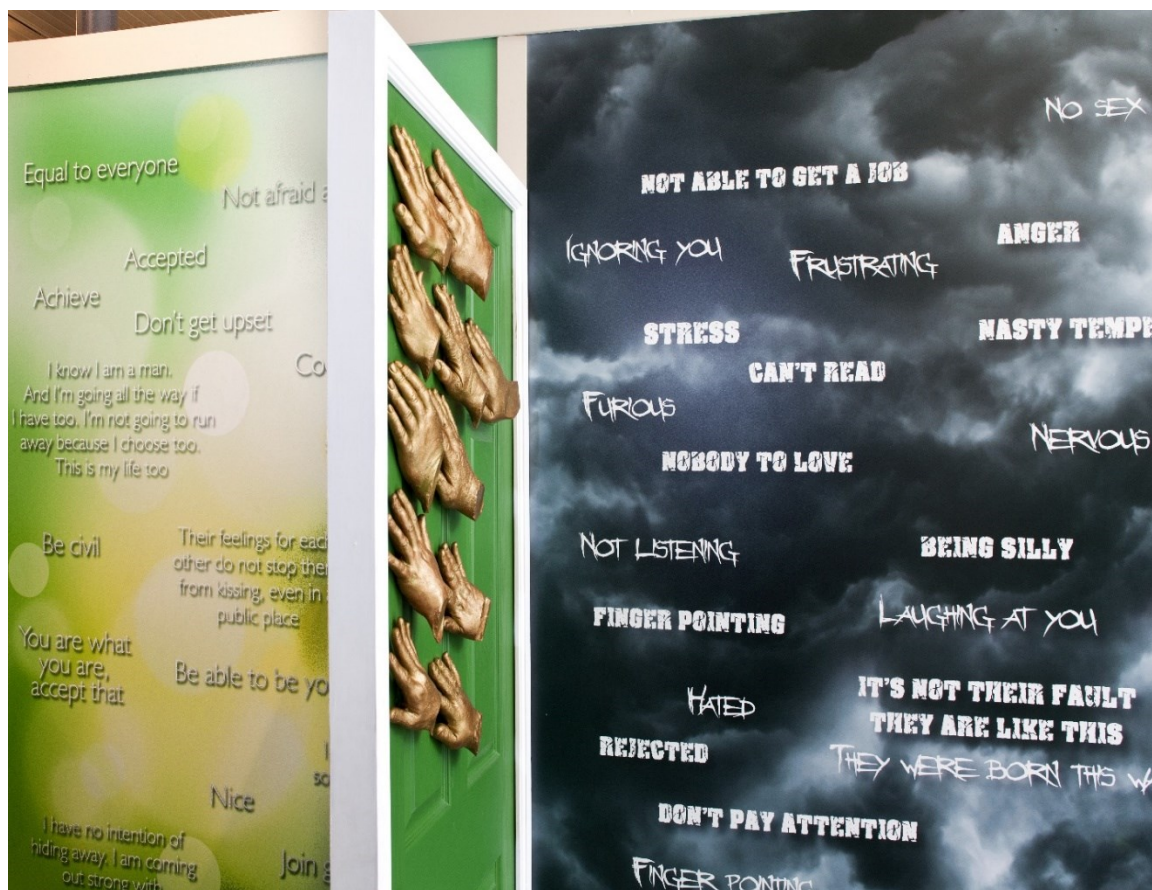


# Confessions of a community psychologist: the tale of a group of men challenging the perceptions of learning difficulties and health promotion.



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**A thesis submitted in partial fulfilment of the requirements of the Manchester Metropolitan University for the degree of Doctor of Philosophy  
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## **Abstract**

This thesis draws on ideas from disability studies (Oliver, 1990) and critical community psychology (Kagan et al, 2011a) as well as ethnography (Anderson, 1989), critical theory (Parker, 2007) and posthuman philosophy (Braidotti, 2013), to suggest a new understanding between critical community psychology and disability studies. However, I have argued that research is limited in making the inter-connection between disability studies and critical community psychology, and also that there is limited research which considers men labelled with learning difficulties and health promotion. Whilst literature exists on men's health (see Branney, 2012), health promotion (see World Report on Disability, 2011) and learning difficulties (see Goodley, 2004), these do not include a detailed discussion of the experiences of men, labelled with learning difficulties, men's health and health promotion, as an entity drawing on a critical community psychology and disability studies approach.

This research is of current policy relevance with its exploration of the experiences of a group of men labelled with learning difficulties people, in times of austerity during the current Conservative-led Coalition government (Phillimore et al, 2010). My research aimed to provide a rich and contextualised account from the perspective of men labelled with learning difficulties in the development of forty-five workshops throughout 2011. Using qualitative, autoethnographic and participatory approaches (which I adopted and applied in this research), I uncovered the ways in which these men demonstrated understanding for health promotion using visual methods such as art, drama, poetry, sculpture and photography. This contrasts with other research that have explored these concepts quantitatively (see Geary et al, 2012; Peng and Fuchs, 2014) or used qualitative methods that are mainly interview based (see Heslop et al, 2013). The findings from the various sources of data analysed suggest four overarching themes. First, the need to listen more to people labelled with learning difficulties who have knowledge and experience to share about health promotion. Second, there are different levels of participation, with decision-making being complex and likely to be out of the hands of marginalised groups, but a 'community of practice' (Lave and Wenger, 1992) can potentially lead to a more bottom up approach to participation and collective action. Third, a posthuman perspective can build on multiple interdisciplinarity and employ aspects of the social model of disability in the UK, from the multiple perspectives of those who are labelled in this way. Finally, the relationship between disability studies and critical community psychology can provide an interdisciplinary and practical understanding of the causes of oppression, which can be a guide to take action or as a way of interrogating the problem space (Goodley and Lawthom, 2005a).

## **Key Words**

<b>Critical Community Psychology</b>	<b>Disability Studies</b>	<b>Health Promotion</b>	<b>Visual Methods</b>	<b>Learning Difficulties</b>
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To my dad, who I do not think really understands what I have achieved over the years and yet he has been the cornerstone to all that success. My success is symbolic of his hard work, dedication, unquestionable love and sacrifice.

## *In Memory*

In Memory of Greg Harewood (Joseph) who co-founded the project and contributed greatly to the continuous development of this research.

Greg played a big part in the development of projects post-Manpower too. A great, lovely, humorous man who will not be forgotten by me or his friends.



