# Meltdowns in the mud: A spatial, emotional and relational approach to the experience of 'care' in the micro-spatialities of Glastonbury Festival

Presented by

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# <u>Preface</u>

Initially this research project intended to focus on how learning disabled adults experience Glastonbury Festival (as reflected in my ethics forms), however, preliminary investigations proved that this would be logistically and ethically problematic.  Consultations with both the Gig Buddies charity manager and my Gig Buddy Rona (pseudonym), confirmed that to focus on Rona's experience's alone would be problematic in the chaotic environment of the festival and may impact negatively on Rona's experiences of Glastonbury.  Consequently, I chose instead to focus on my own experiences of my relationship(s) with Rona; which remains within the scope of my ethics approval (Appendix 3.0).

Presented alongside this research project is a short film made up of clips recorded by Rona.  This film shows what Rona thought people who were not present at Glastonbury would want to see of our experiences and is to be watched for context.

# Abstract

In a climate where conventional understandings of care as a private affair have dominated its study, this work hopes to move beyond these values, taking an experimental approach to explore care in the chaotic landscape of Glastonbury Festival - a space often considered 'inappropriate' for learning disabled people. This dissertation explores the complex interactions between space, emotions and relations in forming experiences of care, with a specific focus on my own experiences in a relationship involving care at Glastonbury Festival. Grounded in feminist and non-representational theories, this research draws upon auto-ethnographic research techniques to explore my own subjective experiences of a care relationship at Glastonbury Festival. Informed by non-representational theories, this dissertation combinines a fragmentary writing style from field diary extracts and stills from the video recording, with the aim of conveying to the reader the disjointed experience of care at Glastonbury Festival. In contrast to totalising accounts that depict care as forming dependencies and disempowerment, the findings of this dissertation provide a more nuanced insight into the lived realities of care. This experimental approach to examining 'care' aspires to create a space for progressive change and acceptance of differing care relations.

**Key words**: Care, Emotion, Relational approach, Glastonbury Festival

**Word Count:** 12,982

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# 1.0 Introduction

This research project does not aim to be representative or create objective knowledges of the nuances of experiences of 'care' or 'care relationships'. Rather, within the context of feminist and non-representational geographies, this dissertation offers a personal account of an individual and unique 'care relationship' enacted in the micro-spatialities of Glastonbury Festival. Such an experimental approach to 'care' comes with the hope that, by making our relationship visible, it will start to create a space for progressive change and acceptance for differing disabled care relations.

Such an approach diverges from previous care discourses which have dominated care literature, highlighting care as an activity imbued with feelings of dependency, passivity and disempowerment (Waerness, 1984; Oliver, 1998; Thomas, 2007; Power, 2010; Shakespeare, 2014). Rather than viewing 'care' through this lens, this research project demonstrates the highly emotional interdepencies involved in care (explored in sections 5.2 and 5.3), thus drawing on Held (2006:43)

*'We should not lose sight of the deeper reality of human interdependency.'*

This project responds to the knowledge gap in the literature surrounding the spatialities of 'care' and 'care relationships'. Conventional understandings of care as a private affair, most suited to the domestic space of the home, have dominated the study of care (Tronto, 1993; Twigg, 2000; Conradson, 2003). Rather than conforming to these principles, section 5.1 of this dissertation instead demonstrates the spatial influence over my own experiences of a 'care' relationship with my Gig Buddy Rona (a pseudonym) in the often chaotic and exceptional landscapes of Glastonbury festival.

This research project was carried out and enabled through the active participation in the voluntary organisation Gig Buddies, part of Stay Up Late. Working against the understandings of care being a private, domestic, affair, Gig Buddies transports care into often public undomesticated spaces, thus breaking social norms (Shakespeare, 2014; Stay Up Late, 2016). As demonstrated in Figure 1, the aim of Gig Buddies is to

match an adult with learning disabilities to a volunteer who has similar interests, in order to attend different events including the theatre, music concerts and wrestling matches which might be inaccessible or deemed inappropriate for those who are disabled (Stay Up Late, 2014).  Gig Buddies suggests that every mainstream event should be, and could be, made accessible for learning disabled people (Stay Up Late, 2016).



*Figure 1: Illustration of Gig Buddies aims (Stay Up Late, 2016)*

Gig Buddies promotes a volunteer–participant relationship based on mutual respect and shared interests, believing that 'relationships are built on what's brilliant about

people', with care being the 'scaffolding of the friendship… rather than being at the centre' (Stay Up Late, 2016); putting Held's (2006) ideas of interdependency into practice.  I have been paired with my Gig Buddy, Rona, for three years. We have developed a close but complex relationship (explored in section 5.3) based on necessary care, shared interests and our mutual love of Ronan Keating.  For me, our relationship is unlike anything experienced before; as the organisation states, 'the gig buddy friendship is one of mutual growth and exploration' (Stay Up Late, 2016).

Moving beyond the conventional understandings of care, and acknowledging Gig Buddies ideas of 'care relationships', this dissertation re-examines care as a complex interdependent act, in which space, emotions and relations interact to inform my own 'care relationship' experiences.  Accordingly, this research project is guided by the following research aim and objectives:

**Aim:** To explore my experience of 'care' with a disabled person within the micro-spatialities of Glastonbury Festival.

**Research Objectives:**

1. How do the different spaces of Glastonbury Festival impact on care relationships, and how do care relationships impact the spaces of Glastonbury Festival?
2. What is the role of emotions in shaping care relationships, and how can these emotions be represented?
3. How can we conceptualise a relationship of care in the context of Glastonbury Festival?

The dissertation begins by contextualising this study within previous interdisciplinary interpretations of 'care' and 'care relationships' in Chapter Two.  Through highlighting the gaps in the previous literature, this dissertation will then suggest a more nuanced approach to 'care'.  By drawing upon feminist and non-representational methodologies, Chapter Three will explore the qualitative research approach of auto-ethnography.  Chapter Three will also address the ethical considerations made.  Chapter Four will describe the background of my relationship with Rona discuss the

site of research.  This information is vital to set our relationship in context and assists in the visualisation of where this narrative begins.  In Chapter Five, analysis and discussion, the relationship between Rona and I will take centre stage.  This chapter will be broken down into three sections: spaces of care, emotions in care and relational care.  Each section will explore one of the objectives set out above, through the use of feminist and non-representational theory, the presentation and deconstruction of my own fieldwork diary and Rona's film of Glastonbury.  Finally, Chapter Six will summarise the main findings of this dissertation, discussing how these ideas could be explored further through future research.

# 2.0 Literature Review

This chapter explores the previous literature surrounding 'care' and 'care relationships'. In the literature care is portrayed as disempowering and creating dependencies with a focus on the private spaces of the home or institutional spaces of care. In highlighting and problematizing the gaps in the current literature, this literature review will offer a more nuanced approach to understanding care as intrinsically linked to space, highly emotional and relational.

## 2.1 Care as creating dependencies and disempowerment

Power and inequality within care relationships is a primary focus in the literature, as for many scholars, care and care discourse has become imbued with dependency, passivity and disempowerment (Waerness, 1984; Morris, 1993, 1997; Tronto, 1993 Oliver, 1998; Shakespeare, 2000; Orme, 2001; Fine & Glendinning, 2005; Thomas, 2007; Milligan & Wiles, 2010; Power, 2010; Shakespeare, 2014). For these reasons, in disability studies the concept of care has been widely critiqued (Waerness, 1984; Morris, 1993, 1997; Shakespeare, 2000; Orme, 2001; Fine & Glendinning, 2005; Thomas, 2007; Power, 2010). Shakespeare (2000) asserts that the act of care is imperialist by subjugating the person classified as disabled. Thus in order to empower D/disabled people it is crucial to question the ideology of caring which may oppresses and expresses prejudices (Morris, 1997:54; Milligan & Wiles, 2010).

The forces of disempowerment and dependencies are reinforced through ideas of: who needs care and why, definitions of care, who does the caring and in what spaces and how those interactions take place. This next section will further discuss these elements and their role in reinforcing dependency and disempowerment.

### 2.11 Who needs care and why?

Thomas (2007) discusses that some adults with impairment(s), require assistance with everyday tasks, such as dressing and travelling. However, for the majority of D/disabled people, the need for care is also an outcome of everyday exclusions in society (Shakespeare, 2000), such as inaccessible physical landscape (Imrie, 1996; Kitchin & Law, 2001; Hall, 2005) and political and social segregation (Goffman, 1990;

Kitchin, 1998; Shakespeare, 2000; Hall, 2005). Power (2010) and Baker, et al., (2004) agree, arguing that the exclusion of D/disabled people from everyday activities, alongside the stigma attached to the image of D/disability marks D/disabled people as 'other' and limits opportunities for developing relations of love, care and solidarity with others. This, they argue, reinforces the deep set belief that disabled people 'need' caring for.

*'They [disabled people] can be seen as objects of care, as patients, as needing protection, as incapable of exercising autonomy, as in-valid.'* (Shakespeare, 2000:X)

Shakespeare's (2000) idea that D/disabled people become objects of need, and therefore care, is held to be especially true for adults with learning disabilities (Swain, et al., 2003; Power, 2008), with intellectual impairments being understood as a direct cause of dependency (Thomas, 2007). Thomas (2007) amongst others (Morris, 1993; Morris, 1997; Watson et al., 2004; Fine and Glendinning, 2005) argue that central to the concept of care is the power held by the caregiver. This power may foster a patronising attitude towards the care recipient who is then portrayed/percieved as infantile. However, alongside the critique of disempowering ideas of D/disabiltiy in the literature, there is also (re)inforcement. For example, Kittay (1999) who argues that people with severe learning impairments are dependent on the help of others and are unable to reciprocate, hence with 'childlike' needs.

## 2.12 Definitions of care
*'the meeting of the needs of one person by another person where face-to-face interaction… is a crucial element… and where the need is of such a nature that it cannot possibly be met by the person in need herself.'* (Bubeck, 1995:129)

Bubeck's (1995) definition above explores care boundaries. She suggests that care is solely the act of meeting a need which the care receiver cannot meet themselves, highlighting the power imbalances and high dependencies in her definition of 'care' relationships. Bubeck's (1995) definition stresses a unidirectional care relationship, in which one person gains (care receiver) whilst the other is burdened (care giver). It is argued by Milligan and Wiles (2010), Tronto (1993) and Held (2006) that Bubeck's

(1995) definition foregrounds the fixed task element of care and fails to acknowledge the changing environment surrounding the diversity of care relationships.

Tronto (1993), Held (2006) and Milligan and Wiles (2010) all define care in a starkly different way to Bubeck (1995). They view care as a multidirectional relationship defined by Milligan and Wiles (2010) as 'interdependency, reciprocity and multi-directionality' p737. Both Tronto (1993) and Milligan and Wiles (2010) suggest the definition of care should not be fixed but respond to cultural and social change. Furthermore, Held (2006) stresses the multiplicity of 'care' and 'care relationships' and reiterates the idea that any definition of care should be fluid acknowledging the diversity of factors within the care dynamic. This speaks to Thomas (2007) who suggests that 'our embodied needs are many and varied, far exceeding those required for basic survival' p87 emphasising the complexity and multiplicity of care. Definitions of care which acknowledging reciprocity and interdependency are however, underrepresented in the literature; the majority of care definitions highlight the disempowerment dynamic (Pitkeathley, 1989; Bubeck, 1995).

*'Care has been for a long time synonymous with health/medical care and the medicalisation of disability/impairment, which led to the institutionalisation of people with intellectual disabilities'* (Power, 2008:835)

As Power (2008) asserts, the medicalisation and institutionalisation of care often works to further exclude those with learning D/disabilities. It is crucial therefore to understand how these constructions of 'care', which use a medical lens (Krahn, et al., 2006), synonymous with the 'medical model of disability', have influenced other literature on the topic of learning D/disability care. In disability studies, medicalisation of care systems is viewed as a central force in contemporary disabling structures (Thomas, 2007; Power, 2008), with suggestions that institutionalised care only focuses on dependency levels and eligibility criterias which work to de-humanise the individual (Power, 2008; Kröger, 2009).

## 2.13 Who does the caring?

For learning D/disabled people, institutions and the family provide the largest source of care (Thomas, 2007; Power, 2008) despite their involvement in a large network of relationships (Thomas, 2007). However, Fine and Glendinning (2005) highlight that a central problem in care relationships is the conflicting ideas of 'needs' between the care giver and care reciever. Care givers are caught in the dilemma between the 'duty' of care and the risk of (re)enforcing dependencies for the care receiver (Fine & Glendinning, 2005; Lawson, 2007; Thomas, 2007; Power, 2008). Lawson (2007) describes how care givers often unwittingly exercise control and power over the 'cared for', creating an active (care giver)/ passive (care receiver) dualistic relationship.

