1993, Morrison and Cosden, 1997, Nunkoosing and John, 1997, Knox and Bigby, 2007, Northway, 2015, Hastings et al., 2005). Similarly, friendships are extremely important and beneficial to people with learning disabilities (Knox and Hickson, 2001, Bigby, 2008) so one would expect these types of relationships to be encouraged and supported in any inpatient service.

This paper describes a theme that arose from my PhD research project with women with learning disabilities in the north of England. I used ethnography to explore the daily life of staff and service-users on three of the wards at an NHS learning disability secure unit in the north of England ('Unit C') in 2011-2012. These types of units are custodial - people are detained here if they are labelled as learning disabled and they have committed an offence, or if their behaviour has been considered a risk to themselves or others, leading to a breakdown of a previous community placement. Women are a minority in this service; amounting to only 20% of service-users. A major theme arising from the field-notes and interviews was relationships – in particular the types of relationships that people are required to negotiate in such an unnatural environment.

In my study, there were many important points made by the participants about how relationships were regulated and managed on the wards, and the relationships theme

encompassed some sub-themes –sexual relationships which I discuss elsewhere (Fish, 2016), staff/service-user relationships – examining how institutional practices maintain dependence and power imbalances, and indeed damage relationships – as well as peer and family relationships, which I will explore here.

Existing literature – family relationships

In *Asylums*, Goffman highlights the incompatibility of two forms of social organisation (households and institutions). Family life is contrasted with 'batch living' by Goffman, he points out that maintaining a family life is precisely what enables staff members to remain integrated with the outside world and 'escape the encompassing tendency of the total institution' (1961:20). When a person enters an institution, they come with a 'presenting culture', which has been their way of life and of coping with conflicts, discrediting and failures in their home world. Goffman describes the process of 'disculturation', and this 'untraining' will render the person 'temporarily incapable of managing certain features of daily life on the outside' (1961:23). In this sense institutions do not look for cultural victory, they 'create and sustain a particular kind of tension between the home world and the institutional world and use this persistent tension as strategic leverage' (1961:24). This complete separation between home (family) and institutional life is highlighted by recent authors as a particularly negative aspect of inpatient placements from the point of view of both service-users and families or carers (Bonell et al., 2011, Chinn et al., 2011, Rogers, 2015, James, 2015, Walsh et al., 2001). This body of literature describes family concerns such as the lack of contact with their family member as well as the lack of opportunities for involvement in their care and treatment.

The Justice for LB (JusticeforLB.org) and Seven Days of Action (Sevendaysofaction.net) campaigns were initiated by families of people with learning disabilities who have been detained in inpatient units. From the many testimonies on these pages and related blogs, we can clearly see that families have abundant knowledge about the person and their health, and importantly, how to avoid and manage their anxiety and the escalation of agitation. Yet these families describe being actively excluded from their family member's care. This is despite the Mental Health Act's Code of Practice requiring that 'the views of families, carers and others, if appropriate, should be fully considered when taking decisions' (Department of Health, 2007). Human Rights policies also recognize the importance of family, and emphasize the right to family life. The UN Convention on the Rights of Persons with Disabilities includes families of disabled people when discussing Human Rights, acknowledging that family members should receive the

necessary protection and assistance they need to support this (Equality and Human Rights Commission, 2010).

Existing literature – peer relationships

Almost all of the research which mentions relationships on inpatient units focusses only on the therapeutic relationship between staff and service-users. Service-users' relationships with each other are discussed occasionally within literature that explores service-user satisfaction with services and papers which discuss the 'ward milieu' (Long et al., 2012). The reported significance of peer relationships differs greatly in the available accounts; Goffman (1961) in *Asylums* describes little solidarity and support between service-users, and Bressington (2011), for example, observed that peer support had very little to do with how satisfied service-users were with their inpatient stay in secure services. Opposing views come from the participants in Thomas et al's (2002) study with psychiatric inpatients. They reported that universally, peer-administered 'therapy' was the most beneficial aspect of hospitalization, which usually took place in the smoke room away from staff. This sentiment was similar to Howard et al's (2001) study, again on a psychiatric ward, where participants rated their satisfaction with opportunities to talk with other patients as more significant than any other aspect of their hospital experience. Peer support groups such as the Hearing Voices Network are becoming established in England, where service users can describe their experiences and understandings about their conditions in a supportive atmosphere (Hornstein, 2013). Further, user led organisations for disabled people can offer peer support, mentoring and empowerment (Campbell et al., 2007).

McWade (2014) found that relationships with peers in an English NHS 'Arts for Mental Health' service were very important to service users. Her participants said that these relationships enabled them to feel less isolated, and to realise that there were people with whom they had some shared experiences and understanding with. They linked meaningful relationships with feelings of joy and excitement, and pathways to recovery. According to Wolfson et al (2009), service-users with mental health conditions who are recovering are able to help others and this should be encouraged by staff, however they also emphasise that peer relationships are not always about support, people experiencing different conditions are 'thrown together' which can result in hostility, bullying and harassment.