**Greg with little Robin at his first social gathering.**

## Table of contents

<b>Title page</b> .....	<b>1</b>
<b>Abstract</b> .....	<b>2</b>
<b>Acknowledgements</b> .....	<b>3</b>
<b>In memory</b> .....	<b>4</b>
<b>Table of contents</b> .....	<b>5</b>
<b>Prologue</b> .....	<b>9</b>
<b>Chapter 1 – Once upon a time</b> .....	<b>15</b>
1.1 Introduction .....	15
1.2 Beginning to reflect .....	16
1.3 Reminiscing and dreaming .....	18
1.4 Starting out as a critical community psychologist .....	19
1.5 Health promotion .....	24
1.6 Disability and health .....	25
1.7 Men’s health .....	28
1.8 The significance of the research .....	30
1.9 The research aim and objectives .....	31
1.10 Summary .....	32
<b>Chapter 2 – Situating the background: disability studies</b> .....	<b>34</b>
2.1 Introduction .....	34
2.2 Playing in the community .....	35
2.3 Psychology and disability – some of the problems .....	36
2.4 How do we come to understand the label of ‘learning difficulties’? .....	39
2.5 Normalisation .....	40
2.6 Social model of disability in the UK.....	42
2.7 Critical disability studies .....	46
2.8 Self-advocacy in the UK.....	48
2.9 Summary .....	51
<b>Chapter 3 – Situating the background: critical community psychology..</b> <b>52</b>	
3.1 Introduction .....	52
3.2 Watching Dad and listening to stories .....	53
3.3 Critical community psychology .....	54
3.4 Ecological metaphor .....	57
3.5 Interdisciplinarity .....	59
3.6 Change and resistance to change .....	60
3.7 Problems with critical community psychology .....	61
3.8 Critical community psychology and disability in austerity .....	63
3.9 Disability studies and critical community psychology – the connection ....	65
3.10 Summary .....	68
<b>Chapter 4 – Creating the story: approach</b> .....	<b>70</b>
4.1 Introduction .....	70
4.2 Scaffolding my own way to new knowledge and understanding .....	71
4.3 Structure of the thesis .....	73
4.4 Autoethnography – turning back to my story .....	75
4.5 Reflexive approaches – research story .....	78

4.6 Participatory approaches .....	80
4.7 Mapping the terrain .....	83
4.8 Summary .....	87
<b>Chapter 5 – Creating the story: tools .....</b>	<b>88</b>
5.1 Introduction .....	88
5.2 Having problems and making things work .....	89
5.3 Accessing the field - Springfields and members forum .....	90
5.4 Accessing the field - Galaxy .....	93
5.5 Getting to know the men and other stakeholders.....	97
5.5.1 The men .....	97
5.5.2 Volunteers .....	100
5.5.3 Organisational staff .....	101
5.6 Location of the project .....	102
5.7 Ethics – working with adults labelled with learning difficulties .....	102
5.8 Negotiating my role – the complexity of roles .....	105
5.9 Finding creative ways to participate .....	108
5.9.1 Photography .....	110
5.9.2 Arts (including drama, art and craft, sculpture) .....	111
5.10 Capturing the experiences and stories .....	112
5.11 Analysing the research findings .....	113
5.11.1 Thematic analysis .....	113
5.11.2 Narrative analysis .....	123
5.12 Sharing the story .....	127
5.13 Summary .....	127
<b>Cast list .....</b>	<b>129</b>
<b>Typical workshop vignette .....</b>	<b>131</b>
<b>Chapter 6 – Act one: making choices .....</b>	<b>132</b>
6.1 Introduction .....	132
6.2 Fighting for control and choice for myself .....	135
6.3 Making decisions about health .....	136
6.4 Individual choices .....	142
6.5 Workshop activity choices .....	149
6.6 Summary .....	153
<b>Chapter 7 – Act two: sharing knowledges .....</b>	<b>154</b>
7.1 Introduction .....	154
7.2 You're 'intelligent', a 'genius', 'knowledgeable' Michael .....	156
7.3 Knowledge of citizenship, equality and politics .....	157
7.4 Knowledge of the label of learning difficulties .....	161
7.5 Knowledge of daily and practical living .....	163
7.6 Knowledge of personal health .....	167
7.7 Knowledge about the self .....	171
7.8 Knowledge and sexuality .....	179
7.9 Summary .....	183

<b>Chapter 8 – Act three: participation .....</b>	<b>186</b>
8.1 Introduction .....	186
8.2 Developing my character and participation .....	188
8.3 Creating a group story .....	189
8.4 Art and participation .....	194
8.5 Participation and health promotion .....	196
8.6 Capturing the men’s journey – working together .....	200
8.7 Summary .....	205
<b>Chapter 9 – Soliloquies .....</b>	<b>207</b>
9.1 Introduction .....	207
9.2 Using soliloquies to focus the lens further on the data .....	208
9.3 Thinking to and with myself .....	210
9.4 The making of a project: how did we all feel at the beginning? .....	212
9.5 The first experiences: day one and beyond.....	217
9.6 Tensions – Winston being banned for life from Galaxy .....	225
9.7 Further tensions – location of the community exhibition and other issues .....	230
9.8 What did we all gain from this experience? .....	241
9.9 Summary .....	244
<b>Chapter 10 – Dénouement .....</b>	<b>248</b>
10.1 Introduction .....	248
10.2 Making sense of things .....	250
10.3 To have knowledge or not to have knowledge – that is the question .....	251
10.4 The merry men of Galaxy - creating a ‘community of practice’ together .....	256
10.5 How do we come to understand the label of learning difficulties? – A medical comedy of errors! .....	261
10.6 Disability studies and critical community psychology’s dénouement - measure for measure? .....	269
10.7 Were the aims and objectives achieved in this study? .....	274
10.8 Summary .....	277
<b>Chapter 11 – Sequel: what happened next? .....</b>	<b>279</b>
11.1 Introduction .....	279
11.2 The story coming to an end at Galaxy.....	280
11.3 Creative and participative advocacy - as they like it! .....	281
11.4 LGBTQ and the label of learning difficulty - much ado about our identity .....	283
11.5 Shall I compare intelligence to a creative way? .....	286
11.6 ‘The taming of the shrew’ - taking on psychology using the radio .....	288
11.7 Summary .....	292
<b>Epilogue .....</b>	<b>293</b>
<b>References .....</b>	<b>296</b>
<b>List of photographs, figures, tables, comic strips, scenes, vignettes and soliloquies .....</b>	<b>331</b>