Bubeck (1995) and Pitkeathley (1989) explore this notion of an active/passive relationship. Bubeck (1995:139) suggests that 'While the carer gives her time and energy, attention and skill, the cared for's needs are met'. Bubeck (1995) states this is true for unpaid for and unreciprocated care resulting in a 'material net burden'. Bubeck (1995:39) suggests care is an asymmetrical transaction of material benefits, "Caring is not mutually beneficial, but consists of an activity engaged in by the carer which results in a benefit for the cared for." She often highlights the 'burden' on the 'care giver' comparing care to work. Similarly, Birenbaum (1971), Kittay (1999) and Pruncho & Meeks (2004) describe the difficulty in caring for D/disabled family members.

## 2.14 In what spaces?

This literature review will now examine how the literature looks at the spatialities of care. Milligan and Wiles (2010) amongst others (Parr, 1997; Hall & Kearns, 2001; Bondi & Fewell, 2003; Brown, 2003; Conradson, 2003, 2005; Thein, 2005; Popke, 2006) stress the importance of geography when looking at care; they state:

*'Care and care relationships are located in, shaped by, and shape particular spaces and places that stretch from the local to the global.'* (Milligan & Wiles, 2010:736)

Lawson (2007) also highlights the importance of geography, discussing how it enables us to look at the specific sites and social relations that (re)produce the need for care.

Scholars such as Hall & Kearns (2001) and Hall (2005) have been influential in the increased understanding into the role of space in dependency creation.

The literature on care recognises a distinct binary between 'public' and 'private' space (Lawson, 2007; Milligan, 2005; Milligan & Wiles, 2010).  Conventional understandings of care argue that intimate care is a private affair often associated with the domestic space of the home (Tronto, 1993; Twigg, 2000; Conradson, 2003; Staeheli & Brown, 2003; Thein, 2005; Dyck, et al., 2005; Popke, 2006; Milligan & Wiles, 2010).  Lawson (2007), Dyck et al (2005), Kittay (1999), Wiles (2003), Bubeck (1995) and Power (2010) look at care within the space of the private, with a specific interest in the home and family care.  As mentioned above, traditional research on care for D/disabled people focuses on the 'burden' imposed on the parents and family therefore, the home is seen as a focal care space (Lawson, 2007; Conradson, 2003; Power, 2010).

Literature on the performance of care in public spaces, that might speak to my experience at Glastonbury Festival, is sparse.  The majority of literature addressing care in the public sphere focuses on care institutions (Bubeck, 1995; Lawson, 2007), such as hospitals and community care centres (Kittay, 1999).  One exception is Conradson (2005) who looks at care encounters in the rural.  Institutional and community care spaces are portrayed as central to the process of disabalism, dependency and disempowerment (Abberley, 1987; Morris, 1993; Twigg & Atkin, 1994; Oliver & Barnes, 1998; Thomas, 2007) and care 'symbolised as a century-long confinement of D/disabled people into institutions and of lives controlled and colonised by others' (Kröger, 2009:403).  Similarly, Thomas (2007) descirbes how the confinement of institutional spaces (re)inforce positions of power and authority over the lives of disabled people in the name of care.

Milligan and Wiles (2010:740) who use the term 'landscapes of care' to refer to the 'complex embodied organisational spatialities that emerge from and through the relationships of care'.  Milligan and Wiles (2010:736) seek to address differing bodies of geographical work in order to conceptualise the 'socio-economic, structural, and temporal processes that shape the experiences and practices of care at various spatial scales'. 'Landscapes of care' allows us to look at care through a wider range of spatial scales, locations and contexts; which is limited within the care literature.  Rather than

looking at the public and private, Milligan and Wiles (2010) look at macro and micro levels, including a wider range of spaces within these scales.  They then look at how these spaces interact with each other to inform the experiences and practices of care.  'Landscapes of care' has been important in informing this dissertation as it prompted thought on how differing social spaces (such as at and within Glastonbury Festival) enable different types of care interactions.

## 2.2 Towards an emotional and relational approach to care

This literature review will now explore the small amount of work, which, in contrast to disempowerment and dependency discourse, looks at care as both highly emotional and relational.  Milligan and Wiles (2010) and Lawson (2007) both emphasise that the act of caring is fundamentally relational.  Greenhough (2010) believes that care can be interpreted within a relational framework.  Kittay (1999) agrees using her own personal experiences to discuss the importance of the 'care relationship' as both a relationship of reciprocal care and companionship.   This idea speaks to my dissertation as I see the relationship between myself and my Gigbuddy as being intrinsically companionship and friendship but also in certain spaces, necessary care.

Critical 'care ethics' or 'ethics of care' is a growing field of interest in geography, with feminist literature playing a large role in its development (Noddings, 2013; Lawson, 2007; Held, 2006; McDowell, 2004; Brown, 2003; Cloke, 2002; Tronto, 1993). 'Ethics of care' focuses on the socially positive and desirable features of care (Fine & Glendinning, 2005).  Lawson (2007) suggests that care ethics challenges us to be aware of our location, both physically and in terms of empowerment, connecting our daily lives to those who are constructed as the 'distant others', both physically detached and socially detached.

In the literature care ethics takes a relational approach, depicting social relations in terms of being contextual, partial, attentive, responsive and responsible (Lawson, 2007; Tronto, 1993; Held, 2006; Jagger, 1989).  Care ethics is presented by Lawson (2007:3) as a 'social ontology of connection: foregrounding social relationships of mutuality and trust (rather than dependence)'.  Bubeck (1995) disagrees that care ethics are relational, advocating the moral necessity of meeting needs.  Koehn (1998)

also critiques the care ethics theory by stating that the concept is too relational and criticises the process of putting caring above other moral values.

The literature that focuses on the role of emotions in care, is feminist literature on care labour in Sociology (Kittay, 1999; Armstrong & Armstrong, 2004; Stacey, 2005; Lynch, 2007; Noddings, 2013). Whilst such analysis has acknowledges emotions in care, this work presented tends to focus on the emotions felt towards the 'care receiver', rather than the emotions expressed between all involved in the care relationship. Milligan and Wiles (2010), Held (2006), Bondi (2005) and Kittay (2001) all discuss the emotional side of caring and how this component is critical to good care. Held (2006) argues that there is a necessity for care to hold emotions, she argues that 'the caring' will be better if we 'care about' the person being 'cared for'. In contrast Bubeck (1995) argues that there is no need for an emotional bond between the 'care giver' and the 'care receiver':

*'Activities and acts expressive of an emotional bond are not necessarily care… they may be and often are services, that is, satisfy needs, wants, or interests that the person could have satisfied herself'* (Bubeck, 1995:134).

Bubeck (1995) believes this to be especially true in the public institutional sphere. Brown (2003) disagrees with Bubeck's (1995) idea of emotionless care stating that care is 'highly emotional and irrational' p835.

Bondi et al. (2005) believe that modes of immaterial emotional representation are fundamental concerns in care and it is very important to 'acknowledge the presence of emotions in our interpretations and understandings of the world' p.1. However, because our embodied emotions are often difficult to define, represent, observe, map and demarcate (Widdowfield, 2000; Bondi, et al., 2005; Conradson, 2005; Carolan, 2008) geographical and social science literature tends to avoid theorising emotions. Bondi (2005) argues for an approach to emotions that unsettles the claims of a position of a rational knower. By acknowledging a non-representational approach, this dissertation offers a unique approach to the topic of emotions in care. The realm of emotions that evade representation in a care relationship remains an un-researched topic in the social science literature. This dissertation therefore aims to extend and

rethink the literature on emotions in care by acknowledging a non-representational approach to consider the sphere of my own emotions, recorded in my field diary at Glastonbury Festival.

Geographical studies of care have overlooked the role of friendship, emotions and alternative care spaces in caring relations. Their focus on disempowerment, dependency and institutional care means that the concept of care is viewed in a negative manner, which homogenises care relationships.  In problematizing these definitions of care, I offer a more nuanced experimental account of care which highlights the interdependent, relational and highly emotional aspects of care relationships at Glastonbury Festival.  This dissertation will build on the small amount of existing literature on emotional and relational care, looking at my own experiences involved in a 'care relationship' at Glastonbury festival through an auto-ethnographic account inspired by feminist and non-representational theory. The aspiration is that by making such a relationship visible a space will be created in the literature for progressive change and acknowledgment of alternative care relationships.

# 3.0 Methodology

This chapter will outline the theoretical and methodological practices used to achieve the proposed aims and objectives.

*'In our rush to be more inclusive and conceptualize difference and diversity, might we be guilty of appropriating the voices of "others"? How do we deal with this when planning and conducting our research? And can we incorporate the voices of "others" without colonizing them in a manner that reinforces patterns of domination?'* (English, 1994:81)

English's quote above demonstrates some of the challenges and questions I faced when approaching fieldwork data collection. This chapter will engage with the challenges laid out in English's quote to argue the case for the methodology used in this research project. The chapter will begin by discussing the theoretical grounding for my methodological approach, then discuss my methodological approach of auto ethnography, and go on to illustrate the techniques used to generate my research material. Finally, this chapter will highlight the ethical considerations of this project.

## 3.1 Theoretical grounding

My research method of auto-ethnography was influenced by two key theories:

### 3.11 Feminist influence

Feminist scholars such as McDowell (1992), English (1994) and Dwyer & Limb (2001) greatly influenced my methodology. Such feminist geographers have fought to challenge neo-positivist methodological approaches which work to dichotomise the researcher and the researched, placing the researcher as 'omnipotent' (English, 1994). Feminist scholars favour research practice which promotes collaboration and non-exploitative behaviour (McDowell, 1992; Dwyer & Limb, 2001). In applying these theories to my fieldwork methodology, I chose the approach of auto-ethnography rather than more traditional qualitative techniques, to avoid the risk of appropriating another's voice in a way that creates power inequalities between myself and the research subject (Valentine, 2003; Etherington, 2007; Ellis, 2007).

## 3.12 Non-representational influence

The second influence that informed my research methodology is non-representational theories.  Non-representational theories give room for new ways of relating, moving and experimenting within research (Anderson & Harrison, 2010).  It attempts to readdress academic research that is based on representation (Lorimer, 2005; Thrift, 2007; Anderson & Harrison, 2010) and which fails to acknowledge, through the use of 'causual' theories or by hermeneutical means, the practices and goings on within the ever changing world (Thrift, 2007; Hoggart, et al., 2002).

Non-representational theories are concerned with the creation of arenas in which non-traditional research methods can be used to help understand the changing body and its interactions with the world (Deleuze & Guattari, 2004; Anderson & Harrison, 2010).  These methods do not settle for a finite conclusion but encourage experimentation and speculation (Anderson & Harrison, 2010).  The field in which research is conducted is continuously refined and transformed, as is the interest and motivation in research (English, 1994; Hammersley & Atkinson, 2007).

My research acknowledges non-representational theory when looking at the 'onflow' of everyday life (Thrift, 2007) within the landscape of Glastonbury Festival and employs it to analyse our more-than-textual, multi-sensual world (Lorimer, 2005).  I recognised the need for a wider and less rigid method, which would allow me to explore my embodied feelings and emotions in an often changing and unpredictable landscape (English,1994; Hammersley & Atkinson, 2007).  Consequently, an auto-ethnographical approach was used used in this research project, acknowledging Hoggart, et al. (2002) assertions, that we can only start to know the changing world through practice and self-reflection.  Furthermore, it accommodates the consideration of practices that are not articulated linguistically (Hoggart, et al., 2002), thus allowing the researcher to engage in activities that are more-than-representational (Carolan, 2008).

## 3.2 Auto-ethnography

Emerging from the preceding literature review, and corresponding to this project's aims and objectives, is the acknowledgment of relationships, emotions and spaces in care. In order to capture the complexities and lived experiences of being involved in a care relationship, this research project required the best method to facilitate the enactment of care and its subsequent analysis and retelling. Acknowledging this, alongside the debates within feminist and non-representational theories discussed above, I adopted the qualitative research approach of auto-ethnography.

Qualitative methods demonstrate an intersubjective understanding of knowledge and focus on positionality and power relations (Dwyer & Limb, 2001). Denzin & Lincoln (2008) argue that qualitative research methods are situated activities consisting of interpretive and material practices which make the world visible. As such, qualitative methods could be considered essential for a feminist and non-representational approach.