Methods and approach

This paper is drawn from ethnographic research with women with learning disabilities in locked wards. Ethnographic researchers are concerned with the meanings people

attach to things in their lives (Taylor and Bogdan, 1998, Goodley, 2001, Smith, 2006). By observing people in context during their everyday lives, researchers are able to develop concepts from the data rather than testing preconceived models or theories.

Since Goffman's classic study of St Elizabeth's asylum (1961), many institutional ethnographies have been published, for example ethnographies of prisons (Owen, 1998, Rhodes, 2004), psychiatric units (Quirk et al., 2006), and locked wards for people with learning disabilities (Johnson, 1998, Hubert and Hollins, 2006, Owen et al., 2008). Researchers want to venture behind the smooth outer walls of the institution to find out how it is experienced on the inside. Further, although there are ethical concerns involved, it is widely established that institutions should be written about and the people who live in them should not be hidden away from the rest of society. This, combined with the paucity of writing which includes women with learning disabilities, indicates the importance of studying women who are detained in contemporary institutions. Finally,, using ethnographic methods enables service users who are less articulate to participate in research (e.g. Booth and Booth, 1996).

My observations included daily life on three of the wards where the women lived, over a period of nine months, and I subsequently interviewed 16 service-users and 10 staff. The wards that I observed were designated to me by the ward manager. Two of the wards were classified as low secure (wards are locked but service-users are able to access other areas of the unit) and one was the only women's ward on the medium secure unit (wards are locked and service-users must stay within the two-storey enclosure at all times).

Doing ethnography enabled me to spend time getting to know service-users and staff, and also talk about my reasons for carrying out the research, which were to find out what life was like for women and to find out their ideas for improvement. Additionally, ethnography facilitated a trusting two way relationship, and although I was concerned about inequalities in the research relationship as described by researchers such as Stacey (1988), my aims were to make recommendations which I hoped would improve the lives of women on the unit.

Access, Consent and Ethics

Prior to the study, I had been a researcher member of a women's group consisting of staff and service-users on the unit for 12 months, therefore I knew some of the women and staff beforehand. Despite this status, gaining access to the wards was still difficult and time consuming, largely due to the physical procedures of accessing the wards, which involved obtaining a belt and special pouch, keys and a personal alarm system.

I spent over 120 hours observing life on the wards at different times of the day, over a period of nine months. This involved much sitting and talking, with many of the women mentioning that they were happy to have someone to talk to who did not have the duties of other staff. I was called upon to help out occasionally, for example to escort people to work or stay outside with them whilst they smoked. I purposefully did not spend too much time talking with staff, so that the service-users would not consider me to be part of the staff group. I believe that my presence did change what happened on the wards, for example there was very little conflict between the women whilst I was there despite this being a significant theme in the interviews. The fact that conflict was reduced during my time on the wards may reflect my status as a partial 'outsider' (Mercer, 2007).

My research was given ethical approval from the National Health Service Local Research Ethics Committee. One of the prerequisites of approval was that I had to gain written consent from all the people involved, to allow me to write about any observation. This was a lengthy and difficult process, but it nevertheless enabled me to discuss the research in-depth with people in the unit. The women who participated in the research were all labelled as having mild to moderate learning disabilities and were judged by their case managers to be able to give consent. They were informed that the information that they gave would be anonymous and that their name would not be written down anywhere. Pseudonyms were given during the transcription process and I have made attempts to exclude any information that could identify participants (Rogers and Ludhra, 2012, Ellis and Bochner, 2000).

Ethical adherence followed the guidance of Perry (2004) who advises that ethical concerns should be paramount throughout the research. People who did not give consent at the time were not repeatedly invited, nor were any field-notes taken about situations that they were involved in. Separate consent forms were completed by staff and service-users, and for participation in the observation and interviews. In accordance with the Mental Capacity Act (Department of Health, 2007), verbal checks were performed with service-users to make sure they had understood the process of the research. Any participant who disclosed that they had been subject to abuse were offered support to approach their case manager if the issue had not been already dealt with.

Interviews

My observations produced field-notes, which I arranged into themes and used these to develop interview questions. All participants in the observation phase of the research

were invited to be interviewed, and although some declined, ten staff and sixteen service-users agreed to be involved. All were white British and between the ages of 18 and 60. The women I interviewed had lived at the hospital for between 5 months and 19 years. Four out of the 16 women I talked to had lived there for longer than 15 years. Most of the women had come here from other units or hospitals, some from private services and one came from prison. The staff I interviewed consisted of two ward managers, eleven qualified nursing staff, two support workers and one clinical psychologist; they had worked at the unit between 2 and 28 years. The questions were open ended and general, such as, 'How do you feel about living here?' and 'How do you think services for women could be improved?' followed by further probing as appropriate.

Many of the things I was told as a researcher were distressing and difficult to hear, and I felt privileged to be in the trusted situation that allowed this, but also conscious that I was using this trust as a way to get a PhD and advance my own career. Disengaging myself from these relationships that had developed was difficult (Rogers, 2003, Oliver, 1992) but was made easier by my leaving to take maternity leave, providing a natural break. I provided feedback in the form of presentations as well as written staff and service-user briefs about the research for the organisation and participants.