Photographs .....	331
Figures .....	332
Tables .....	332
Comic Strips .....	332
Scenes .....	333
Vignettes .....	333
Soliloquies .....	333
<b>Appendices .....</b>	<b>335</b>
Appendix 1	
Member's forum questionnaire .....	335
Appendix 2	
Proposed structured timetable .....	339
Appendix 3	
Ethics form and consent form .....	340



## Prologue

***Pinocchio: Father, whatcha crying for?***

***Geppetto: Because... you're dead, Pinocchio.***

***Pinocchio: No! No, I'm not.***

***Geppetto: Yes. Yes, you are. Now, lie down...***

***Pinocchio: But father, I'm alive. See?***

***Pinocchio: And... and I'm... I'm real. I'm a real boy!***

***Geppetto: You're alive! And... and you are a real boy!***

***(Pinocchio, 1940 film, directed by Sharpsteen and Luske)***

During the making of this research project, unbeknown to me at the time, I was to become a dad. Robin was inside his mother's womb when the project that encompasses this thesis was taking place and we now often say how lovely it was that Robin was a part of the story of this project in his own little way, the beginning of Robin's story and a new story for me.

Not long after his birth, the first film we watched together was *'Pinocchio'* from 1940. The scene above reminded me of the emotions I experienced when the birth almost became a disaster, and the relief of finding out that he was alive after his heart had stopped beating. Watching Robin and his mother being dragged out of the room surrounded by about ten nurses, with blood everywhere, in a matter of minutes, was dramatic and felt impossible, everything around me seemed like it was in slow motion. Here I was in an empty room, alone, and not knowing what to do. I walked away and walked around the hospital, again still feeling like everything was in slow motion. I thought about what I would say in my 'death speech' to my family who were on their way, them not knowing about the dramatic turn of events. I was singing Welsh hymns and songs to myself, 'Cwm Rhondda', 'Men of Harlech', 'Calon Ian', waiting in hope, trying to keep positive, even reciting some old prayers in Latin, which I thought I had forgotten. Thankfully it ended in the best possible way, like it had for Pinocchio.

Seeing the film again was great because I always loved to watch this film when I was younger. I use to re-enact the film with my brother and sisters and the film reminded me of me and my own dad. My dad always looked and still looks like a granddad and behaved like one similar to Geppetto because he was always creating things from wood and was very caring. I was an over-enthusiastic little

boy like Pinocchio, always falling over, always trusting people and wanting to be good, in the way little Robin (little because he was named after my dad) is now, falling over, always asking 'why?' or 'what is it?' like Pinocchio. Although twenty-five years on, being a researcher, those questions have not really changed from when I was a little boy. Watching the film also reminded me of the mysticism of growing up, listening to stories and creating new ideas, which you might re-enact in the school playground or at home or like now, as is done in research.

As I started to write and think more about the write up of this thesis during this emotional and exciting time of new and old stories, these experiences also took me back to a presentation I witnessed from a fellow researcher from Sao Paulo University in Brazil. Junior Nadir spoke at a seminar some years ago at my university, about his work with the Brazil Landless Workers Movement, a social movement influenced by the works of Freire and his work on 'conscientisation' and critical pedagogy (see Freire, 1972). Junior Nadir spoke about what he called the '*mistica*', Portuguese for 'mystical'/'mysteries' for which he claimed there was no particular meaning and he refrained from trying to define '*misticas*', but provided examples of what misticas could be including spontaneous behaviour through speeches, performance, dance and prayers which evoked collective action. Junior Nadir suggested that misticas were a particular element in the construction of the workers movement in Brazil and that misticas were very different from the religious mysticism that it appropriates. Instead, the misticas of this social movement articulated discursive elements provided not only with religion, but also with politics to produce unique social bonds and collective action. From this work the people of this social movement encountered forms of social and political resistance through the use of misticas (Junior Nadir, 2005, also see Hammond, 2014).

What endeared me to the idea of misticas and still does (or at least my interpretation of what misticas mean), is how they convey spontaneity and free expression of thought and creativity, with no restrictions or control, similar to the way you would create a story or re-enact a story when you were a child. Although you might try to copy a story or scene, the story becomes your own version, constructed in your own way. Similarly, in this thesis, I want to tell the story of this research project through a mixture of the traditions of a story or play in my own way, so in using a story/play as a metaphor throughout. For example, this thesis has a prologue, beginning, middle and end, a sequel and an epilogue, which still corresponds with the traditions of an academic thesis (introduction, methodology,

analysis, discussion and conclusion). This thesis will not account for a social movement from which misticas emerged in Brazil and will not be accounting for misticas as such. However, the creative, surprising, spontaneous element of a mistica, like a Disney film story when you see it for the first time, will help bring the story of this thesis together as well as the plots, and creative surprises that emerged. A good story is one that keeps the reader engaged to make the reader want to know more about the story (Sykes and Gale, 2006) and telling a good story can be evocative and allows for creativity, which was what I aimed to do in this thesis by writing autoethnographically (Spry, 2001). I will also be working with multidisciplinary perspectives ranging from insights from ethnography (Anderson, 1989), disability studies (Oliver, 1990), critical community psychology (Kagan et al, 2011a), critical theory (Parker, 2007) and philosophy (Braidotti, 2013). Deleuze and Guattari (1994:5) described narrative forms and their thinking and creative processes in relation to philosophy:

Philosophy is the discipline that involves creating concepts ... the object of philosophy is to create concepts that are always new.

In this respect, the creative value of a narrative exists in the narrative's ability to represent the fluidity and multiple meanings that accompanies any story, which makes creating concepts new (Sykes and Gale, 2006). The underlying themes of the framework that makes this story include participation, the sharing of knowledge and experience and making choices using methods such as, drama, debate as well as arts and craft to re-create stories, and express feelings. These themes connect to the research aims and research objectives and influences the subsequent titles of the chapters in this thesis to come.