The qualitative research method of auto-ethnography is a distinct strand of ethnography. Both ethnography and auto-ethnography draw upon empathy and human concern applying a contextual and experiential research approach (Stacey, 1988) that requires the researcher to make on-the-spot analysis and interpretations of social situations (Kitchin & Tate, 2000).

The two approaches do differ however. The research product of ethnography is ultimately crafted by the researcher, and if the research is focused on others, elements of inequality and exploitation may be evident (Stacey, 1988) despite the researcher's attempts to hold a neutral position (Stacey, 1988; Kitchin & Tate, 2000; Berg & Lune, 2012). Feminist studies critique ethnographic research methods, stating that they cannot be assumed to be empowering (Stacey, 1988; Dwyer & Limb, 2001).

The research method of auto-ethnography can be viewed as a response to a lack of recognition of the researcher's influence over the research project in traditional ethnographic methods (English, 1994) where the distraction of attempting to understand the experiences of others may work to appropriate others voices (Stacey,

1988; Dwyer & Limb, 2001; Pink, 2009). Auto-ethnography was an appropriate method to use, as placing the researcher as an actor within the (care) event itself, removes ideas of the researcher being an independent, objective observer (Kitchin & Tate, 2000; Berg & Lune, 2012), and can produce accounts of the social world which do not rely on empiricism of positivist or naturalist research (Hammersley & Atkinson, 2007). This was important in this research project since mine and Rona's relationship was pre-existing and it was therefore impossible for me to be a 'neutral observer'. In auto-ethnography, there is no one set of rules, it is based on iterative experimentation and learning from ours and others experiences (Ellis, 2007) which suits the chaotic nature of both care and Glastonbury Festival. However, some criticise auto-ethnography as being pure introspection and as such has no checks on verification bias (Kitchin & Tate, 2000; Ellis, et al., 2011). Greetz (1995) contradicts this argument by maintaining the benefits of the 'closeness' to the studied phenomenon rather than 'detachment': the objective, rationalist ideal.

*'"The Field" itself is… a powerful disciplinary force: assertive, demanding, even coercive… it cannot, at least if one is not going to disengage altogether… be simply evaded. It is too insistent for that.'* (Greetz, 1995:119)

English (1994) argues that the highly personal nature of fieldwork lends itself to a highly personal research method such as auto-ethnography; this is not just confined to fieldwork, but also flows through the writing which transforms our experience into text (Reed-Danahay, 1997; Hammersley & Atkinson, 2007). Auto-ethnography lends itself to a self-reflective and autobiographical style of writing (Reed-Danahay, 1997; Berg & Lune, 2012), which brings to consciousness some of the complex ideological views hidden within our fieldwork process (Richardson, 2000). Feminist principles regarding equality and power work to legitimise the reflexive use of 'self' in research (Etherington, 2007). Although Smith (2001) argues that too much self-reflection may make the final text exclusionary, self-justified and self-centred; Reed-Danahay (1997) and Ellis (2007) assert that auto-ethnography is gaining increased acceptance and usage in Human Geography. For this reason, this dissertation will be written in first person, weaving a personal story with theory, in the hope that the reader will better understand the emotional journey of conducting this research. By combining a

fragmentary writing style with stills from the video recorded by Rona, I hope to express to the reader the disjointed, non-representational, experience of care at Glastonbury.

## 3.3 Techniques for generating material

Using multiple data collection methods enabled me to secure a more in-depth understanding and confirmation of key themes (Denzin & Lincoln, 2008; Flick, 2009), with each method revealing a different facet of the same reality (Berg & Lune, 2012).

### 3.31 Field Diary

English (1994) and Ellis (2007) describe auto-ethnographic research as a reflexive process which involves the interchange between experiencing and examining an emotional and vulnerable self thus revealing a broader context of the experience.  As such, a key part of my auto-ethnographic research was the account produced (Berg & Lune, 2012).   My auto-ethnographic account was primarily recorded in an unstructured field diary (Berg & Lune, 2012). Regular diary entries were essential as my mood/emotions varied drastically throughout the day; this enabled me to analyse the spatial and temporal context in which social practices/key events occurred, allowing for these events to be placed within a broader biographical canvas (Latham, 2010).  MAXQDA software was used for thematic coding of my field diary to draw out themes and categories for analysis within a short amount of time.

### 3.32 Video recording

At Glastonbury Festival, Rona recorded a video as part of the data collection.  This video consisted of short clips on what she thought conveyed our experience at Glastonbury and what she considered people not at Glastonbury would want to know about our experience.

This aspect of my research was very experimental.  There was no set of rules for when/what/how Rona should film and I decided not prompt or remind Rona to film, in order to create a more 'authentic' reflection of her lived experiences.  Although I aimed to have no involvement in the filming, however, Rona had difficulties in operating the camera, and I had to support her with the filming which could have influenced the data collected.

As Denzin and Lincoln (2008) suggest, the video recording can go beyond the practical and involves aesthetics of representations which can create an emotional effect. The original aim of this method of data generation was to give me a 'means for understanding how participants – literally and figuratively – view their world' (Hammersley & Atkinson, 2007:149). However, it was very hard to interpret the video without appropriating Rona's experience. Nevertheless, this method has supported my research by helping me to recall certain events and emotions.

## 3.4 Ethical considerations

At its worst, primary social research may act as a form of 'voyeurism' which works to exploit vulnerable participants in the name of knowledge creation (Dwyer & Limb, 2001; Hammersley & Atkinson, 2007). This is especially pertinent in disability research (Stone & Priestley, 1995; Kitchin & Law, 2001; Milner, 2013). Disability research is often unrepresentative of disabled people's experiences and knowledges because the majority of research is carried out by non-disabled researchers. It is argued that only disabled people know what it is like to be disabled, therefore only disabled people can interpret and present data from other disabled people (Zarb, 1992; Milner, 2013). However, others contend that research done by those of the same social group may not be more representative as homogeny cannot be presumed (Dwyer & Limb, 2001).

Ellis (2007) expresses the importance of relational ethics; acknowledging others who appear in auto ethnographic accounts and taking responsibility for their actions and consequences. These ethical concerns have been applied as the research includes an intimate other (Rona) in accounts focusing on my own experiences (Ellis, 2007).

Ethnographies can often expose informants/participants to ethical dangers, therefore it was crucial for me as a researcher to have rigorous self-awareness of the ethical pitfalls in my methodology in order to monitor and mitigate potential vulnerabilities (Stacey, 1988). I identified five primary ethical concerns highlighted by Hammersley & Atkinson (2007) who focus on ethics in ethnography, and Dalton & McVilly (2004)

who focus on ethics in learning disability research, to use as my guidelines in approaching ethical considerations for my research.

### 3.41 Research Design

Best practice is to seek approval from relevant agencies and procedural ethics boards (Dalton & McVilly, 2004; Guillemin & Gillam, 2004; Hammersley & Atkinson, 2007). Accordingly, I approached the manager of Gig Buddies and the procedural ethics board at Brighton University for approval to undertake my research (Appendix 6.0 and 3.0).

### 3.42 Consent process

Etherington (2007) states that gaining informed consent from a research participant is not a single event, but a process over time. Thus, I regularly reminded Rona about my research and her involvement to ensure she understood that I was recording my experiences. It was important that consent was given in an unconstrained way (Hammersley & Atkinson, 2007), in which the subject could make a decision based on comprehensive and accurate information. Consequently, before we went to Glastonbury I used an easy read clearly formatted consent form and participant information sheet (Appendix 4.0 and 5.0) in order to portray the nature, audience and purpose of my research to Rona. I invited Rona to ask questions and discuss the research with Gig Buddy staff accompanying us to Glastonbury. I discovered that asking Rona to film as part of my research, helped me to ensure she was aware of her consent, as she regularly reminded me to "get going" when she decided to film. I also ensured Rona was aware that she was under no obligation to continue with research, and could drop out at any time, without affecting our time at Glastonbury.

### 3.43 Conducting research

Procedural ethics are instrumental in conducting fieldwork, however they cannot provide all that is required for ethically important moments (Ellis, 2007). When out in the field, unforeseen ethically important moments can arise (Guillemin & Gillam, 2004; Ellis, 2007), therefore it is crucial to put mechanisms into place to counter adverse affects (Hammersley & Atkinson, 2007). Reflexivity was key in ethically important moments (Guillemin & Gillam, 2004) as it helped to challenge myself as a researcher

to sustain an ethic of trust in my relationship with Rona (Etherington, 2007). It was also helpful to talk about ethical issues with others in order to critically relect on my own practices (Ellis, 2007). Another strategy was to acknowledge that in some situations research would halt to engage in acts that did not contribute towards knowledge production (Hammersley & Atkinson, 2007). This was true when my care role would take precedent over my role as researcher.

### 3.44 Privacy

I ensured confidentiality by keeping all my research diaries and notes secure in a locked drawer (Dalton & McVilly, 2004; Hammersley & Atkinson, 2007), and by using a pseudonym to avoid revealing Rona's identity (Ellis, 2007). To ensure confidentiality, Rona does not appear in the film data.

### 3.45 Follow up to the research project

Ellis (2007) discusses our ethical responsibilities towards the intimate others who are featured in the stories we write about ourselves. With this in mind, I believe that is it very important to share my results with Rona. The results of my research project will be made available to Rona, through an 'easy read' summary/abstract[1] and a conversation where we will talk about my findings. She will also have a personal copy of the film. There will be further discussion on our future relationship in Chapter Six.

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[1] This can be made available on request

# 4.0 Setting the context

## 4.1 Rona and I

It is important to recognise that this was not a project simply undertaken to fulfil a research assignment, but an active part of my personal life. My relationship with Rona is established and ongoing.

Throughout my life, I have been privileged to attend music events and festivals regularly. However, for Rona, attending music events and festivals has been more of a challenge. At first I thought the main challenge would relate to the specific care needs for Rona at these events. However, the true challenges came from societal attitudes surrounding what might be considered a 'suitable' activity for Rona. For example, when attending gigs and festivals I started by negotiating with Rona's everyday care support staff[2], despite this being a choice Rona should be able to make (her usual response is 'Yes! Let's do it!' or 'Imogen why can't we go to gigs all night every night?').

I found that these attitudes surrounding appropriate spaces and appropriate activities often impacted on Rona's confidence when out and about, and made her overly aware of her medical needs, which rarely actualised into a problem. Reflecting on Rona's own confidence, it is clear that she has become more sure of herself over the years, with Rona increasingly wanting to stay out later and go to more 'rowdy' gigs.

In 2015, we were both offered the opportunity to volunteer as stewards at Glastonbury Festival which Rona was very keen to do. Rona's care staff and some family members however, had concerns that Glastonbury was not a suitable space for people with learning disabilities. Despite their concerns Rona remained determined to be part of the festival, stating 'they can't stop me'. Therefore, together with the manager of Gig Buddies. I worked in close dialogue with Rona's family and care staff to discuss measures that would ensure Rona's well-being during the festival. These measures

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[2] Rona lives in supported accommodation in which she is able to access care from her support staff daily, on a nine to five basis.

included myself being briefed and trained with regards to Rona's specific medical needs.  As a result of these preparations, Rona's care staff and family were happy for Rona to go to Glastonbury, accompanied by me, as her 'care giver'.

## 4.2 Research parameters

Hammersley & Atkinson (2007) discuss situations in which the researcher (who is already a participant) has to (re)negotiate access with the gate keeper.  This mirrors my own situation, as despite already having access to the Gig Buddies community as a volunteer, I still felt the need to approach the gatekeeper (head of organisation) to ask for her permission and approval to conduct research within the Gig Buddies community (Appendix 6.0).

The research parameters of this project are situated in the micro spatialities of Glastonbury Festival such as the disabled campsite and arenas where we stewarded. Glastonbury Festival is an annual event situated in Somerset which hosts thousands of festival goers (Glastonbury Festival, 2016). Rona and I spent six days at the festival camping in Spring Ground, an accessible campsite for disabled festival goers and their care givers (discussed further in section 5.11).  During our time at the festival Rona and I spent three eight hour shifts acting as stewards for the disabled platforms in various arenas.

# 5.0 Analysis and Discussion

In the discussion that follows, the relationship between Rona and I will take centre stage.  Each section will explore one of the objectives, set out in the introduction, through the presentation and deconstruction of my own fieldwork diary and Rona's film of Glastonbury.  Such an in-depth focus allows for the complexities of care and care relationships to be disentangled, which corresponds with my overarching project aim: to explore the experience of 'care' with a disabled person within the micro-spatialities of Glastonbury Festival.