I analysed the data using the framework of intersectionality (Crenshaw, 1991), noticing instances where gender and disability were highlighted. This was associated with my commitment to feminist and Disability Studies methodologies. I analysed the large body of data using NVIVO, qualitative analysis software which helped me to realise subthemes arising from the data. Therefore, in the following section I discuss two of the emergent themes, family relationships and friendships.

Family relationships – 'I'm just thinking of her today'
Families were extremely important to the women on Unit C. When women talked about their families, it was often in terms of worrying about what was happening to them, looking forward to seeing them and wishing they could be with their families to help them in one way or another. Celebrations such as Christmas and birthdays were particularly difficult (see also Wood et al., 2008), as Sarah told me:

> *Researcher: So what do you <u>not</u> like about living here?*

> *Sarah: Being away from your family, at Christmas time, locked away. What I do like about it is when we have a home visit, that's what I like about it, but what I <u>don't</u> like is when you're just locked here at Christmas time and everything.*

In common with other research conducted, service-users at Unit C often felt that they did not see their family often enough (see also Goodwin, 1999, Wood et al., 2008, Beadle-Brown et al., 2005, Walsh et al., 2001) and women found this frustrating. This might be especially significant due to people with learning disabilities often living at home with their families into their adult lives. Despite policy urging that people access services as near to their families as possible (Reed, 1994, Mansell et al., 2006), it seemed that some of the women were far from home which was detrimental to their family visits as Katrina told me:

> *Researcher: What about the weekends?*
>
> *Katrina: Crap. The only thing that's good is that I see my mum. She comes all the way from [town – about 2 hours' drive away]. I go on home visits to try and save her from driving.*
>
> *Researcher: Do you have to take staff with you?*
>
> *Katrina: Yes two staff.*
>
> *Researcher: I imagine that's quite hard to organise. Is it?*
>
> *Katrina: I haven't been on a home visit for a while.*

Despite recommendations to place people as locally as possible (Department of Health, 2007), specialist services for people with learning disabilities have developed at varying rates, possibly due to the small number of people requiring them. This has resulted in people being placed in secure care hundreds of miles from home, which can present many difficulties such as loss of contact with local services, community networks, and families (Stewart and Dakin, 2009, Beadle-Brown et al., 2005). This is a current issue at the time of writing, as families join together to challenge the available service provision and the acceptability of the removal of their family member for reasons of 'challenging behaviour' (Ryan and Julian, 2015).

This lack of service provision particularly affects women because some of these services are men-only, resulting in a higher probability of being placed far from home. *The Corston Report* (2007), which looked specifically at issues experienced by women in prison, recommended changing the way criminal justice agencies work with women, and replacing women's prisons with local custodial units as a way of addressing these issues. Some academic literature suggests that there is less of a need for high levels of physical security and more need for 'relational security' for the majority of women offenders (Hassell and Bartlett, 2001, Long et al., 2008). Relational security is defined

by the Department of Health as 'the knowledge and understanding staff have of a patient and of the environment; and the translation of that information into appropriate responses and care' (Department of Health, 2010b). Despite this recommendation, some researchers have demonstrated that women are detained within higher levels of security for less severe crimes than men, and certainly higher than can be justified (Bland et al., 1999).

Even with the distance that some people had to travel, all except one of the women I spoke to received visits from their family or partner, and some were allowed to visit home with the support of staff for the occasional weekend, with frequency being dependent on Home Office approval. What they did at the visit depended on the service-user's guidelines, for example some families could take their member out to town or to the Unit cafeteria. Most of the women told me however, that they mainly sat in the visiting room to talk to their families, accompanied by a member of staff, for example:

> *Researcher: Do your family come and see you?*
>
> *Lorna: Yes, we just sit in this room and chat.*
>
> *Researcher: How long for?*
>
> *Lorna: Two hours max.*
>
> *Researcher: And do you like it when they come?*
>
> *Lorna: Yes.*
>
> *Researcher: How often do they come?*
>
> *Lorna: Not often about once a month.*

Kate told me that a family member had been invited to meetings but there did not seem to be any debrief or preparation time:

> *Researcher: Do you ever have family and friends visit?*
>
> *Kate: I've had my granddad come in a few times, but to my CPA [Care Planning] meetings and tribunals.*
>
> *Researcher: And what do you do at those?*
>
> *Kate: Um we can't do nothing really cos it's a meeting isn't it? So I can't really talk to him in a meeting, I usually get ten minutes with him after my meeting before the social worker has to drive him home.*

Three of the women were worried about family members who were in ill health. They

found it distressing that they could not visit them:

> *Bella: [My Mum is very ill and] she says she doesn't want no birthday presents or Christmas presents because she doesn't know how long she's going to be [alive], so I said I'd get her a little cuddly teddy so she can have a teddy with her. I'm just thinking of her today. It's getting harder though because I'm just waiting for the phone call do you know what I mean?*