The aim of this research was to explore the experiences of a group of men, labelled with learning difficulties, in participating in a health promotion project. The project involved forty-five workshops engaging the men in creative and visual activities, which took place in a museum in the North West of England from January 2011 up until February 2012. The research originated from a partnership between Galaxy (a museum) and Springfields (a learning difficulties charity). The project ended with a six-month community exhibition at Galaxy that displayed the work of the men including the presentation of films, art, poetry, sculpture and a giant comic strip. Three research objectives were set out to meet this aim:

1. *To explore the experiences of the men labelled with learning difficulties participating in a group centred around creative activities formed to promote health awareness.*
2. *To collaborate with a group of men labelled as having learning difficulties in understanding how labels are constructed and understood.*
3. *To develop a new understanding of the ways in which a critical community psychology and disability studies perspective can be utilised for men labelled with learning difficulties.*

Due to the contested nature of what is or is not a 'learning difficulty', I refer throughout this research to this as a 'label of learning difficulty' and from the outset, I consider it to be a social construction that is context specific<sup>1</sup> (Higgins et al, 2002; Boxall et al, 2004; Goodley, 2011). I will also consider 'disability' in general as a label in parts because there are overlaps with labels of 'impairment' and 'disability' with the label of 'learning difficulties', acknowledging the contested nature of what being dis/abled means (see Goodley and Runswick-Cole, 2014), but will focus mostly on the label of 'learning difficulties' throughout. In addition, in relation to the development of this thesis, the selection of the literature, research and studies was carried out by using manual library and electronic database searches. The searches were informed by the placing of the research in the global North, which fitted in with the location of the research rather than ignoring contributions from the global South. I will now provide a brief outline of what each chapter will consider:

Chapter one, *Once upon a time*, is the introduction into the story of this thesis which will begin with considering my personal and professional experiences. These experiences have influenced the making of this research story and some of

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<sup>1</sup> Other labels could include 'learning disabilities' and 'intellectual disabilities', which are used widely in medical contexts and by charities. The label often referring to someone with cognitive impairments (see Goodley and Runswick-Cole, 2014). This research prefers to focus on the construction of these labels and the influence of context, hence why I consider it as a label of disability/learning difficulties. Although I am aware that some people do not want any label and some celebrate their label of disability/learning difficulties.

the decision making that occurred during the project's development. I will discuss literature related to health promotion, disability and men's health.

Chapter two, *Situating the background: disability studies*, here I draw on existing interdisciplinary research and theory to contextualise and situate the central concepts that I explore within this research. Specifically, I will consider a brief history of the label 'learning difficulties' and the development of the social model of disability in the UK and introduce the ideas behind 'critical disability studies'.

Chapter three, *Situating the background: critical community psychology*, here I draw on existing interdisciplinary research and theory to contextualise and situate the central concepts that I explore within this research, particularly in relation to critical community psychology. Specifically, I will consider the ecological model and value-laden approach of critical community psychology and then go on to review the connections between critical community psychology and disability studies.

Chapter four, *Creating the story: approach*, here I discuss the methodology that was used to create the project and story. I will explain why I have applied a Freytagian (1863) play structure to the structure of this thesis and will consider the autoethnographic and reflexive nature of this thesis as well as connect to the participatory approaches that I adopted in this research. Finally, I will consider the philosophical location of this research.

Chapter five, *Creating the story: settings and tools*, here I discuss the setting of this research and the creative methods that were used throughout the project. I will consider the ethical implications in working with adults labelled with learning difficulties and will consider the analyses that will be applied to the data collected (including thematic analysis and narrative analysis).

Chapter six, *Act one: making choices*, here I will begin to analyse the story, which emerged from the thematic analysis concerning the theme 'making choices'.

Chapter seven, *Act two: sharing knowledges*, here I will analyse the story, which emerged from the thematic analysis concerning the theme 'sharing knowledges'.

Chapter eight, *Act three: participation*, here I will analyse the story, which emerged from the thematic analysis concerning the theme 'participation'.

Chapter nine, *Soliloquies*, here I will explore the thinking and feelings from the perspective of a person from the four main protagonists in this thesis including me (the researcher), Stephen (pseudonyms are used throughout) one of the men, Janet (community worker) from Galaxy and George (development worker) from Springfields. I will write in the form of fictional, self-addressed soliloquies, which will provide some insight into the effects this research/story had on each of us and will interpret these soliloquies to make sense of the research journey for everyone.

Chapter ten, *Dénouement*, this a theatrical word in a play, which literary means 'untying the knots', in other words, this chapter will try to make sense of what the story of this project means in relation to research and theory and therefore will provide my contribution to knowledge. This chapter will consider whether the aim and objectives were achieved.

Chapter eleven, *Sequel - what happened next?*, will describe some of the events and activities that took place stemming from the research project including, the production of radio shows, lectures and the training the men delivered to aspiring volunteers.

*Epilogue*, this will be a short reflexive piece that reflects on my feelings as the project and thesis came to an end.

## Chapter 1 – Once upon a time ...

***‘Who are better prepared than the oppressed to understand the terrible significance of an oppressive society? Who suffer the effects of oppression more than the oppressed? Who can better understand the necessity of liberation?’ (Freire, 1972: 27).***

***‘Liberation is thus a childbirth, and a painful one’ (Freire, 1972:253).***

### 1.1 Introduction

In the prologue, I started my story by reflecting on my memories of Robin’s difficult birth and the relationship between me, Robin and my own dad, the birth coinciding with the making of this thesis. In keeping with the story/play metaphor, in this chapter I begin to take this thesis forward by beginning to give an account of how the story of this thesis came together. I will reflect back on what led me to the creation of this story and I will consider some of the literature on, health promotion, disability and men’s health. Men’s health promotion formed a substantial part of my community work both directly and indirectly leading up to the development of this research project and beyond. Here I will consider some of these experiences and in particular with relation to my work with young men, on issues to do with ‘health promotion’. Although I will not be addressing other experiences specifically in detail that may have influenced this thesis (directly or indirectly), it is worth noting that I also facilitated another men’s group at a local organisation for men with alcohol and drug problems. I also volunteered with other projects working with men including arts based and mental health projects. In addition, I worked as a lone worker with young people (aged 16-17 years) in a care home, supporting them into getting their own accommodation during the making of this thesis.

The quotes from Freire (1972) above have helped me to reflect on the purpose of this research. The questions he posed above related to the aim of this thesis, suggested that oppressed people, such as those labelled with learning difficulties (male participants in this research), are in a better position to understand their own oppression by society and are the ones who know how they want to be liberated from oppression. This reminds me that although the story of this research is about me, in that I am writing this thesis essentially from my own perspective and interpretations, the characters in this story who will emerge are also central to the

making of the story. The oppression that the men labelled with learning difficulties faced in this story and beyond and, why this happens, is what motivates me in the making of the story. However, Freire's second quote further reminds me that 'change' or challenging the status quo is often difficult, particularly for those who are oppressed. At times, working in the community has been a *'painful one'*, for me and the people I collaborated with. However, so has my own personal story at times, but *'who can better understand the necessity of liberation ... than the oppressed'*, therefore through the dialogue I present in this thesis, I hope these stories are worth re-telling to fully understand the aim and objectives and furthermore the purpose of this research.