## 5.1 Spaces of care

*'Critically, the nature, extent and form of these relationships are affected by where they take place.'* (Milligan & Wiles, 2010:738)

Following Milligan and Wiles's (2010) and Conradson's (2003) call for a look at more spatial scales of care, this section examines how care is enacted and embodied in the micro-spatialities of Glastonbury Festival.  Building on Milligan & Wiles (2010) work on 'landscapes of care', I explore the 'structural and temporal processes that shape the experiences and practices of care at various spatial scales' (Milligan & Wiles, 2010:736) addressing how place and space (of the festival) interacts with relationships of care (Brown, 2003) noting the concept that care is fundementally a spatial practice (Bondi & Fewell, 2003).  My analysis first focuses on the campsite and the 'everyday' care practices which took place between Rona and I in this space, and how this became a space of familiarity and comfort. I will then consider more chaotic spaces of care that occurred in more 'public' settings. My research suggests the enactment of care is heavily influenced by the space, and its implied norms, in which it takes place. This advances on previous debates on care by offering a more detailed insight into a space of care never looked at before going beyond literature regarding care in institutional and private spaces.

## 5.11 The campsite – 'everyday' spaces of care

When at Glastonbury Festival our 'home' was Spring Ground.  Spring Ground is Glastonbury's accessible campsite for disabled festival goers and 'their carers' (Glastonbury Festival, 2015).  The site is described as being essentially the same as other camping areas at Glastonbury, but with additional facilities such as secure fridges to store medicines and accessible toilets and showers (Glastonbury Festival, 2015).  During our time at Glastonbury the campsite became a site of everyday tasks and necessary care.

Throughout the duration of the festival, the landscape of the campsite incurred spatial and temporal changes which meant Rona needed support in some 'everyday' tasks.  Tents would appear and disappear, regularly changing the physical space of the campsite consequently, Rona would often need assistance in mapping and travelling around the campsite due to the altering paths.  The rain brought with it slippery surfaces which were difficult to manoeuvre for Rona because of her reduced mobility.  In addition, at night the darkness meant low visibility and trip hazards which we both supported each other through.  Our bodies were situated in a space which (re)enforced the need for care (Conradson, 2003; Dyck, et al., 2005; Milligan & Wiles, 2010) predominantly for Rona, but also for myself.

In Spring Ground our everyday tasks such as cooking, dressing and showering became imbued with notions of care.  In everyday life outside of the festival setting, Rona would not normally need assistance with these tasks from care facilitators, however, in the festival space, the ever changing landscape and the unfamiliarity with the people in it meant Rona needed support with these tasks and my everyday routines altered accordingly.  As shown in the extract below, the campsite became a space in which both our everyday knowledges and practices became destabilised, and our spatial strategies for negotiating this destabilisation led to the formation of a particular care space (Dyck, et al., 2005).

> *"The mornings are the hardest and most frustrating time of the day. Daily routines which would normally be second nature such as showering and brushing our teeth seem ten times slower.  I have to find my toothbrush which is hidden somewhere in the depth of the tent, I then support Rona in doing the same.  We have to traipse up and down the field to find the nearest water point only to find we have forgotten the toothpaste so have to return to our tent…. We don't talk much, I am so used to doing these activities on my own and miss my privacy in the morning."* (Day 2)



*Figure 2: The water point where we would brush our teeth*

The particular care space formed was one of intimacy and interdependence.  I depended on Rona to describe her individual care needs and she depended on me to support her in fulfilling these needs.  This was not easy, however, and Rona would often tell me how frustrating it was for her to have to rely on assistance for these tasks such as showering, as illustrated in the extract below. I would also find it difficult, and

often intrusive, to share the space of my personal everyday activities with Rona whilst also translating and supporting Rona with her wants and needs.

> "*Despite being covered in mud I don't have enough time to shower myself, I need to support Rona in showering so that we can get to our shift on time… This intimate act isn't what we are used to, we laugh saying 'only at Glastonbury!'."* (Day 4)

On top of these difficulties, negotiating the performance of these intimate care activities within the limited spatialities of the campsite was challenging. Conventional understandings of care state that intimate care is a private affair (Lawson, 2007), usually associated with domestic space of the home (Conradson, 2003). However, at Glastonbury Festival and in the campsite, no space felt private. As such, acts of intimate care suddenly felt very public. Therefore, through our shared experiences in the campsite and a shared sense and want of wellbeing for one another, our acts of caring formed an exceptional space of 'vulnerability' and 'intimacy' (Dyck, et al., 2005; Thein, 2005) which Rona and I had not encountered before, through which we used humour to manouvere.

## 5.12 The campsite – familiarity and comfort

Within Spring Ground's space of intimacy and vulnerability, there were further spaces that felt familiar and comfortable. In particular, the communal areas were identified in my field diary (see extract below) as rare places of comfort and familiarity; far more than that of the chaotic grounds of the festival's music arenas. The communal spaces included the campfire, which was lit every night became the focus of campers before heading out for the evening, and our make shift 'dining area' where all the members of Gig Buddies would gather for our evening meal.

> *"We started off our night sat round the campfire at the disabled campsite getting to know the others staying at the camp.  Myself and Rona chatted to a group of people about their experiences at Glastonbury so far; it was great to hear that others experiences are similar to ours…  The atmosphere was so friendly and welcoming, I felt as if I was part of a community…  I feel like this is my safe space where Rona seems to be happy to interact with others, and I can also receive support and advice from other care givers."* (Day 3)



*Figure 3: Sitting round the campfire*

Care ethics suggest we should construct extensive spaces that enhance connections of interdependence and mutuality (Lawson, 2007) and, whilst at Glastonbury, I felt that the communal spaces of Spring Ground did this.  The feeling of being 'part of a

community' enabled and prompted a sense of belonging and familiarity. The campsite was cultivated by its members and organisers as a space of acceptance for those who are marginalised by mainstream society. This sense of acceptance meant that differences were openly encountered and encouraged, and the space felt like an enabler of positive (care) interactions. Enacting care in front of those who may have experienced similar situations, and also in a space where care was the norm, meant that we could avoid some of the stigma assigned to disabled care relationships (Hall & Kearns, 2001; Hall, 2005).

> *"Having our evening meal in the same place with the same people everyday creates a sense of routine and familiarity where we know exactly what to expect… We can chat about our days with people we both know and trust."*
> (Day 5)

In amongst the chaotic unstructured landscape of the festival, myself, Rona and the rest of the Gig Buddies team created a space of rhythm and habit through meeting up for our evening meals. As depicted in the field diary extract above, I felt that this was a 'safe' space, similar to the bonfire setting, in which we could share problems encountered during the day with people we were both familiar with. This familiar everyday space echoed those discussed in Conradson's (2005) and Lawson's (2007) writing; it had its own localised norms and expectations (Conradson, 2005) which differed from those in the rest of the festival space. These norms and expectations where based on values of empathy, responsiveness and responsibility (Lawson, 2007), with a network of interdependent relations of care from which we both benefitted.

Through the positive interaction of care in the communal spaces of the campsite, I constructed the campsite as an emotionally supportive space in my mind. My appreciation of the campsite environment as a positive space of care highlights the socially-dependent constitution of place (Conradson, 2003; Staeheli & Brown, 2003; Conradson, 2005). The feeling of 'belonging' to a space represented how in Spring Ground the enactment of care between Rona and I became less 'visible' and became a 'normal' and intrinsic part of a relationship (Gilligan, 1984).

## 5.13 Chaotic spaces of care

> *"The festival is packed! We grab onto one other so we don't get lost in the crowd… we take regular breaks at the side of the path, before diving back into the mass of people."* Day 2

Outside Spring Ground campsite was the rest of Glastonbury Festival ground, a much more chaotic space in which 900 acres of land accommodate thousands of people (Glastonbury Festival, 2016). Whilst at the festival Rona and I experienced the many different micro spatialities which make up the festival – described by Rona as being "one big loud club". At different times over the six day period, the intensity of the spatialities of the festival grounds became sites that (re)produced the need for care (Lawson, 2007).

Feminist care ethics argue that we should not have to 'place' care (Staeheli & Brown, 2003), challenging the conventional idea that suggest public spaces are not suitable spaces of care (Lawson, 2007; Staeheli & Brown, 2003) and dominant voices asserting that care spaces should be confined to the private (Popke, 2006). Feminist ethics therefore suggest that care should be able to extend through both the public and private spheres (Staeheli & Brown, 2003). Rona and I knew that we might need to enact necessary care in an 'unusual' public setting, and by attending Glastonbury with this knowledge we were challenging these conventions. However, this was not easy, as social attitudes towards care and care relations formed barriers to the ease of care and also (re)produced the need for care.

Attitudes towards care and care relations in public spaces are influenced by the stigmas surrounding people with intellectual D/disabilities which regulates whether they 'belong' in these spaces. Such attitudes have an effect on the care relationship and the dependencies within this relationship (Tronto, 1993; Power, 2010). This was true for Rona and I. Before we went to the festival we had many people question whether this was a suitable space for Rona; and whilst we were at the festival there were still people who questioned its suitability. This questioning worked to decrease Rona's confidence in the crowded festival space, as (unlike in the campsite where

Rona often felt comfortable to separate from me) outside the campsite Rona and I would spend all our time with each other, and Rona would often need extra support for activities which she would usually negotiate independently. For example, I often had to carry Rona's bag as she was worried about bumping into people. Thus Glastonbury became an intensely relational and interpersonal space.

> "The pressures from the festival landscapes and how 'everyone else' interacts with the space, means that we cannot move at our own pace. We have allotted working hours which echo the beginning of the day's music, meaning that I often felt pressured to hurry Rona." Day 2

As indicated in the extract above, the act of care and type of care that could be enacted was regulated through the temporal and spatial landscapes of Glastonbury festival. In part I also contributed to the act of regulating care: I often became caught up in the 'Glastonbury atmosphere' and felt like I had to rush Rona in order to keep to the schedule we were given, forgetting that my normal pace (the Glastonbury pace) was different to hers. This reflects Power's (2010) assertion that when carers determine what the acceptable public behaviour is, their decisions are often influenced by how the body of the carer is multiply inscribed by 'knowledges' embedded in their lived experience in which they enact and negotiate (Dyck, et al., 2005). On realising that I was inflicting a schedule and rushing Rona, I altered our shifts to later in the day so that Rona and I could negotiate the landscape at our own pace.

> "When buying some drinks Rona takes a while to decide on the drink she wants. I read out the list of drinks to her and people in the queue behind us get audibly frustrated… I need to support Rona in counting the correct amount of change for her drink, and feel very aware of the people around and my instinct is to speed things up, but instead I ignore the people and continue at Rona's pace." Day 5

Dyck et al. (2005) suggests that when necessary care enters a presumed 'non-care' space, the routine activities that constitute that space will be disturbed, alongside the alteration of the identities of those involved in the care relationship (Dyck, et al., 2005).

The extract above demonstrates how care behaviours deemed as abnormal were regulated by others at Glastonbury.  Because of the audible frustration from people around us, I felt uncomfortable in performing this act of care in front of the queue, and felt out of place.  Despite still enacting care in the space, I felt that our identities were often shaped by the pressures to conform to the dominant bodies' ideas of what behaviours are deemed as suitable in certain spaces and their 'sanitising' regulations (Parr, 1997).

This section has looked at how dominant societal ideas suggest care should not be placed in public settings, and if they are in public settings they should not be visible. These ideas are influenced by the stigmatisation of D/disabled people and the presumed spaces they should or should not occupy.  In these spaces our care relationship was regulated and policed by the expectations of how to act in these landscapes, and these expectations where (re)enforced by others at Glastonbury. This in turn influenced my own ideas of how our acts of care should play out - upon realising this I made a conscious effort to change my attitude.

## 5.14 Summary

Enactments of care at Glastonbury festival challenge conventional ideas of appropriate behaviour in public and private space.  In the extracts presented landscapes of care are multi-layered and shaped by issues of responsibility, social, physical and material aspects of caring, is shown to be bound up in dominant voices of power which work to mould identities of care (Milligan & Wiles, 2010).  With different bodies having different capacities in the space.  In Spring Ground, the changing physical and social landscape (re)produced the need for everyday and intimate care, but the space also gave opportunities for social relations that abated and normalised care in such a way that care became less visible and seen as a 'normal' and intrinsic part of a relationship.  Whereas in the more 'public' settings of Glastonbury Festival a number of intersecting factors meant that our acts of care became more than visible and felt out of place.  These examples show the significance of care in particular settings and how 'relations and practices of care… are implicated in the production of certain social spaces' (Conradson, 2003:451).