> *Marion: I'm hoping that if I do move somewhere else I'd be very close to my sister and my nephews and my niece and my brother in law. But I do hope if I do move, sooner or later, that I'll be back before anything happened to my mum. She's carried me through thick and thin.*

Despite these desires, it seemed clear that much of the violence and abuse in the women's pasts had come from family members, and staff naturally had to find a way to protect service-users from those people. Much of staff's discussion about families was negative, they seemed to take on the role of mediator, for example:

> Lorna has been writing a letter in her room. Staff member Candice tells me (with Lorna's agreement) that Lorna has been having some problems with her family and she has been supporting her to write a letter to them telling them how she feels, and making it known that she will not give them money any more. (Fieldnotes)

Staff in the service were supportive in maintaining family links, with phone calls to family evident in the evenings and some discussion about both staff and service-users' families on the wards. Phone times were allocated to service-users on the low-secure unit and they could use the telephone sited in the kitchen to make calls in the evening. In the medium-secure unit there was a mobile phone which service-users could take into their room. However, Annie told me that her phone calls had been limited because of her financial situation:

> *Annie: In here you can only have certain phone nights. Whereas my phone night originally were Wednesdays and Saturdays but because my mum knows I've not got a lot of money it's got to the point where I'm [borrowing] other people's clothes and trainers I said to Mum 'I'm going to have to cut down on my phone calls' and she's giving me a hard time over that but it's something that I've had to do so I only get to speak for her for ten minutes every Sunday.*

Women's income was often tied to their incentive system, and as such if they had broken rules such as refusing to attend day-service, they may not have money to contact their family. There was no discussion about to what extent family were included in any

consultation about the women's care and no reference made to service-users' families in staff interviews (although I did not ask about this specifically and this could have been related to confidentiality).

People with learning disabilities commonly live with their families into adulthood, with their family providing their main system of support (Walmsley, 1996). However, this was not particularly evident here. I think the reason for this could be due to the focus on negative family experiences and how this did not leave very much space for positive discussion. One of the staff roles seemed to be protecting service-users from these negative relationships. From spending time with the service-users, I became aware that even though they had experienced bad things at the hands of their family members, there was usually at least one person from their past with whom they retained (or wanted to retain) a good relationship. It seems that efforts could be made to increase involvement and encourage positive links with families and friends as well as providing access to Independent Mental Capacity Advocates, as recommended in the Mental Health Act Code of Practice (Department of Health, 2007).

Service-users spoke about how important family was to them, and families formed a fundamental part of people's conceptions about their future. Even though many people had negative relationships with some family members, they generally spoke about *other* family members as significant and their relationships with them as positive (see also Beadle-Brown et al., 2005).

Service-users' peer relationships - 'We've managed to lean on each other'

This was a larger theme and incorporated four sub themes: conflict and compatibility; supportive relationships; regulation of relationships and ways forward:

Conflict and compatibility

Although I did see some supportive relationships between service-users, by far the largest interview theme relating to service-users' relationships with each other was conflict; people talking about arguments and fights with others. When service-users are forced to live in close proximity with others who are not of their choosing, spending large parts of their day in their company, this often causes problems. This was especially the case when service-users were obliged to remain in the same physical area for surveillance reasons. Even though some service-users may not be designated to need this level of observation, due to staffing regulations, they had to remain in the same spaces. When I was spending time on the wards, two service-users who lived in the same flat were arguing after previously being good friends:

Teresa is having a cigarette outside and I am with her. Elaine comes through the door and says, 'Say anything about me and I'll smash your head in.' Teresa's bottom lip wobbles and she has a very sad face. It is time for me to go, I ask Teresa, 'Will you be OK?' She replies, 'No.' I ask her, 'Are you scared?' She replies, 'Yes.' She goes inside and says she doesn't want her food. I ask her if she will eat it if I stay and she agrees. The staff member gives me some background to this exchange, she says that Elaine has lived alone for years and she is very outspoken if she's annoyed about something. Teresa adds that it is because Elaine kept asking for the sweets that Teresa's partner had brought her. Both women have been avoiding each other and not eating because of this. When she has gone, the staff member tells me that she also thinks Elaine is jealous of the things that Teresa's partner brings for her. Although Elaine gets to go home and see her mum, she always has to take something, her mum never gives Elaine anything. The staff have tried to explain to her that everyone is different and has different amounts of stuff, but she hasn't accepted it. (Fieldnotes,)

Jealousy was attributed as the cause for many problems and was a recurring theme when discussing service-users' arguments, as pointed out by staff member Stewart:

> Stewart: The main thing again, is – and I keep repeating myself – the relationships, 90%, just to pluck a figure – of incidents on the ward are usually revolving around high-expressed emotions of jealousy or things like that really. Someone'll get a visit which will annoy the other person because they haven't had a visit for maybe two weeks, or someone will get down and things like that really. Certainly the jealousy between service-users is big, certainly when you're dealing with people with personality disorders, they might seem to go out of their way to cause friction and light the touch paper then retreat. They seem to enjoy someone else losing it because of what they've said to wind them up.