## **1.2 Beginning to reflect**

The aim of this research was to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. Hence, the concepts of 'health promotion' and 'men's health' for men labelled with learning difficulties are central concepts to this thesis. The choice of topic for this research was influenced by my personal and professional experiences over the last seven years with marginalised young people and adults in central Bromhead (pseudonym, see chapter five for more details on Bromhead, page 102). This is a city comprising some of the most socio-economically deprived areas in the UK. In this chapter I provide some explanation of my professional experiences, in relation to 'health promotion' and 'men's health' and begin to link these experiences with research concerning people labelled with disabilities, and specifically consider research regarding the label of learning difficulties. This will provide some context and anchor the reflexive approach that underpins this research. To begin exploring these stories from the past, I felt I needed to reflect on my previous work in the community and reflect on my own identity to provide a rich context to this research. In relation to reflexivity, Hardy et al (2001:531) stated that:

Reflexivity involves reflecting on the way in which research is carried out and understanding how the process of doing research shapes its outcomes.

In other words, evaluating and thinking about how actions do or do not work and, how they could be better during the research process was important. For me, this



was central to this thesis, to give the research every chance to be successful and to achieve the research's aim and objectives. In addition, despite reflexivity being a contested term (Gough, 2003), Finlay and Gough (2003:14) suggest that:

Reflexivity requires critical self-reflection of the ways in which researchers' social background, assumptions, positioning and behaviour impact on the research process ... reflexivity both challenges treasured research traditions and is challenging to apply in practice.

Thus, to be able to critically self-reflect, I needed to reach back into my past to re-understand who I am and this has influenced the framework of the story (Noy, 2003; McAdams, 2006) by writing autoethnographically (Berger, 2001; Ellis and Rawicki, 2013; Speedy, 2013). By doing so, it has helped me to challenge the traditions of research to an extent, particularly in psychology, in which disability writers have emphasised that psychology has contributed to the exclusion of people labelled with disabilities through pathologising and individualising (Oliver, 1990; Finkelstein and French, 1993; Shakespeare and Watson, 1997; Goodley and Lawthom, 2005a; Ryan and Runswick-Cole, 2008). The challenges I have faced working in the community as well as my personal motivations and interests have influenced this research (directly or indirectly), and although this research story is linear, in that it is framed in the traditions of a story i.e. a beginning, middle and end, the development, practice and reflexivity of the study is fluid and complex.

Hence through writing personal narratives a conceptual and emotional space can be opened between expected phenomenological and existential personal experiences (Hanauer, 2003). Therefore, writing personal narratives by the author/researcher (me) can be a form of research inquiry (Richardson, 2000) and allows the writing of personal stories to ensure that witnessing is possible (Ellis et al, 2010). In turn, this allows 'participants and readers to observe and, consequently, better testify on behalf of an event, problem or experience' (Hanauer, 2012:6). Writing about aspects of my own life has helped me to be a witness to my own life and to be able to explore the complexities of personal experience alongside the making of this research and by doing so I present these experiences to the reader for observation. Thus, before I consider some of the work I facilitated in the community (prior to this research), and how this has

influenced the present research, I want to start to unpack my identity, to some extent, and by going back in time I will continue to take this approach throughout this thesis.

### 1.3 Reminiscing and dreaming

When I was a child, I was known for having two identities, two identities that remain the cornerstone for how I am known today. Firstly, my pride for my Welsh identity and being the son of an ex-miner from Blaenafon, Gwent. This town now being a world heritage site famous for its mining history. Secondly, for my passion and love of learning. For instance, when I was ten years old, I became obsessed with the identity of an old great uncle of mine, a Roman Catholic priest in Canada. Despite coming from an impoverished background, he had been to grammar school, educated at Melbourne University in Australia and got his PhD at the University of Oxford at Pembroke College. I have only met him on two occasions in my life, many years ago, but always remember all the titles he had gained through his education and his journeys in lecturing around the world, in Australia, South Africa and North America. I also remember a present he gave me, a badge of Pembroke College, which felt like I had been given a piece of gold at the time. I too wanted these things (particularly the titles), which I thought looked so regal against my name as I used to write my name down on paper pretending I had these titles, *Professor, Doctor Michael Richards BSc MSc* and any other educational title I could think of I added on. These titles made me feel dignified and powerful at that young age, which was probably influenced by the importance my family placed on 'intelligence' and 'being clever' and, that by having these titles it was symbolic of 'intelligence'. There grew an expectation in the family that I would follow in my uncle's footsteps and even become a priest.

However, twenty years on, I very rarely refer to my titles and I am far removed from the conservatism of Roman Catholicism. In fact, I even published a poetry collection, *'Misfeasance'* (Richards, 2013), that parodies the functioning of Roman Catholicism and Canon law<sup>2</sup> and reflects on the well-published stories of abuse and the clergy. However, despite this rebellion towards my conservative past, the

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<sup>2</sup> Canon law is a body of laws and regulations made by the church leadership of a Christian organisation, in this instance being the Roman Catholic Church.

passion for learning and knowledge and sharing that knowledge has always remained. Although twenty years ago I did not know I would do a couple of degrees or a PhD in psychology, the decision to study psychology and critical community psychology have played a part in developing my ideas and, to an extent, directed me towards the type of story/study I have developed in this thesis (See chapter four, page 75 for my review on the justification of using 'autoethnography' in this thesis). Next I will consider some of the more recent influences that have contributed to the making of this story in this thesis and to the beginning of my journey as a critical community psychologist.

#### **1.4 Starting out as a critical community psychologist**

Completing my first degree in 2008 was like winning a world title for me, a genuine ambition and a dream come true. This success still brings a smile to my face after what seemed so long to complete, a lifelong ambition. Equally, I felt the same when I received my Master's degree a year later (in community psychology), but it was also during this time that I started to lay the foundations, looking towards an academic career, within critical community psychology. Critical community psychology is a disciplinary field which has developed in Manchester and Manchester Metropolitan University over the past thirty years (Kagan et al, 2011a), with values of 'community', 'justice' and 'stewardship' at the heart of its philosophy (Kagan, 2007a and 2007b – critical community psychology will be discussed in more detail in chapter three, page 54). My interest grew in critical community psychology as a response to my frustrations with psychology. For example, I was troubled by the way a forensic psychologist might psychopathologically analyse a 'criminal' rather than consider the 'criminal's' context or how a cognitive psychologist analyses 'thinking' in terms of structural thought patterns instead of considering the broader, complex nature of thinking with people coming from different contexts and backgrounds. Shealy (2005: 83) summed up some of the problems with psychology:

One of the problems for psychology is that we have yet to figure out how to integrate 'science' and 'humanism' in a way that is credible, recognisable, and compelling. Instead, the scientific theories we create, studies we construct, analyses we conduct, and findings we report are too often too far

removed from whatever human phenomena they are designed to explain, predict, or control.