## 5.2 Sonic Haze – emotions in care

The previous section explored how the different spatialities within Glastonbury Festival worked to influence my relationship with Rona. This section will examine this further by deconstructing the emotions embedded in and informing the experiences of our relationship. Twigg (2000) discusses how emotions are regarded as sitting uneasily in the bureaucratic notions of care which call for impartiality, efficiency and predictability. However, since my experiences at Glastonbury festival where in stark contrast to the bureaucratic notions of care I feel it is important to reflect on and analyse the complexity of my emotions.

As Bondi (2007) recognises, emotions are a valuable substance for analysis, underpinning care and care interactions (Milligan, 2005; Bondi, 2007; Milligan & Wiles, 2010). Accordingly, using stills from Rona's video and extracts from my research field diary, this section explores the importance of my emotions in shaping my care relationship and, moreover, how my emotions were intrinsically linked to space (Bondi, et al., 2005). By exploring my emotions as a carer at Glastonbury, I move beyond the simplistic accounts of care as an un-emotional act and demonstrate instead the highly emotional characteristics of care.

### 5.21 My emotions unpacked

Relationships of care often entail varying degrees of emotion. However, I found the embodied emotions I felt influenced my experience of Glastonbury festival (Bondi, et al., 2005); they were not my 'normal' emotions, but emotions that disrupted the ordinary 'flow' of my feelings (Bondi, 2007). Thus my emotions guided my way of being-in-the-world. Twigg (2000) highlights the difficulties and importance of acknowledging the contribution of emotions in the act of care, as emotions are not always tangible and therefore can be overlooked, despite playing a key role in shaping care. Consequently, this section attempts to deconstruct some of the emotions involved in care into constituent elements (Figure 4) in order to gain a more comprehensive understanding of the role of emotions in care. There were a multitude of emotions recorded in my field diary; however, the four I have focused on are those which had the most profound effect on my experiences at Glastonbury. The section

will conclude by reflecting on the more-than-representational nature of my experiences at Glastonbury (Carolan, 2008).
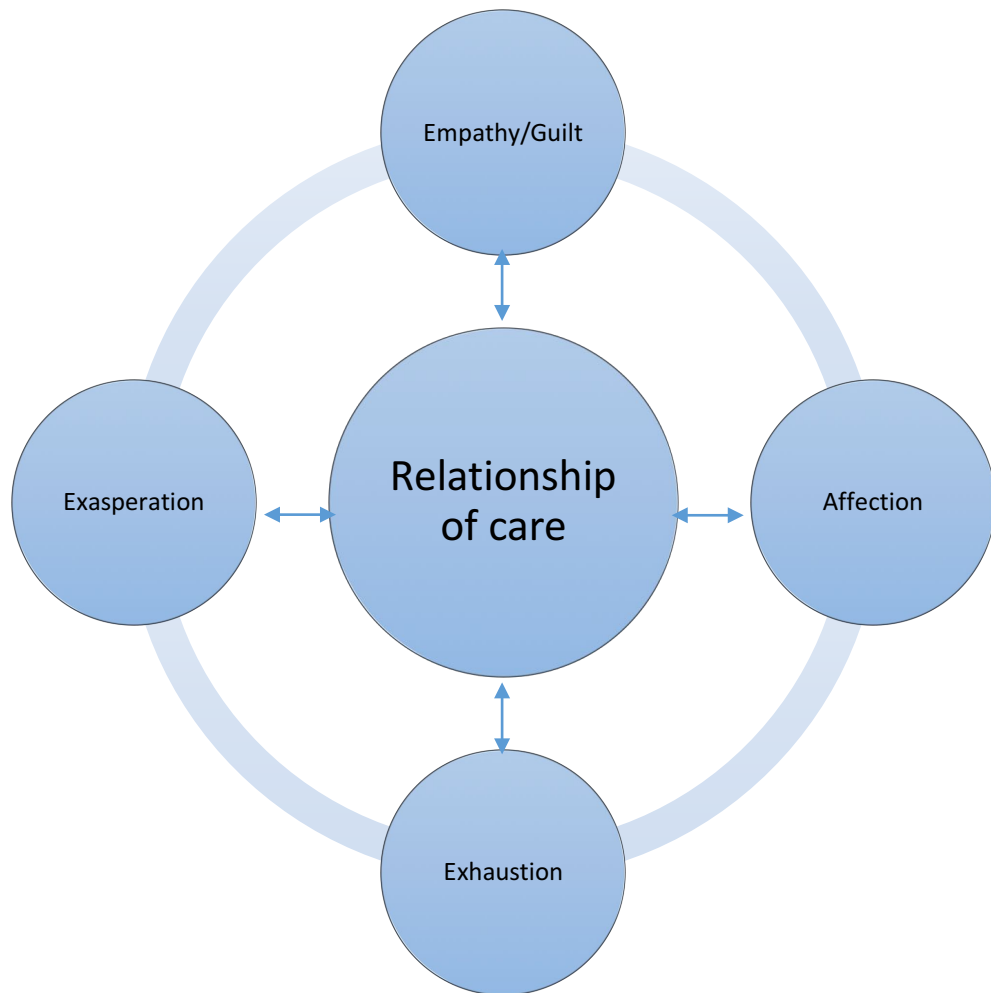


*Figure 4: The 'care relationship' deconstructed*

> *"Had a really difficult day – we probably needed a bit of space from each other. Rona needed to use the toilet but was unable to unlock the padlock, therefore I had to accompany her… Before, she had explicitly told me that she did not want me to join her. However, I had to go and unlock the door for her. The locks were so small and because of her mobility, she couldn't move it. So I followed her and we didn't talk. I stayed one or two metres behind her, in silence, aware that she was angry... We walked together yet away from each other. I unlocked it for her and waited out of sight. When she had finished, she walked back to our stewarding platform and I discreetly locked the door, gave her a couple of minutes and then followed her."* Day 3

The basis of the relationship between Rona and I was founded on equality and the mutual understanding of music and its experiences.  However, in this particular extract (see above), in the space of Glastonbury where accessible toilets and lock mechanisms were not offered, our relationship was, temporarily, forced into one of asymmetry based on power and dependency (Shakespeare, 2000).  The padlock was there to keep "able bodied" people out and maintain the toilet as a space reserved for disabled people only.  Ironically in this case, it meant that Rona actually needed to ask for my assistance in order to access it.  Therefore, the lock acted as a barrier to Rona accessing the landscape, signifying that Glastonbury is an exclusionary space which places certain people above others: in this case the 'care giver' over the 'care receiver'.

This scenario led to feelings of guilt; I did not want to be in the position in which I had been placed, yet because of my social positioning I still had to carry out this act.  I empathised with Rona, as I knew that she has the capacity to perform such a daily task herself and would never want to have to ask for assistance in such tasks. And yet because of the spatial arrangement, I was made to feel guilty, as I was placed as a dependent care giver – a role which I do not otherwise identify.  Lawson (2007) discusses the importance of acknowledging such interchanges between power, emotions and social relations.  My feelings of guilt and empathy were created through

the asymmetrical care relationship imbued with (unwanted) power produced by the landscape, unbalancing our existing social relationship.

The everyday, chaotic spaces of care created by Glastonbury, such as the campsite, meant that guilt, akin to that expressed in the extract above, became an overwhelming feeling for me a lot of the time.  This shows how despite the embodiment of emotions being deeply personal, our emotions can be influenced and shaped by other bodies which are similarly placed (Bondi, et al., 2005).  In this example, my emotions where heavily impacted by the interactions with Rona in certain disabling spaces, thus reinforcing Bondi's (2007) ideas that people are highly sensitive and responsive to others, supposedly 'internal', feelings.

**Exasperation**



*Figure 5: Sonic Haze dance stage, a site of exasperation*

> *"Today's shift is at Sonic Haze dance stage; it is an extremely difficult space to spend time in. The music is so loud and doesn't seem like it will ever stop! Rona is being really difficult and getting easily cross about things out of our control, I really want to shout back at her but instead go to the toilet where I can cool down… four hours into our six hour shift I want to scream/cry, I want to help Rona but I don't know how… Today has been the first day where I have questioned our relationship."* Day 3

The extract above represents one of the most challenging times I faced when at Glastonbury Festival. The combination of the unremitting heavy music (see video 2.54 – 3.13), the cut off confined space of the disabled platform we were stewarding, the six hour shift ahead of us and Rona's extreme emotions expressed towards me, all worked together to form an overpowering feeling of exasperation. The communication between us was almost non-existent, partly because we could not hear each other, but also because the extended time period in which to sustain our conversation. As a result of the whole situation, my field diary illustrated the feeling of exasperation and impotence to change the scenario we had been placed in.

In accordance with Twigg (2000) one of the hardest things to cope with, and one of the focal catalysts for my feelings of exasperation, was the active unhappiness of the other person in the care relationship. During my time at Glastonbury, I often found my moods and actions would mirror Rona's, and in this specific scenario her unhappiness and anger inspired my own unhappiness and anger. At the time, I questioned whether I was responsible for Rona's mood, rather than acknowledging the inter-relational impacts we had on each other. In line with Bondi's (2007) and Brandon's (1976) discussions, I believed that as a care giver it was my responsibility and job to protect Rona from both her emotions and mine. This self-monitoring, and presumption that, as a care giver, I could influence the situation, links to Shakespeare's (2000) discussion on power and how, when care givers identify a need (not always identified by the 'cared for'), this need is then translated into something that needs correcting or compensating for on behalf the care receiver (Brandon, 1976).

Reflecting back on this experience now, I have come to recognise the multiplicity of factors which influenced our respective moods. Emotions do not just reside within the body and between different bodies, as I presumed, but can also reside in space (Bondi, et al., 2005). The intensity of the space in which Rona and I were placed had a dramatic influence on both of our emotions, and furthermore it influenced the way I reacted to said emotions. By acknowledging this idea, my experience demonstrated in the extract above exemplify how we were not always reflexively aware of, or in control of, how our emotions were mapped onto and between our bodies (Jones, 2005).

## Affection

> *"On our last shift Rona and I get the chance to sit together and share our photos which we have both taken at Glastonbury. Eventually, we come across a photo taken of the both of us. It was so awful; we both couldn't stop laughing! Such a special moment reminds me of how lucky I am to share this experience with Rona."* Day 5

This extract demonstrates how, through sharing memories and pictures taken during the festival, emotional care was reciprocated between Rona and I. Such encounters signify the joy and affection which emerges through shared experiences of care (Brandon, 1976; Twigg, 2000; Brown, 2003). During this time, my field diary reflects the sense of mutual support and mutual gratitude present in our care relationship, mirroring Wiles' (2003) discussion on the interdependency of care relationships.

I captured in my field diary how, through this affectionate encounter, Rona and I created a space in which we could 'just have a laugh'. This cheerful space felt more familiar to what we were used to at home and brought a sense of normality into the chaotic space of Glastonbury Festival. Moreover, the empathy and support fostered through this interaction gave me a new perspective on our circumstances at Glastonbury contrasting to those imbued with emotions of exhaustion and exasperation.

The idea that our care relationship was cultivated through experiences of mutual affection, corresponds to feminist conceptualisations of care as an orientation framed by mutual empathy and compassion (Staeheli & Brown, 2003), rather than that of dependency and burden most often discussed in the literature (Pitkeathley, 1989; Bubeck, 1995). The significance of this move towards feminist conceptualisation sheds light on how this moment was important in re-claiming our care relationship as one of equality and interdependency. This was in stark contrast to moments permeated and bound up within power inequalities produced by particular Glastonbury landscapes.

## Exhaustion

> *'I have had two hours sleep, I feel like I have nothing more to give emotionally or physically… It feels like the hottest day so far, my eyes feel dreary and my skin sore from previous day's sun burn… Packing up our belongings feels like and impossible effort, Rona is also exhausted but I need her support, packing away our tent is a two-person job… All I want to do is climb back into my tent and be on my own. Glastonbury has defeated me I am ready to go home.'* Day 6

This extract from my field diary shows that by day six I was mentally and physically exhausted; I found it difficult to appreciate the experience and landscape I was in. During this time, I questioned my reasons for caring, my ability to care and how to care. The care relationship that I was in required a huge amount of mental and physical energy (Ruddick, 1998), which at this time I did not have. These feelings of exhaustion were intensified by the space in which we were located (Bondi, et al., 2005). The multiple landscapes of Glastonbury Festival had intensified our relationship, we had spent six days together creating shared experiences, we were no longer just friends but relied and depended on each other for support and care within the landscape of Glastonbury leaving me feeling vulnerable, exposed (Lawson, 2007) and, as a result exhausted.