Stewart attributed some of the jealousy on the unit to the behaviour of particular women here, indicating that feelings of jealousy are not always unavoidable but brought about on purpose. Annie, a service-user gave me an example of conflict which could be considered to be due to jealousy, here:

> Annie: I'd been nagging and nagging and nagging for ages to go and get this MP3 player, and Tilly knew I wanted this MP3 player, and my mum bought it with a message that my (late) grandma apparently wrote to me saying goodbye and all this sort of stuff. And she put mine and my grandma's favourite song on this MP3 player. And to cut a long story short it was in my bedroom and I'd hid it purposely because of the way that she was, and she went in my bedroom and she hunted high and low for my MP3 player, she smashed it to smithereens and then was singing the song at the top of her voice on the corridor but doing it to the point where I could hear it.
>
> Researcher: How did she get in your room?

> *Annie: Because my door wasn't locked at that time. And she went in, smashed it up and put it on a chair so when I went in I could see it. But no one had actually heard Tilly turn round and say, 'Ha I've smashed it up, she's never going to remember her grandma again.'*
>
> *Researcher: That's terrible, what happened?*
>
> *Annie: I was basically devastated, I went to the night staff, threw it at the night staff and said 'Look what I have to put up with!' and they said, 'Well you shouldn't have left it in your room you should have locked it up.' But it was two night staff that was on that night that love Tilly to bits, they'll go up to her hug her and hold her hands, if she cuts up [self-harms] they look after her and make sure she's alright.*

Annie suggested that Tilly was jealous of her MP3 player, but then she also implied that she herself was jealous of Tilly's relationships with the staff. This, along with my previous observations suggests that there was conflict between them already and Tilly may have been using the MP3 player as retaliation for what has happened previously. Annie was using the MP3 player as a symbol of her continued relationship with her family, and as a way to explain her behaviour in response to its destruction. The importance of material items as symbols of relationship is described by Parrott (2005) who points out how these items can be experienced as interpersonal connections with family and future. It seems that both staff and service-users used a rationale of 'jealousy' about relationships and material items as an accepted way to explain disputes which may have much more complex origins. These explanations are unhelpful and generate further arguments.

Forcing service-users who are experiencing different levels of distress to live together in close conditions, may result in conflict and challenging behaviour, which can be described as effected by interpersonal influences (Clements et al., 1995). I saw evidence of much conflict and aggression between service-users, which superficially seemed to be about material items or family visits but was likely to reflect deeper issues. Issues of confidentiality sometimes provoked conflict, when service-users considered other service-users to be gossiping about them. This was described to be an issue in Koller and Hantikainen's (2002) study, where narratives of two people living in forensic psychiatric units demonstrated that a great deal of staff time was taken up by dealing with these conflicts, finding ways to avoid contact between seemingly incompatible people.

Because of the amount of conflict between service-users, many discussions about activities and visits to different areas of the unit included concerns of compatibility. Problems arose when two service-users were seen to have had a long-term conflict and one of the service-users had been moved because of this. Often, time was spent deciding who could go where and with whom, however it was often evident that women were living with other women that they clashed with in some way, as described by staff member Adele:

> *Adele: But in relation to [living on the unit], making people worse, I think there's probably inevitably a sense that people who're distressed living with other people who're distressed, it's not ideal is it really? Compatibility issues are huge aren't they here? And in places like this, and I think because we're often at full capacity you have people living together who, for all sorts of reasons, see each other - when they were living together - they see themselves in the other person and it's almost unbearable.*

Adele's answer implies that conflicts between women were as a result of them seeing 'themselves in the other person'. Research in the mental health and disability studies fields show that people who have similar issues are able to offer coping strategies and hope for the future to each other (Dillon and Hornstein, 2013, Department of Health, 2010a). It is interesting that Adele considered this to be a cause of problems, rather than contextual issues on the wards such as the lack of privacy.

Supportive relationships

Despite the level of conflict between service-users, there were many positive relationships being played out on the ward. I saw evidence of service-users helping and supporting each other, cheering each other up and offering consolation in bad times. I also saw examples of service-users offering ways of coping to other service-users, such as suggesting ways of thinking about the future and family to keep them going, Annie pinpoints this in her statement:

> *Annie: We've managed to lean on each other and pick each other up and when one's down, the other one's alright so whoever's alright manages to pick the other person up.*

I saw Marion and another service-user helping and reassuring each other often, during times of distress for both of them. Here, she explains about their relationship in an interview:

> *Marion: We just sit and talk, (name) is very very helpful, she's very very good to me is (name). She helps me put my necklaces on for me because I have problems getting them on myself so she helps me.*

When women were described (and described themselves) as 'unwell' it indicated that they were going through a time of particular distress and might self-harm or act aggressively towards staff or other service-users. During these times it was common for them to turn to each other for support. Kate told me about her relationship with an older woman on her flat:

> *Kate: I'm not allowed to see my Mum. So we've got a nice lady on here called (name). She's um, she's my mum. She says, 'I'm your adoptive mother now,' and she looks after me in any way possible. Like before she said if I told her I was going to self-harm, she'd go straight to the staff, she wouldn't try and stop me, she'd just say 'Look Kate don't.' But if I was determined, she wouldn't intervene but she'd go and tell staff before I had chance to do it. So erm yes she's good with me.*
>
> *Researcher: And what kind of things do you do together?*
>
> *Kate: Oh we sit, we chat, we read magazines together, sometimes we watch films together. We just do all sorts really, board games, colouring, all sorts we do together.*

Kate described a supportive relationship which was played out in terms of a mother/daughter dynamic. The older service-user she described as her 'Mum' used to self-harm but managed to stop, and helped Kate when she felt like self-harming.