In other words, there are parts of psychology that generally seem to ignore thinking about the effects of contexts on people. In addition, mainstream psychology has continued to focus on the individual level of analysis (Orford, 1992; Smail, 1993; Danziger, 1994). For example, neuropsychologists may consider brain structures and forensic psychologists may focus on psychopathology. In fact, most theories of personality emphasise individualistic perspectives of behaviour, focusing on medical diagnosis or one-to-one psychotherapy or counselling (Richards, 2011). Furthermore, with the worldwide economic collapse (in 2008), my awareness was enhanced further in terms of the place in society for marginalised groups. Simply the same people and groups will suffer the most during times of economic difficulties including the unemployed (Gallie et al, 2003), ethnic minorities (Nazroo, 1998) and women (Women's Budget Group, 2008). Therefore being introduced to critical community psychology in my third year of my psychology degree proved to be an important moment for me. Critical community psychology did not just help to begin my academic journey in being a critical community psychologist, with the privilege of teaching at universities, publishing (Kagan et al, 2011b; Lawthom et al, 2012) and working with many community projects. The ideas and practices behind critical community psychology gave me a new lease of life in how I felt about psychology and how psychology could work for the better for marginalised groups.

One of the main pieces of work I was involved with early on in my critical community psychology career was funded by a local authority in Bromhead (a city in the North West of England), to work specifically with young men aged 13 – 25 years on issues relating to identity and health. The main aim was to contribute to initiatives that aimed to reduce teenage pregnancy rates in the city of Bromhead, within the most socially and economically deprived areas of Bromhead. Funding was made available for this project in response to the UK having some of the highest teenage birth rates in Europe (Avery and Lazdane, 2008) and Bromhead has one of highest rates in the UK. High levels of teenage pregnancy can be attributed to many things including poverty, incomplete education and peer pressure (Kagan et al, 2011b). Equally, Bromhead is one of the most socially deprived districts in England (Talukder and Frost, 2008), where educational

attainment is low and work prospects are limited. Specifically white working class young men (the group I was commissioned to target), are the most persistent low educational achievers compared to other ethnic groups and women (Cassen and Kingdon, 2007). My work involved working with these young men in creating programmes of activity in community projects, schools and colleges, in which I would facilitate discussion and debate on the contextual issues relating to teenage pregnancy such as gender inequality. I also facilitated discussion on contraception and sexually transmitted infections, and how to prevent catching these infections and avoiding unwanted pregnancies. My personal aim was not to simply just hand out condoms (which was an expectation by the funders), but to facilitate young men into thinking critically (Freire, 1972; Kagan, 2011b), about issues connected to decision making in relation to sex such as identity, fatherhood, equality and diversity issues and sexuality. Below is a vignette that captures one type of workshop I facilitated with young men on the theme of 'fatherhood':

*John was a 16 year old male, who was unemployed and sat in his room all night playing on video games and slept for most of the day. He smelt of the sweet smell that comes from someone who had not washed himself or his clothes for some time and probably slept in the clothes he wore during the day. He was constantly encouraged to seek employment training to get into employment by his family, but always missed his appointments. He did not see the point of getting up and doing anything. He was finally convinced to get up during the day, to stop his family from nagging him, but just getting out of bed and having a wash was hard work. Since the courts prevented him from seeing his daughter, he found it hard to get into a regular routine. He continued to smoke spliffs and drink alcohol, when he could get it, of which the courts disapproved and the courts demanded that he should change his ways to be a better role model to his daughter if he wanted to see his daughter.*

*One aspect of the training John participated within, usually set in a community/training room, involved participating in debates and discussions about 'fatherhood'. This activity involved working with a group of young men from a similar poor socio-economic background, to talk about the meaning of 'fatherhood'. However, John was not really into talking about his emotions and expressing his opinion. He just wanted to get home and get onto the next level of his new game he borrowed from a friend. Eventually he was convinced to start talking about his views on fatherhood. Seeing as everyone else was starting to talk about it, he*

*thought he would. The other men seemed comfortable doing it, so he thought he could do the same.*

*John talked about the importance of fatherhood to him and how much he loved the daughter he could not see. He talked about what made a good and bad dad in relation to his own dad who he had not seen since he was five years old. He did not want to have a non-existent relationship with his daughter like he had had with his dad. He considered the importance of fatherhood and the effects a good and bad father might have on children. You could see tears in his eyes and there was a deadly silence in the room. It was clear that John's story had touched the other young men's hearts, hearts these young men normally keep hidden away.*

*There were different responses to this session from the group and John. Some young men felt uncomfortable talking about the negative experiences of fatherhood, while other seemed to use it as a chance to cathartically express their positive and negative experiences. It was particularly poignant in some sessions when some young men expressed their feelings following their partners' miscarriage or abortion. The group listened attentively and showed support by offering a cigarette at the break or swapping numbers to go out. John attended now and again thereafter, which was his choice, but when he came, he came because he felt that in this safe space he could express himself and talk about his identity.*

**Vignette 1 – An example of how a workshop generally worked with the young men I worked with in the community.**

For me, the story of this vignette, similar to many other stories in my work with young people, were special moments because these young men are often labelled as 'troublemakers' or 'hooligans', yet when the chance arose and they felt comfortable within the context they were in, the young men would express their feelings and even cry. The above vignette is an example of a workshop in which the young men talked openly about their experiences with people listening. Despite the positivity that emerged from my work with young men such as witnessing the young men 'opening up' about their feelings, forming long term relationships with them was difficult for me because of the restraints that came with funding, I was only allocated a certain amount of time to work with young people in different projects. In addition, I was caught between working as a critical community psychology practitioner and as a youth worker, each with its own value

base and ideology. For example, 'youth work' can be understood as activities that seek to impact *upon* young people (Smith, 2003). On the other hand, the focus of critical community psychology is on working *with* people in their social contexts with power and empowerment being central themes (Orford, 1992; Kagan et al, 2011a). Of course, the aim to reduce teenage pregnancies was difficult to achieve and is a contested aim because the issue of 'teenage pregnancy' is a complex phenomenon that needs a more complex solution than informal education with young men. In other words, just handing out condoms and talking about sexually transmitted infections was simply not enough, but more deeper critical awareness and the building of dialogical relationships (Freire, 1972) was the aim to understand the deeper contexts and complexities of being a young man.