The vast and chaotic landscape in which we had resided for the past six days had taken its toll on me physically; my body ached from trekking through mud and sleeping on the ground. My emotions therefore in part resided in my body (Bondi, et al., 2005),

and feelings of bodily and emotional exhaustion became an important influence on my experiences and interpretations of care (Widdowfield, 2000). The simple task of dismantling Rona's tent seemed slow, arduous and frustrating. I became immersed in this activity ignoring and avoiding what was going on around me, and when Rona started getting cross and upset I found it exceptionally difficult to help her calm down. Caring for Rona and indeed myself had become emotionally exhausting (Twigg, 2000) consequently I became dependent on other Gig Buddies members in supporting Rona and myself – in doing this I found that I resented my need for emotional care (Ruddick, 1998). As Bondi et al. (2005) discuss, our emotions affect our way of sensing and measuring the substance of our present. In this scenario, my exhaustion influenced my dependency on others and my frustration with the situation; consequently I felt that I had failed in my caring 'duties'.

## 5.22 Bringing my emotions back together (summary)

I deconstructed my care relationship into constituent emotions in order to explore how certain individual emotions have the power to transform and shape our lived experiences (Bondi, et al., 2005). My field diary extracts show how my experiences of Glastonbury Festival and my relationship, were shaped by certain emotions. The sections above show how guilt/empathy, exasperation, affection and exhaustion, were intrinsically linked to the space in which we were placed.

Although the deconstruction of my care relationship into constituent emotions is useful in giving a partial insight into care relationships, it does not capture the multiplicity, fluidity and ubiquitous nature of emotions in care (Bondi, 2007). Despite my attempts to represent and capture my emotional experiences through extracts of my field diary, my experiences at Glastonbury Festival continue to be more-than-representational (Carolan, 2008) and my field diary is insufficient in representing the intricacy of 'how life takes shape and gains expression' (Lorimer, 2005:84).

*'There is a sense in which the embodied and emotional immediacy of particular relational encounters may be elided or even lost in a subsequent retelling.'* (Conradson, 2005:346)

Considering Conradson's (2005) quote, my emotions at Glastonbury are perpetually more than I can theorise.  I have presented from my field diary just a few emotions which I felt informed my care experience, however, my overall emotional experience of care at Glastonbury Festival was always in excess, and to attempt to capture and retell this would not be sufficient in representing my experiences.

## 5.3 Mud – the 'indefinable' relationship



*Figure 6: Mud. Photo taken by author*

Following Conradson's (2005) call for a more relational approach to care, this section will work to deconstruct and examine my relationship with Rona.  Through recognising that relational care is a type of thinking that acknowledges the multiple and necessary relationships involved in the act of care (Ruddick, 1998; Lawson, 2007), this section will build upon previous accounts that explore care as a mulitude of complex transactions between people, and influenced by the socio-environmental spaces they inhabit (Conradson, 2005).  These understandings are in contrast to those which dichotomise the 'care giver' and 'care receiver' as active and passive respectively (Pitkeathley, 1989; Bubeck, 1995; Kittay, 1999), and which ignore the inter-relational

interactions which happen between all involved in the care relationship (Milligan & Wiles, 2010).

Drawing upon feminist ideas that recognise care as an inherently social, intersubjective relationship (Tronto, 1993; Popke, 2006), this section will explore the complexities/'muddiness' of the relationship between Rona and I by disentangling our lived experiences in the landscape of Glastonbury Festival, as presented through extracts of my field diary.  It will start by looking at our relationship as one of care, followed by the exploration of our relationship as one of friendship.  After critiquing this dichotomisation, this section will then explain how these two contrasting images of our relationship interact to create what I term, a 'muddy companionship'.

## 5.31 Friendship or care?

As Twigg (2000) notes, normative discourses on values of care often mean it is difficult to separate care from acts of friendship or love.  However, Power (2010) suggests that by separating these acts we will gain a more comprehensive understanding of care, and the wider relations with which care is involved.  Therefore, this section will begin by attempting to deconstruct the aspects of care and friendship in the relationship between Rona and I.

## 5.311 Dancing in the mud - Relationship of friendship

> 'On our last night at Glastonbury after a few drinks at the campsite we went to the silent disco… It felt good to spend time with Rona in such a fun laid back environment… we had such a great time dancing in the mud together and singing/shouting along to our favourite songs.' Day 5

Friendship is a predominant and important aspect of our relationship.  Our friendship is structured in a way that enhances well-being and mutuality (Staeheli & Brown, 2003; Lawson, 2007), through the fostering of shared commitment and involvement in this relationship (Brandon, 1976).  Rona and I were 'paired up' by Gig Buddies based on our mutual interest in live music and Ronan Keating.  Since this pairing we have developed a unique friendship based on shared experiences and understandings as

equals.  Our friendship is different to those I have experienced before, we don't talk much, but communicate in other ways such as drinking, dancing and sharing music. Despite the lack of 'normal' communication, we have an active friendship in which we both contribute.  The extract above offers an example of a moment of friendship shared at Glastonbury which stood out for me.

### 5.312 Relationship of care – Stuck in the mud

> *'The mud is really making our lives difficult… Rona is really nervous about slipping over so I physically support her when we walk between the different arenas, whilst also talking to her to distract her from her worries.'* Day 3

As shown in the extract above, caring was an integral part of our relationship at Glastonbury Festival.  For those who are disabled, depending on the space they are in, practical and emotional care dependencies may be present (Ruddick, 1998; Twigg, 2000; Thomas, 2007).  When Rona and I were first introduced to each other by Gig Buddies, we discussed Rona's care needs with the understanding that when out together, I would provide any necessary support for Rona.  Until Glastonbury Festival, however, there was minimal practical care involved in our relationship.

Whilst acknowledging that all care relationships are different (Ruddick, 1998), care ethicists highlight the importance of recognising and responding to dependency relations (Tronto, 1993; Ruddick, 1998; Held, 2006) in terms of interconnectedness and interdependency (Milligan & Wiles, 2010).  At Glastonbury Festival because of the environment we were in, Rona depended on myself for certain care, to which I responded.  However, in certain spaces I was also dependent on Rona for care.  In the extract above I was offering Rona both physical and emotional support to tackle the obstacle the mud had offered us.  However, in the act of offering support to Rona, I also received a steadying grip to prevent me from slipping, epitomising the reciprocal and interdependent nature of our care relationship.

### 5.32 The 'muddy companionship'

Above I have presented two contrasting images of the relationship between Rona and I, one of friendship and one of care. I will now go on to discuss the problems of

deconstructing the relationship in this way, followed by offering a more nuanced interpretation.

Deconstructing our relationship as above offers a rich insight into different elements of our relationship.  However, as Ruddick (1998:7) identifies 'there are problems in interpreting care's ideals of rationality and relationships too narrowly'.  Observing Ruddick's (1998) point, my attempts to define and categorise my relationship with Rona in such narrow parameters causes problems, is it suggests a static and determinate relationship (Conradson, 2005); it also forces me to separate certain emotional acts of care and acts of friendship which are otherwise inseparable (Ruddick, 1998).

Moreover, it is problematic to limit our relationship to one of either care or friendship (Tronto, 1993).  Bubeck's (1995) suggests that care is not relational and is limited to the meeting ones needs that someone cannot meet themselves.  This ignores the multiplicity of relations involved in care which offer reciprocal benefits to those involved (Power, 2010), and also suggests that care cannot involve a meaningful friendship (Gleeson, 1996).  By limiting our relationship to either care or friendship also ignores elements which cannot be categorised (Tronto, 1993), as discussed in non-representational theories, such as the scenario presented below.

> *'Because of the rain it was so muddy today! Every step we took we would slip around and nearly fall so we would cling onto each other so we wouldn't fall…
> Both of our welly boots were stuck in the mud, I managed to pull myself out the mud but Rona couldn't without my help.'* Day 4

This extract illustrates the complexity of the relationship I was involved in.  Following Conradson's (2005) ideas of 'the self' emerging through relations to others, in our relationship elements of care and friendship worked together to influence my way of knowing and understanding the spaces of Glastonbury Festival.  In regards to the quote above, my understandings of how to 'tackle' the muddy landscape was the combination of shared experiences of friendship and what I thought of as necessary care.  However, as Williams (2001) points out, it is often hard to distinguish between the two with acts of emotional care often blurring into acts of friendship.

Noting Williams' (2001) point, distinguishing between friendship and care became ever more difficult in the high intensity, ever changing, unfamiliar landscape of Glastonbury Festival, and I felt that our relationship lurched uncontrollably between friendship and care.  The predominant driver for this unbalancing of friendship and care was the spaces we inhabited at Glastonbury, and the social and physical accessibility to these spaces (Conradson, 2005; Lawson, 2007).  Despite this unbalancing, there was a foregrounding element of equality and mutuality in our relationship that worked against structures that (re)produced the need for disempowering care (Waerness, 1984; Tronto, 1993; Staeheli & Brown, 2003; Power, 2010).

Although acts of care can be disempowering, Milligan and Wiles (2010) argue that care can also create a mutual sense of wellbeing and happiness; such acts of care form a central aspect of our relationship and friendship.  Although some argue that care interdependencies are limitations (Bubeck, 1995), Sevenhuijsen (1998) asserts that interdependencies and vulnerabilities are not always weaknesses or limitations but rather elements that actively contribute to relationships. Accordingly, our relationship recognises and acknowledges each other's vulnerabilities as productive differences.

## 5.33 Summary
Through drawing upon feminist understandings of care, and by using a relational theory approach, the findings discussed in this section move beyond the totalising accounts of care as a purely passive/active relationship, to acknowledge the complexity and interconnected nature of relationships which involve elements of care. By deconstructing care and friendship, I discovered that in fact, in the relationship between Rona and I, care and friendship intertwine to form an undefinable and 'muddy' companionship.  Moreover, using a spacial approach to look at my relationship, highlighted the important interconnections between my relationship and the space inhabited (Lawson, 2007), as our relationship lurched between care and friendship.  At Glastonbury Festival our relationship ventured new territories, which stepped out of the realms of what the literature covers and the presumed 'suitable'

spaces of care (Bubeck, 1995; Conradson, 2005; Noddings, 2013).  Our relationship became one based on being with one another, grounded through the combination of friendship and care, with the aim of equality but also celebrating productive differences.

# 6.0 Conclusions

This dissertation has explored the experience of 'care' with a disabled person within the micro-spatialities of Glastonbury Festival. This dissertation has been directed by feminist and non-representational theory and the application of auto-ethnographical methods to produce a personal narrative of my subjectively constituted experiences. Although often characterised within the literature as a disempowering and dependency creating act, 'care' in practice is much more complex. Moving beyond these totalising accounts of care, this dissertation has offered a more nuanced approach to understanding care, demonstrating how experiences of care are guided by: the spaces in which it is situated, embodied emotions and complex (muddy) relations.

This spatial analysis of care has shown how different spaces of Glastonbury Festival impact on care relationships, and in turn how care relationships impact the spaces of Glastonbury Festival. As a landscape of care, the intensities and chaos in the micro-spatialities of Glastonbury festival worked to challenge conventional ideas of appropriate 'care' behaviour. The campsite became a space of rhythm and habit; offering both a space which (re)produced the need for care, and a space that abated and normalised care as an intrinsic part of a relationship. Intimate acts of care, often labelled a private affair (Lawson, 2007), transgressed into what seemed like a public space within the campsite. In the more public and chaotic spaces of Glastonbury Festival, our acts of care became more 'visible' and felt 'out of place'. Thus this section demonstrated how spaces of performed care are multi-layered; shaped by issues of responsibility and bound up in dominant voices of power which work to mould identities of care (Milligan & Wiles, 2010).

Emotions played a crucial role in directing my experiences of care at Glastonbury festival. Through the deconstruction of my care relationships into constituent emotions, I was able to reflect on how certain individual emotions had the power to transform and shape my lived experiences at Glastonbury festival (Bondi, et al., 2005). Section 5.1 revealed the importance of the role of place in shaping our emotions which are imbued in experiences of care. However, despite my attempts to represent my emotions; I found that my emotions existed in the consciousness of being present in

that moment, thus affirming lived experiences as more-than-representational (Carolan, 2008). Consequently my field diary was insufficient in representing the intricacy of the multiplicity, fluidity and ubiquitous nature of emotions within care relationships (Bondi, 2007).