Regulation of relationships

A number of service-users pointed out to me that they were not encouraged to have certain close relationships with other service-users. Here, Helen explained that service-users as well as staff could get moved when a good relationship had been established:

> *Researcher: What about another service-user, do you have a good friend here?*
>
> *Helen: Not really, I've been told not to get too close to people because you end up losing them or something, or they end up getting moved or something like that. So there's no point having a relationship because they might get moved one day and then you've lost that relationship.*
>
> *Researcher: So you're trying your best not to get close to anyone?*

> *Helen: Well I get close to them but there's only a certain point now that will happen, because it's happened too many times before, I'm getting on well with staff and they get moved.*
>
> *Researcher: And how do you feel when they get moved?*
>
> *Helen: I think that it's my fault but I've been told it's not my fault.*

Although it seems as though Helen was repeating something she had been told often by staff - that staff moves were not her fault - it seems that she still felt responsible for them. Although it is not clear why staff were moved from working with Helen, as I show elsewhere (Harker-Longton and Fish, 2002) it is extremely distressing for service-users when people are moved and relationships break down as a result.   Service-user moves were also described as distressing by some women in this study. I saw two service-users preparing to move wards and witnessed the tears and sadness from others, as well as service-users feeling upset and worried that others seemed to be progressing but they themselves were not moving on. In this example, Annie pointed out why she was not encouraged to meet up with another service-user after moving:

> *Annie: [we don't meet up] because they said the relationship was getting too personal for Jane, because she is ill, but she needed that 1:1 with me because she knew I was the only person that she could trust, from day one I'd been there with her, I'd been there when she were cutting up and [extremely graphic descriptions of self-harm incidents and expressions of distress]. I just used to sit there with her and none of the staff would go anywhere near because they were too scared. I'm like 'No just let me be with her I'm alright.' And she just used to come out and get hold of me, yes I'd lose my rag with her I'd shout and scream at her and she'd just take it. But anyone else did it she'd lose her rag with them. And it got to the point where we'd built up a good relationship with her and we all worked really well with her and then everyone turned on me then, they didn't want her to know me. So then Jane started hurting herself then because she felt sorry for me, so it's all gone different.*

There are a number of things happening here. Annie said that she was told that her relationship was getting 'too personal' with the other service-user, which may have been the case, with Annie suggesting the service-user's self-harm was because of her. However, Annie also mentioned that the relationship was of benefit for some time previously. It is unclear why the staff were discouraging this supportive relationship since the service-user had moved wards. Annie told me that she had asked to see this

service-user many times but this had not happened.

This discouragement is referred to in literature, Clements et al's (1995) research in a learning disability challenging behaviour service, for example, illustrates how services promote independence and autonomy and devote very little attention to supportive relationships. They put this down to the elevation of 'independent functioning' (Clements et al., 1995:429) as the most important goal of services, due to the style of care being focussed on traditionally masculine values:

> The goal is to help those who use services develop towards some notion of (lonely) self sufficiency. Loneliness and the absence of friendship are often remarked upon. Yet services do little to address this issue - how often do those who use services exercise any control over something as basic as who they live with? (Clements et al., 1995:428)

Clements et al further comment on the ideology within services, as the 'individual as the focus for change' and point out the absence of focus on *relationships* and *feelings* in services (Clements et al., 1995:429). Becker (1997:98) puts this down to the fact that 'the glorification of autonomous functioning has been achieved by excluding a sense of relatedness from the pantheon of cultural values' in society. She describes how 'effectiveness and competence' are valued and only achievable by individual action, that women are socialised to define their identity based on relational experiences and this is then pathologised due to the implicit connection of weakness with dependence (see also Roulstone and Morgan, 2009). This suggests that although more recent policy focusses on natural supports and listening to families (Broad, 2012, National Development Team for Inclusion, 2010, Emerson and Hatton, 2008), this is not filtering through to inpatient services and early policy goals prevail.

Ways forward

Although service-users' relationships on Unit C were complex and it is impossible to make judgements about them here, it does seem that more focus should be placed on understanding and supporting relationships, rather than mainly treating them as negative. In my time at the unit it seemed that whether or not supportive relationships were accepted depended on staff's judgement of the relationship. Encouragingly, the organisation was making moves to remedy the issues of conflict between service-users; during my time on the unit 'community meetings' were being introduced, as staff-member Adele described:

> *Adele: The staff support sessions on the women's flat for the medium secure unit is not around one client, it's around all of them and the dynamics of them all living together and how difficult that is, and it's basically about the psychological treatment service supporting the staff that look after those five women together.*

Although Adele was mainly focussing on staff support to enable women to live together, this was a step in the right direction. Nevertheless, Adele was still framing service-users' relationships with each other in a negative sense, as 'difficult'.