One of the issues that constantly emerged in my work with young people was the labels that were attached to them that did not always make sense to me. In other words, the meaning of labels given to young people by professionals or their families did not match with how they behaved, in my view. For example, so many of the young men I worked with had been diagnosed with some form of autism, often Asperger Syndrome (Wheeler, 2011; Bertilsdotter-Rosqvist, 2012). In some cases, from the descriptions provided by community workers, the label of autism was attached because a young person was constantly shouting loud or a young person was always quiet. I could not understand why shouting loud or being too quiet should be considered wrong or a problem, but with some of my professional colleagues these attributes were considered an 'issue' or 'problem' for which they never gave any reasoned explanation other than a diagnosis they had read in a book. Furthermore, other professionals I worked with on occasions gave some of these young men a 'diagnosis' even if they had not met the young man/men I was working with. This sometimes occurred in team meetings and particularly with social workers and student social workers. Once, I witnessed a qualified social worker make a 'diagnosis', a judgment, based on a page from Wikipedia on autism to a young man who had started taking drugs. This kind of example made me frustrated about the label of 'learning difficulty' because fundamentally what was being ignored was the skills, talents and aspirations the young men had and it seemed to me that the problem was contextual, not the young man/men themselves.

Accordingly, with my interests and experiences in health promotion and men and the growing interest in how easily people were labelled, the ideas for this

thesis started to emerge. Having worked with so many young men throughout Bromhead at the time, I personally wanted to explore if what I was finding with young men was the same with adult men and the label of learning difficulties. With this in mind I want to now start to explore the connections between health and disability before considering more specifically men's health and learning difficulties, but first, I want to explore briefly, in the next section, what is meant by the term 'health promotion'.

## **1.5 Health promotion**

According to the World Health Organisation (1986:73), health promotion can be defined as a:

Unifying concept for those who recognise the need for change in the ways and conditions of living ... a mediating strategy between people and their environments synthesising personal choice and social responsibility.

This elucidates that it is not just lifestyle factors of an individual that needs to be considered, but health promotion goes beyond that and also means living conditions, environmental and financial factors, in other words, the contexts in which people live in. Naidoo and Wills (1998) suggested that health promotion refers to activities that help to prevent infections, diseases and improve health and well-being, which again alludes to the importance of the influence of contextual factors in helping to improve health and well-being. However, Epp (1986) considered that some people have unequal chances of achieving 'improved' health and well-being because health is often related to contextual and environmental factors, which can be alienating for some e.g. people labelled with disabilities. But how does health promotion work?

In relation to disability, there have been attempts to use a variety of methods to promote health and well-being in health promotion work. Researchers have used poetry recalling autobiographical accounts (Atkinson and Walmsley, 1999; also see Koppers, 2008), photography (Booth and Booth, 2003; Aldridge, 2007), film (Rojasl and Sanahuja, 2012) and arts (Carawan and Nalavany, 2010) to promote health and well-being with people labelled with disabilities. However, despite these interventions appearing to be engaging, fun and interactive, people labelled with



disabilities still experience health inequalities to a greater extent than the general population. This may contribute to premature death and chronic ill health (Durvasula et al, 2002; NHS Health Scotland, 2004; Emerson and Hatton, 2008, 2010). In the next section, I will discuss this further, with reference to disability and health.

## **1.6 Disability and health**

Despite there being a plethora of evidence showing that health promotion interventions including physical activities may be beneficial for people labelled with disabilities (Durstine, 2000; Allen, 2004; Rimmer, 2004; Fragala-Pinkham et al, 2006; Mead et al, 2008), health promotion activities still infrequently target people labelled with disabilities and so they experience numerous barriers to participation. For example, limited access to health promotion resources for people with physical impairments such as multiple sclerosis (Becker and Stuijbergen, 2004), stroke and poliomyelitis (Rimmer et al, 2008) and learning difficulties and mental health problems (See 'Equality treatment: closing the gap' report, 2008). Additionally, people labelled with disabilities can expect to find barriers in relation to health service providers' attitudes, knowledge and skills that ensure health practices are in conflict (although they may not realise that they are and should not be) with the rights of people labelled with disabilities (Alborz et al, 2004; Disability Rights Commission, 2006; also see World Report on Disability at World Health Organisation and World Bank, 2011). Therefore people labelled with disabilities may be hesitant to seek health care because of experiences of stigmatisation and discrimination.

Moreover, the socio-economic context to this thesis means that during these times of austerity and welfare cuts, Emerson and Hatton (2008a) predicted an increase in the number of adults labelled with learning difficulties known to services from 15% during 2001-2011 and up to 20% over the two decades 2001-2021. This is a serious concern considering social deprivation is seen as a major contributor to health inequalities (Wilkinson and Pickett, 2009), particularly for people labelled with learning difficulties who are at the highest risk of poverty:

The lack of health promotion, service access and equal treatment were also cited as significant barriers. Disabled people identified fear and mistrust,

limited access to general practice lists, difficulty negotiating appointment systems, inaccessible information, poor communication and diagnostic overshadowing. Service providers identified issues such as fear, ignorance and inadequate training (World Health Organisation and World Bank, World Report on Disability, 2011:77).

Consequently, this suggests that negative implications of health inequality for people labelled with disabilities are strongly related to context and not the individual. However, Emerson and Baines (2010:3) put it in simple terms concerning the health of people labelled with learning difficulties specifically that:

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable.

If poor health is avoidable for people labelled with learning difficulties, then the health issues people labelled with learning difficulties face must lie within the surrounding contexts including the care homes, the family households, hospitals and other similar places in which people labelled with learning difficulties live.

Furthermore, a recurrent problem for people labelled with disabilities is their experiences of institutionalisation or involuntary treatment as well as abuse and neglect (Carlson et al, 2012), these examples being contextual. For example, a public funded hospital, Winterbourne View, based in Gloucester, in 2011, was subject to criminal investigation and was found to be subjecting people, labelled with learning difficulties, to physical and psychological abuse. A serious case review was commissioned and Mencap published a report that warned of similar abuse going on in other places caring for people labelled with learning difficulties (Mencap, 2014), highlighting that the problems lay not with the people labelled with learning difficulties, but with the people who care for them and the failing care system.