Section 5.3 examined my relationship with Rona, asking what is a relationship of care in the context of Glastonbury Festival? Drawing upon feminist understandings of care, my relationship with Rona can be understood as complex and interconnected. Our relationship lurched uncontrollably between care and friendship depending on the space we inhabited. Both friendship and elements of care intertwine to form what I term a 'muddy companionship'. Thus our relationship became one based on being with one another, substantiated through the interconnection between friendship and care, but also built on the celebration of our productive differences.

Beyond the scope of this project, a significant research path could be for Rona to conduct her own auto-ethnographic account of her experiences within our care relationship. This could be accomplished in a number of ways, such as video diaries rather than written entries, in order to "recognise the presence of diverse interests and forms of knowledge" (Milner, 2013:29) thus, allowing for us to become co-investigators (Stone & Priestley, 1995; Milner, 2013). Equally, this intensely subjective and unique research model could act as a framework for exploring other care relationships in different spaces.

In summary, through exploring alternative spaces of care, embodied emotions and 'muddy companionships', this dissertation has provided a more nuanced analysis of lived experiences of care. Informed by non-representational theories, this dissertation recognises the difficulties of expressing the essence of experience; perpetually more than can be vocalised. Nevertheless, my research suggests how these three constituent elements worked together to form my experiences of care in the chaotic landscapes of Glastonbury Festival.

Rona and I remain close friends and are in regular contact. We have a number of music concerts lined up, including finally getting the chance to see our favourite artist:

Ronan Keating.  We are planning on going back to Glastonbury Festival in summer 2017, once we have finally recovered from the mud.

# **<u>Acknowledgments</u>**

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# **<u>Appendices</u>**

**2.0 - Ethics checklist**

SCHOOL OF ENVIRONMENT AND TECHNOLOGY

RESEARCH ETHICS CHECKLISTS FOR UNDERGRADUATE AND MASTERS
LEVEL RESEARCH PROJECTS

Ethics Checklist

Section A Project details **-** to be completed by the project student

1. Name of student/s: Imogen Fox

2. Name of supervisor: Leila Dawney

3. Title of project (no more than 20 words): The experiences of an adult with learning disabilities at Glastonbury festival and other music events

4. Outline of the research (1-2 sentences):  The aim of this project is to explore the experiences of adults with learning disabilities at Glastonbury festival and other music events, whilst exploring senses of feeling 'in-place' and/or 'out of place' in these environments.

5. Timescale and date of completion: June 2014 - May
2016

6. Location of research: Glastonbury festival

7. Course module code for which research is undertaken: BA Geography

8. Email address: imogenfox@hotmail.com

9. Contact address:  8a, Bellefields Road, Brixton, SW9 9UQ

10. Telephone number:     07531410000

Section B Ethics Checklist questions

| | | |
|---|---|---|
| 1. Is this research likely to have significant negative impacts on the environment? (*For example, the release of dangerous substances or damaging intrusions into protected habitats.*) | | X |
| 2. Does the study involve participants who might be considered vulnerable due to age or to a social, psychological or medical condition? (*Examples include children, people with learning disabilities or mental health problems, but participants who may be considered vulnerable are not confined to these groups.*) | X | |
| 3. Does the study require the co-operation of an individual to gain access to the participants? (*e.g. a teacher at a school or a manager of sheltered housing*) | | X |
| 4. Will the participants be asked to discuss what might be perceived as sensitive topics? (*e.g. sexual behaviour, drug use, religious belief, detailed financial matters*) | | X |
| 5. Will individual participants be involved in repetitive or prolonged testing? | | X |
| 6. Could participants experience psychological stress, anxiety or other negative consequences (beyond what would be expected to be encountered in normal life)? | | X |
| 7. Will any participants be likely to undergo vigorous physical activity, pain, or exposure to dangerous situations, environments or materials as part of the research? | | X |
| 8. Will photographic or video recordings of research participants be collected as part of the research? | X | |
| 9. Will any participants receive financial reimbursement for their time? (*excluding reasonable expenses to cover travel and other costs*) | | X |
| 10. Will members of the public be indirectly involved in the research without their knowledge at the time? (*e.g. covert observation of people in non-public places, the use of methods that will affect privacy*) | | X |
| 11. Does this research include secondary data that may carry personal or sensitive organisational information? (S*econdary data refers to any data you plan to use that you did not collect yourself.* | | X |

| | | |
|---|---|---|
| *Examples of sensitive secondary data include datasets held by organisations, patient records, confidential minutes of meetings, personal diary entries. These are only examples and not an exhaustive list).* | | |
| 12. Are there any other ethical concerns associated with the research that are not covered in the questions above? | | X |

All Undergraduate and Masters level projects or dissertations in the School of Environment and Technology must adhere to the following procedures on data storage and confidentiality:

Once a mark for the project or dissertation has been published, all data must be removed from personal computers, and original questionnaires and consent forms should be destroyed unless the research is likely to be published or data re-used.

Please sign below to confirm that you have completed the Ethics Checklist and will adhere to these procedures on data storage and confidentiality. *Then give this form to your supervisor to complete their checklist.*

Signed (Student):  Imogen Fox

Date: 24/10/2014

***Supervisor Checklist:*** Project approval - to be completed by the project supervisor

If the student answered YES to any of the questions in the Student Checklist then he/she is required to complete an ethics approval form (please circle as appropriate)

> Form required      Form not required

If required, please advise the student on completing the ethics approval form

If the student answered NO to all Student Checklist questions, please complete the following table. *The project should not begin until all boxes are ticked (use N/A if appropriate):*

| | |
|---|---|
| | (If applicable) A risk assessment form has been completed |
| | This is a practicable and worthwhile research project? |
| | The student has the skills necessary to carry out the research effectively |
| | (If applicable) A participant information sheet or leaflet has been completed |
| | (If applicable) The procedures for participant recruitment and obtaining informed consent are appropriate (e.g. consent form or questionnaire introduction) |

If the student answered 'no' to all checklist questions, please remind them that they must notify you of any significant change in the structure, design or conduct of the project or dissertation that would alter their answers to the Ethics Checklist questions.

Any further comments from supervisor:



Supervisor name:

Signed:

Date:

If any of the questions in the checklist have been answered 'YES', then please submit the Ethics Checklist along with an Ethics Approval Form to the Chair of the School Research Ethics and Governance Committee.

If all of the questions in the Ethics Checklist have been answered 'NO', then please submit a copy of this checklist to the School office for filing.

Students must keep a copy of the Ethics Checklist and submit it as part of their project or dissertation. If the project changes significantly, a new checklist must be completed and included.

**3.0 – Ethics Approval Form for working title**

UNIVERSITY OF BRIGHTON
SCHOOL OF ENVIRONMENT AND TECHNOLOGY
ETHICS APPROVAL FORM – UNDERGRADUATE AND MASTERS LEVEL
RESEARCH PROJECTS

This form is to be used by undergraduate and Masters level students seeking ethical approval for their research from the School of Environment and Technology Research Ethics and Governance Committee.

All those completing this form must receive approval from an appropriate ethics committee (usually the School of Environment and Technology Research Ethics and Governance Committee) prior to beginning their research.

Please read the University Guidance on Good Practice in Research Ethics and Governance before completing this form. This form should be checked carefully for typographical and grammatical errors before submission. Incomplete or badly presented forms will be returned. Supervisors of student projects have a responsibility to ensure that the guidance is followed and that applications are properly presented.

If after considering this form the School Research Ethics and Governance Committee consider Tier Two approval is required, the project student will be notified and this form will be automatically passed to the Chair of the Faculty Research Ethics and Governance Committee for consideration.

Please attach the SET Research Ethics Checklist you have already completed to this form.

Section A – Key details

1. Name of student/s

Imogen Fox

2. Name of supervisor

Leila Dawney

3. Title of project (no more than 20 words)

The experiences of an adult with learning disabilities at Glastonbury festival and other

music events

## 4. Aims of the study

The aim of this project is to explore the experiences of adults with learning disabilities at Glastonbury festival and other music events, whilst exploring senses of feeling 'in-place' and/or 'out of place' in these environments.

## 5. Research context

A large amount of the research surrounding disabilities focuses on 'physical disabilities' (Bennett, 2004; Swain, 2004; Porter, 2010), whereas my research project will focus intellectual disabilities using Porter's (2010) discussion around the issues faced by this group (adults with intellectual disabilities).

Stone and Priestley (1996) discuss how in the past research into those with disabilities often added to the discrimination and oppression which disabled people faced. Therefore they examine the importance of 'emancipatory research' which focuses on the social model of disability (disability as a social construction) rather than seeing disability as biologically determined. I will use these ideas to inform the design of my research method.

Bennett (2004) looks at how music is a key factor in how different people can make sense of and negotiate the 'everyday' whilst looking at the different settings in which music can be consumed. Bennett (2004) discusses the importance of music in people's lives. He focuses on the intertwining of music, space and place; and how these factors can be experienced. Bennett (2004) argues that music puts a meaning and significance to space therefore creating a collective identity which situates in both space and time.

Kitchin (1998) discusses how different definitions of disability have come about. Kitchin (1998) comes to the conclusion that 'disability' is a social construct which focuses on notions of power. Kitchin (1998) discusses how disabled people are marginalised from today's society by being made to feel 'kept in place' or 'out of place'.

## 6. Research design

This research project will use qualitative research methods. It will interview people with learning difficulties by going along with them to gigs and events. The researcher is already a member of the 'gig buddies' group, and has the full support of those who run this group.

Go along interviews will be used as these allow for the participants to play an active role in shaping the interview (Garcia, et al., 2012). Video interviews will be conducted with the adults with learning disabilities as frequently as possible (when it is feasible with the agreement from participants) throughout the events. The method of go along interviews will be beneficial as will allow for a more fluid 'conversation' like interview making the participants feel at ease. I will also ask the participant to film parts of the gig so they can actively show me their favorite parts of the gig. Photographic and video recording may be collected as part of the research/interviews in order to make my research findings accessible to a wider audience whilst encapsulating the feelings and emotions during the music events. Rose (2007) discusses the importance of images in the conveying of messages; there for the use of images in my dissertation will aid the understanding of my research.

A focus group will take part with the 'Storm and Thunder' group at 'Gig Buddies', with a discussion being held around the topic of "how do you feel at music events".

The videos and transcripts gained during the interviews will then be coded by counting the frequency of particular phrases; themes and subthemes will then be highlighted and analysed.

Please use Section B of the SET Research Ethics Checklist to decide which section(s) of this form to complete, and complete those sections appropriately:

If you ticked 'yes' to Question 1 in the checklist (Negative Environmental impacts), complete Section B

If you ticked 'yes' to any of Questions 2 – 9 (Human Participant Issues), complete Section C

If you ticked 'yes' to Question 10 (Indirect Involvement of the Public), complete Section D

If you ticked 'yes' to Question 11 (Secondary Data Sources), complete Section E

The project student and the supervisor must sign the form in Section F.

Section C – Potential Risk to human participants directly working with the researcher

*The aim of this section is to check whether you have taken the necessary steps to ensure your research will avoid causing physical or emotional harm, pain, discomfort or stress to human participants.*

9. If human participants are directly involved, provide brief details regarding the participants and how they will be contacted (*e.g. number, age, gender, ethnicity, general residential location*).

I will be working with a mixture of disabled adults who are in their mid-30s from South East England; all are members of Gig Buddies (the charity I volunteer with). Gig Buddies is a scheme that supports people with learning disabilities to access mainstream cultural events. It describes itself as 'a project that pairs up people with and without learning disabilities to be friends and to go to events together'. My role as a volunteer is to accompany an adult with intellectual disabilities to a gig. http://stayuplate.org/gig-buddies-project/ (See website for more information on the charity). Gig buddies fully supports this research and will be available to consult with throughout the research. They already undertake videos of the events and publish these on their website.

The focus group will take part with the 'Storm and Thunder' group. Storm and Thunder are a group of learning disabled adults who are an advisory group which oversee the Gig Buddies project and the overall work of the charity. (http://stayuplate.org/storm-and-thunder-team/ please see link for more details about Storm and Thunder).