Despite all this negativity, staff-member Jackie had great things to say about the 'care' that women can offer to each other, particularly in terms of being part of a group:

> *Jackie: [Women], they have a huge capacity to care for other people and each other and so many want to work with animals, or older people or children. And I think there's something about when you get them together as well and you empower them and you give them a voice. So rather than competing with each other in a negative way for what they feel is a scarce resource in terms of care, they can care about each other and when that happens it's brilliant. They're really wise as well; they can give each other sometimes really good advice. They can't always follow it themselves, because they can't always see. And that's great because it's not relying necessarily on the staff for all the advice, but it comes from within them.*

Jackie's powerful words are advocating the encouragement of women as caring for each other, rather than competing with each other. Despite the constant threat of conflict, service-users found ways to maintain supportive relationships and help each other by offering coping strategies when they perceive they are needed, for example suggesting that the service-user 'think of their family' or 'think about the future'. This is described by some researchers as 'peer administered therapy' as I have mentioned, which often takes place away from the gaze of staff (Thomas et al., 2002, Shattell et al., 2008) and can be more beneficial to some service-users than any other intervention (Thomas et al., 2002, Happell, 2008). A significant theme in the disability studies literature is one of 'interdependence', acknowledging that nobody is fully independent and therefore this should not be an expectation (Walmsley, 1993, Reindal, 1999, Lloyd, 2001, Garland-Thomson, 2003, White et al., 2010, Carnaby, 1998). The importance of mutually supportive relationships within Disability Studies and the mental health literature is clear and I would argue that this concept of interdependence should be the way forward for learning disability services.

Conclusion

The relationships of women in my research were highly regulated (Lafferty et al., 2013). Unit C had policies that provided guidance on safeguarding service-users and supporting personal relationships. These made reference to and were a reflection of national policy, however national guidance on safeguarding at the time of fieldwork, the Department of Health document *No Secrets* (Department of Health, 2000) was criticised for emphasising the vulnerability of people rather than recognising and encouraging their strengths and capabilities. Consequently, this resulted in staff focussing on 'protection' rather than 'choice' (Braye et al., 2010). This established the need for local policy that takes into account individual needs established in collaboration with service-users (Dein and Williams, 2008, Fyson and Kitson, 2010). The issue of relationships on Unit C adds to the discussion about the extent to which individual needs are taken into account in such units.

Throughout this paper, it becomes clear that the value and importance of relationships on Unit C was misrecognised. This ambivalence is acknowledged in the literature as a by-product of 'promoting independence' (Burns, 1993:104) and encouraging self-sufficiency, motivating service users to progress through the service. Some authors claim concepts of independence proliferate because services are built on 'masculine' principles of self-sufficiency (Burns, 1993, Clements et al., 1995, Powell, 2001), whereas others suggest this is due to neoliberal policy making where premium is placed on individuals having freedom and choice (Hannah-Moffat, 2000, Kendall, 2004b, Pollack and Kendall, 2005).

I would argue that all of these things come into play here. During the project, I was told about how the unit was set up mainly with men in mind, and women staff had to push for women-only spaces to be created. Further, there was a discourse of predation vs. vulnerability on the wards, mainly due to the presence of men on the unit (Fish, 2016), instilling feelings of protection and paternalism in staff. This discourse seemed to influence the regulation of relationships between residents. The focus of 'independence' in policy for people with learning disabilities is a constant presence, as is the legacy of discourse surrounding institutionalised people, which presupposes people as at risk of relying on the institution (McWade, 2014) – these factors can result in positive relationships being treated with ambivalence. Chappell (1994) notes the constraints placed on friendships of people with learning disabilities and argues that this is because relationships with non-learning disabled people are more valued in services.

Powell (2001) argues that women who end up in secure care have a fundamental need

for therapy and empowerment rather than containment and security, and claims that the treatment regime they are subjected to is based on a masculine model of secure services due to men being the majority group. As I have argued, this prevailing principle of masculinity is directly related to the expectation of independence.

Furthermore, positive peer relationships were often not encouraged by staff or could even be discounted by them; staff might perceive them to be 'too personal', because of the issue of services promoting independence and autonomy (Clements et al., 1995, Thomas et al., 2002, Shattell et al., 2008), and staff can feel that 'they know best' about such relationships (Scior, 2003).   This was not helpful and service-users pointed out that they would have liked their relationships to be encouraged and valued, even when their friend had moved on. Rather than constructing relationships as negative, I argue that it is possible to acknowledge difficulties and work towards supporting and encouraging them.