10. If human participants are directly involved, provide details of any participants who might be considered vulnerable due to age or to a social, psychological or medical condition. Examples include children, people with learning disabilities or mental health problems, but participants who may be vulnerable are not confined to these groups. *(See the University's 'Guidance on Good Practice in Research Ethics and Governance' for more details. Proposals involving vulnerable participants are often likely to require ethical approval from Tier 2, the Faculty of Science & Engineering Research Ethics and Governance Committee).*

The participants have mild to moderate learning disabilities however; they do not consider themselves as vulnerable adults.  As part of the charity ethos as volunteers we do not get told specific details on disabilities, as this can often reinforce socially constructed stereotypes that are associated with certain disabilities.  However, we do get informed of specific medical needs as required.  Gig Buddies uses the social model of disability, believing that "Disability is caused by the way society is organised, rather than by a person's impairment or difference." (Scope, 2014).  This approach is also the predominant model used in scholarship.  Thus, it is not appropriate to catagorise or measure disability on a scale.

The participants may be considered vulnerable by others, because they could be seen to be vulnerable to abuse (such as being taken advantage of), vulnerability can also be associated with ability to consent.

The participants live in sheltered accommodation with the freedom to make independent decisions in their daily lives (such as catching the bus, cooking independently and having part time employment).  These examples display that the participants make daily choices independent of the guidance of carers or guardians.

11. If human participants are directly involved, provide details of any risks participants are likely to face that would not be considered minimal risks. *(See the University's 'Guidance on Good Practice in Research Ethics and Governance' for details of possible risks including, but not limited to, physical risks to participants, distress arising from prolonged testing or questions of a sensitive nature, risks for researchers, and risks for vulnerable people)*. If risks are only minimal please describe the risks and explain why you believe they are only minimal.

I believe there is a minimal risk of distress in this project as the participant has independently chosen to go to the event and has been to similar events before.  However, if the participant does become distressed, there is a large support network provided by colleagues at the charity who will also be present at Glastonbury.  At other events, the support network is also easily accessed through the emergency phone line set up by the charity.

Another risk would be that the participants consent to something they do not understand fully.  I will avoid this by clearly explaining what my research is about and what their involvement consists of.  I will then ask the participant to explain the project in their own words back to me.  If I believe that the participants do not fully understand I will terminate the research.  The charity has also offered me support in helping to explain my project and also talking to the participant about the research project if the

participants want to. They have extensive experience of gaining consent and will support this research to do so.

12. Describe the procedures that will be put in place to ensure safe and ethical direct involvement of human participants. (*Where necessary and as appropriate, include comments on obtaining informed consent, reducing harm, providing feedback, and accessing participants through an individual providing information such as a teacher, manager, employer etc.*) Example consent and information forms can be found on StudentCentral.

The participants will be accessed through the charity I work for called 'Gig Buddies'. I have already volunteered to work with one participant as her personal assistant whilst at Glastonbury festival. I volunteered before deciding on my research project therefore the access has already been confirmed. I have also already volunteered with the other participant as her 'Gig Buddy' and I have already attended music events with her in the past. I have also discussed my research ideas with the head of the charity and received her support and approval in leading a focus group with 'Storm and Thunder'.

By working with the charity 'Gig Buddies', I have been taught different methods of written communication that is accessible by all. When creating consent and information forms I have used a mixture of pictures and words to help with a clear understanding I will also talk through each section to ensure that the participant has understood what is meant.

The final videos will blur out the faces of the participants in order to keep the participants anonymous; non-video data will also be kept anonymized. A CD of the video will be included in my dissertation and also stills from the video will be used throughout the written work. This will also be made available through the charity's website and video programme that is already in place and independent of this research.

I will also make it clear that participating in this research project is optional and if they choose not to take part it will not affect the trip to Glastonbury or their attendance other music events.

13. If covert or other controversial research methods are to be used or if the research procedures contravene conventional ethical protocols (*including consent, confidentiality and feedback*), justify the use of such methods and procedures here and outline the measures that will be put into place to mitigate against potential harm

Not Applicable

14. If human participants are to receive financial reimbursement for their time *(excluding reasonable expenses to cover travel and other costs)*, provide details and a short justification (*e.g. amounts and form of reimbursement*).

| Not Applicable |
| --- |

15. Describe in 50-100 words how you will ensure data collection is confidential and anonymous (*e.g. interviews cannot be overheard, details will not be accessible to others*), how data will be stored and who will have access to the data. If the data will not be confidential or anonymous, outline the justification for this decision here and procedures for mitigating against potential harm. *In particular, if photographic or video recordings are to be made in the course of the research, please outline consent and data protection procedures for the use of participants' images.*
All data should be stored securely. Documentation should be kept in a locked cabinet or desk, and electronic data should preferably be kept on a removable disk or data stick which can be locked away, or if this is not possible on a password protected computer. For undergraduate projects, normally only the student and supervisor will have access to the data *(see the University's 'Guidance on Good Practice in Research Ethics and Governance for further details).*

The sound and video data recordings will be kept in a locked cabinet or transferred onto a password protected computer. The data that is collected during the interviews will be stored securely in locked drawers and in password protected files and will only be accessed by the researcher and supervisors. The data collected will be used for a student research project and will be retained for up to two year and then disposed of securely. The information will be kept private during any discussions about the project. The interviews will take place where they cannot be overheard and will be terminated if they could be overheard. Consent for the use of video images and recordings as part of initial consent form. Confidentiality will be dealt with in the videos by blurring the faces of the participants. The focus groups will not be videoed.

Section F – Further details, accompanying documentation and signature

23. Please add anything relating to ethical issues that should be considered when assessing this project that has not been addressed elsewhere on this form. Continue on another sheet if necessary.

I want to use image recording as part of my dissertation as this is a good way of encapsulating emotions that will act as research data. The end video will also be an accessible way of understanding my research for someone with learning disabilities; therefore the participants will be able to see what they were involved in. Both participants have already consented to pictures and videos for use by 'Gig Buddies', and the video I make will be used on the 'Gig Buddies' website. I will make sure that the participants understand that if they consent to it, I will be using the video as part of my dissertation research and final dissertation. I will give them the option of blurring out their faces so that they cannot be identified.

24. Indicate which of the following are attached to this form:
*The Research Ethics Checklist should be attached for all projects; you only need to provide the other documents if they are applicable to your project*

Attached

SET research Ethics Checklist (please remember to
attach) ..X.

Participant information sheet ..X.

Participant consent form (or introduction to be used on questionnaire, see below) ..X.


25. Please sign this form.

Student name: Imogen Fox


Signed: Imogen Fox


Date: 24/10/2014



26. This form must be checked and approved by your supervisor.


Any further comments from supervisor:



Supervisor name:


Signed:


Date:

# Participant Information sheet



## Title

The experiences of care at Glastonbury Festival



## Invitation

Take time to read though the following information.

You can show this form to other people to get some advice

And ask Imogen if you need any help or more information.





## What is the work about?

The aim of this study is to research the care experiences we have as Gig Buddies at Glastonbury Festival.

| | |
|---|---|
|  | **Why have you been chosen?**<br><br>You are my Gig Buddy, and I am interested in looking at our experiences at Glastonbury Festival. |
|  | **What will I be doing?**<br><br>You will be filming parts of the festival on a camera I will give you, so we can show others what the festival is like.<br><br>You will not need to do anything differently. |
|  | **What will Imogen be doing?**<br><br>I will be taking notes about the experiences we have. You can read these notes whenever you want to.<br><br>I will then turn these into a piece of writing. |

| | |
|---|---|
|  | **Do I have to take part?**<br><br>You do **NOT** have to take part<br>You can pull out from the project at any time<br>Pulling out **WILL NOT** affect your time at Glastonbury Festival |
|  | **What are the disadvantages?**<br><br>There should be **NO** disadvantages.  If you are worried please talk to Imogen |
|  | **Will the information collected be kept private?**<br><br>Your information will be kept private and in a safe place.<br>The information will only be shown to my supervisor.<br>You will also be able to see my final piece of work |

| | |
|---|---|
| **?** | **Do you have any questions or concerns?**<br><br>Please talk to Imogen or  someone else if you have any worries or questions<br><br><br><br>You can also contact my dissertation supervisor Leila Dawney if you have any worries or complaints.<br><br>L.Dawney@brighton.ac.uk |

## 5.0 – Copy of consent form

### Consent Form

**Title:** The experiences of care at Glastonbury Festival

| | |
|---|---|
|  | Imogen Fox has explained the project  |
|  | I understand what the project is about and what I will be doing |
|  | I understand that all my information and data will be kept private.<br><br>I understand that Imogen's supervisor will look at the data |
|  | I understand that I can pull out from the study at any time without giving a reason<br><br>I understand that pulling out will not affect my time at Glastonbury Festival |
|  | I understand that the data collected will be used for Imogen's research project. |

## I agree to take part in the study

_____          _____

Name of

Participant                              Date



_____          _____

Researcher                              Date
                                        Date
                                        Signature

## 6.0 - Gig Buddies letter of approval

<div align="right">
Madeline Denny

Stay Up Late

2 Bell Lane

Lewes

East Sussex BN7 1JU
</div>

22nd October 2014

**Statement of Support for Research Project**

To whom it may concern,

I am the Volunteer Manager of Imogen Fox, who has been volunteering as a Gig Buddy Befriender with Stay Up Late, for over a year. I understand that Imogen plans to undertake a research project entitled 'The experiences of an adult with learning disabilities at Glastonbury festival and other music events' for her final project for her BA Geography degree. I am in total support of Imogen using her position as a volunteer for Stay Up Late to undertake this piece of research.

As a Gig Buddy Imogen's role has involved developing a friendship with a woman in Brighton who has a learning disability, through attending gigs and events together. She has also supported some people with learning disabilities to be volunteers at Glastonbury Festival 2014. Imogen has been an exceptional volunteer since beginning with Stay Up Late, and is always careful to promote the needs, wishes and choices of the people with learning disabilities that she supports to access music events.

As a charity, our aim is to promote social inclusion for people with learning disabilities, and we are deeply interested in the experiences that our participants have at music events, and particularly their experiences of inclusion and exclusion. Through Imogen's research project we will have more evidence of the importance of people having opportunities to be included and to access social activities. We will also be able to use

the knowledge gathered from this project to improve accessibility of Brighton and the wider UK's music scene for adults who have a learning disability.

Yours truly,

Madeline Denny
Gig Buddies Project Manager

## 7.0 – Risk assessment

| School / Department: | Environment and Technology | Date of assessment: | |
|---|---|---|---|
| Activity / area: | Glastonbury Festival | Next review date: | |
| Student and Adviser names: | Imogen Fox   Leila Dawney | RA Ref NO: | |

| No. | What are the hazards? | Who might be harmed and how? | What controls do you already have in place? | Risk (H/M/L) | What further action is necessary to reduce the risk to Low? | Action by whom? | Action by when? | D |
|---|---|---|---|---|---|---|---|---|
| 1 | Tripping/Falling | Those attending Glastonbury, due to uneven surfaces and possible mud. | Wearing suitable footwear, sticking to paths when possible and being aware of uneven surfaces. | L | | | | |

| No. | What are the hazards? | Who might be harmed and how? | What controls do you already have in place? | Risk (H/M/L) | What further action is necessary to reduce the risk to Low? | Action by whom? | Action by when? | D |
|---|---|---|---|---|---|---|---|---|
| 2 | Getting hurt in crowd situation | Those attending Glastonbury. By getting into a busy crown situation. | Staying in areas which are less busy (Glastonbury = raised viewing area) (Gigs = at the back where less people tend to be). If crows is getting to busy we would leave the venue. | L | | | | |
| 3 | Damage to hearing | Those attending Glastonbury. By getting to close to the speakers. | Avoid getting too close to the speakers and being aware of how load it will be. | L | | | | |

| No. | What are the hazards? | Who might be harmed and how? | What controls do you already have in place? | Risk (H/M/L) | What further action is necessary to reduce the risk to Low? | Action by whom? | Action by when? | D |
|-----|----------------------|------------------------------|----------------------------------------------|--------------|--------------------------------------------------------------|-----------------|-----------------|---|
| 4 | Difficult social situations | Those attending Glastonbury.  Getting into difficult situations with people who are under the influence of drugs or alcohol. | Being aware of people around you and walk away if tempers get raised or you feel uncomfortable threatened. | L | | | | |
| 5 | Sun stroke/heat related ilness | Those attending Glastonbury.  If the weather is very warm/sunny, possibility of getting heat related illnesses. | Wearing sun cream and hat, also keeping hydrated throughout the day. | L | | | 5 | |

## 8.0 - Appendices References

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