For Travers, the aim for secure service for women should be to 'maximise the empowerment process, whilst allowing [the woman] to acknowledge and accept her own responsibility and accountability for both her behaviours and their consequences' (2013:81). I conclude that this can only happen if there is recognition of supportive relationships at an organisational level, and importantly there needs to be a two-way process of communication, where women are not judged on their behavioural responses without consideration of the relational contexts and preceding events.   Success in future community integration and accessing community resources can be dependent on the nature and quality of ones relationships (Broad, 2012), so although aspirations of independence on behalf of people are reflected in policy documents such as *Valuing People* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2009), *inter*dependence should be key (Carnaby, 1998).

Staff at such institutions should be provided with training and guidance about the social model of disability. Morgan (2012) recommends that the social model of disability be taken on board as a 'threshold concept', a concept which disrupts traditional ways of thinking and cultivates a new discourse. I argue that the social model would be one which focusses on bringing about positive adjustments to the service, rather than centring on the imbalance that women are perceived to bring about. Morgan further warns about the dangers of 'mimicry', where services appropriate the language of the social model in a 'ritualised' rather than real way, using terms such as 'independent living' without reflection (see also Morris, 2011)

Reflections

My research explored how women's experiences relate to intersectionality (Crenshaw, 1991), which can be described as the analysis of the interplay between different categories of identity. My thesis concluded that clients in my study may be predisposed to particular experiences because they are situated at the intersection of disability, gender and criminality (Kendall, 2004a, Björnsdóttir and Traustadóttir, 2010). Disabled women have been subject to varying experiences of oppression and discrimination (Thomas, 2006) and there are often well-meaning yet highly damaging motivations behind injustices that they experience (Young, 2009). Theories of intersectionality explore inequality focussing on the interplay between different categories of oppression (Mattsson, 2014). The UNCRPD recognizes that disabled women face multiple layers of discrimination and advises that governments must take steps specifically related to disabled women as a discrete group (Equality and Human Rights Commission, 2010).

Gender and disability cannot be disentangled from women's experiences and the accounts that are used to understand them. The history relating to women's admittance and management in these services cannot be denied; pre 1970s, women were incarcerated against their will and often kept within the asylum for life. I have shown that some aspects of this history are still evident today, whilst at the same time contemporary policy has taken an extreme opposite position. This is most evident in the controlling measures used to keep women in line, inciting dependence, whilst expectations within policy and practice are that clients are responsible for themselves and independent. This is what McWade describes so well when she talks of how the 'shame of the asylum years where patients were often incarcerated for life now manifests itself in a fear of, or aversion to, patient dependency on services' (McWade, 2014:182).

The presumption of incompetence is inherent in notions of learning disability, which provides justification for others making decisions on behalf of people and this in turn influences the continuation of dependency. Phillips discusses the reasons for this control when she refers to how the 'perceived incompetence of the mind is then transported to a perceived incompetence of the body. Hence a situation is created where the body has to be controlled, cared for and regulated' (Phillips, 2007). Often, this situation is created with the best will in the world, as people with learning disabilities are considered to need protection and care (Lövgren and Bertilsdotter Rosqvist, 2014), and this was evident on Unit C particularly around the regulation of relationships.

This ethnographic project allowed me to see people in the context of their daily lives, interacting and supporting each other. Goodley and Rapley's article looking at self-advocacy groups argues that investigating the lived experience of people with learning disabilities can enable the 're-socializing of impairment' (2001:231). They discuss how assumptions of incapability can be disrupted by instances of resistance which situate the person in 'relational understandings' (2001:231), in other words looking at how people manage interdependently, despite the dominant way of thinking which naturalizes and individualizes impairment. I think my work exemplifies this idea, by showing how women retain their sense of self despite significant regulation.

Although I do feel that my status as a researcher employed by the organisation (rather than as an external or independent researcher) placed some limitations to what I observed, the scope of the data suggests that I was well placed to access the opinions of the women about the service they were receiving. Ethnography allowed me to comment on silences and absences, which would not have been possible if solely using an interview method (Ryan-Flood and Gill, 2013, Schatzberg, 2008). Although to notice an absence, the researcher must have preconceived expectations of what they think should be observable which may limit the research at the outset. In my fieldwork I noticed a lack of discussion around fundamental topics such as family which may reflect an adherence to confidentiality, or may indicate that these are not being dealt with. So although I cannot make specific claims about these absences, I can flag them up to the organization as issues which may need addressing.

My work has offered many recommendations for change to inpatient services for women with learning disabilities. The Justice for LB campaign (see Ryan and Julian, 2015) has produced much scholarship suggesting alternative futures for service provision, in particular to address the lack of transparency and exclusion of families. Rogers' (2015) paper criticizes such careless spaces and calls for *care-full* ones:

> . . . care-full spaces are always necessary, or tragic circumstances occur: they are needed for the mothers, fathers, siblings and for those caring. The National Health Service should know this? The socio-political sphere does know this. (Rogers, 2015:1441)

Rogers' description of care-full services for people with learning disabilities encapsulates my ideas for the future of services in a nutshell. Only by listening to the people and those who know them best can we envisage a future which wipes away the legacy of institutionalisation.

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