Connected to this are the more intricate examples of adverse experience in the health system such as instances of inconsideration, which have resulted in a distrust of health providers, subsequently leading to people labelled with disabilities not wanting to seek care and rely upon self-diagnosis and treatment (Van Loon et al, 2005; Drainoni, 2006). For example, attitudes among health care providers remain barriers to health care for people labelled with disabilities

(McColl, 2008) such as some health care providers (i.e. workers in care homes) feeling uncomfortable about 'treating' people labelled with disabilities (Aulagnier, 2005) and decision-making may be influenced by negative assumptions, learned from their own personal contexts. For instance, the common misconception that people with labelled disabilities are not sexually active often leads health professionals to fail to offer sexual health services (Kroll and Neri, 2003; Nosek and Simmons, 2007). Likewise, health care workers can lack adequate skills associated with the label of disabilities and how to effectively manage the health care needs of people labelled with disabilities (Kroll and Neri, 2003; Morrison and Mosqueda, 2008). Therefore, service providers may be uncertain on how to confront the health needs directly related to a disability, resulting in misunderstanding the need for comprehensive health care services (Scheer et al, 2003).

The report 'Equal treatment: closing the gap' (2008) by the Disability Rights Commission in the UK, investigated premature deaths among people labelled with learning difficulties and reports of unequal access to health care in 2004-2006. The study found that people with labels of learning difficulty such as autism had more chronic health conditions than the general population such as diabetes and heart disease as well as high rates of respiratory disease. Similarly, people labelled with disabilities in general also developed chronic health conditions at a younger age than other people and die sooner following diagnosis. Thus, the health of people with labels of learning difficulty and disability in general is in a poor way. In fact, health inequalities faced by people labelled with learning difficulties specifically in the UK start early in life (Kerr et al, 2005; Emerson and Hatton, 2008) and result to an extent, from barriers they face in accessing effective health care (Mencap: Death by Indifference, 2007; Valuing People Now: From Progress to Transformation, 2007). For example, in 2013, Connor Sparrowhawk who was labelled with learning difficulties was admitted to the Slade House Assessment and Treatment Unit run by Southern Health NHS Foundation Trust. 107 days later, he drowned in a bath and died a death that was preventable (#107 Days of Action Campaign, 2014). As Walmsley (2004:55) stated:

Health issues for people with learning disabilities have been a neglected area, despite earlier initiatives in England and Wales to focus energy and attention.

With respect to this, there is a need to educate and support people to manage their health because education and support may help to improve the likelihood of healthy outcomes (Wagner et al, 2005; Lorig et al, 2006; Meng, 2007). This could result in supporting people labelled with learning difficulties to negotiate the health system effectively and they are then more likely to generally be more satisfied with their care (Leveille, 2009). However, with the story looking depressing in terms of people labelled with disabilities being able to control their own choices concerning health promotion, it is clearly difficult to challenge and celebrate the knowledge people labelled with disabilities have to share about health because of the restrictions discussed so far in this chapter.

This section has identified the significance of health promotion and about health 'treatment' and the problems with it in relation to people labelled disabilities in general. Essentially, the study of health promotion and disability (particularly for people labelled with learning difficulties) have been ignored in these debates. My other main interest in the making of this thesis is men's health and identity, stemming from my work with young people. Although the study of men's health has increased in the past decade (Ruxton, 2004), the study of men's health and the label of disability is not as developed. Despite some work such as Redley et al's (2012) work on healthcare for men in understanding inequalities to access and Inglis and French's (2012) work on men labelled with learning difficulties doing research (also see Inglis, 2012, 2013), there is limited research on men labelled with learning difficulties and health promotion. Next, I start to consider men's health and start to link this with the label of learning difficulties.

## **1.7 Men's health**

Health is difficult to define because it can be seen as a '*multifaceted dimension of human life*' (Blaxter, 2003:1; 2004). Therefore, 'health' is complex and diverse to different people. However, the health of people with labelled with disabilities is much more complex. For instance, according to the World Report on Disability (2011:32) 'the relationship between health conditions and disabilities is complicated ... [because health is both] interacting with contextual factors ... personal and environmental'.

Similarly the study of men's health is complicated. For example, the health problems described in the 'The State of Men's Health in Europe' report (European Commission Directorate-General for Health and Consumers, 2011) have been attributed to men's tendency towards unhealthy behaviour (Faramond, 2011). Examples of this behaviour include, higher rates of drug-use, smoking and drinking alcohol (Courtenay, 2000). Furthermore, men visit the doctors less than women (Stoverinck et al, 1996); men may also be less likely to seek help for psychological problems such as depression (Ussher, 1991) and may also need reassurances to seek help from family members (Norcross et al, 1996). Hence there seems to be a gendered dimension to lifestyle choices, with men at higher risk of poor health than women, which needs to be 'considered within the context of economic, social, environmental and cultural factors' (The State of Men's Health in Europe' report, 2011:8). Nevertheless, I feel that these indicators are focused too much on 'men' or individual 'men' when really the authors are in fact highlighting that these examples indicate a need to move beyond medicine and individualism, with the need to focus more on surrounding contexts to go some way in challenging men's attitudes towards their health.

However, a major problem for me with 'The State of Men's Health in Europe' report (2011), is that it did not focus on disability at all in relation to men's health. This is a concern with an ageing male population and a likely increase in people labelled with learning difficulties to come (Emerson and Hatton, 2008a). Despite it being considered a landmark report on men's health, the research talks about men in general and not the specific circumstances of men from different groups. On the other hand, the report goes on to say that in every country in all European Union states, men in poor social conditions are less likely to take exercise, be obese, smoke and drink alcohol more as well as eat less healthily. Thus, according to 'The State of Men's Health in Europe' report (2011:10), a better understanding of men's health is important for two main reasons:

1. The need for the male population to be as 'fit and able as possible'.
2. Tied to the values of equality and equity because many men have lives that are blighted through a collective lack of awareness and action on problems they face.

By acknowledging this, the report should also refer to men labelled with learning difficulties or/and disabilities in general, to be inclusive of all groups, but does not do so. Putting this alongside the problems associated with men's health, the issue becomes a bigger problem. The problems predominately lie not in the genetic makeup of an individual, but in the surrounding contexts of people labelled with disabilities. In the next section, I consider why this research is both relevant and significant.

## **1.8 The significance of this research**

In undertaking this doctoral thesis, I intended to contribute to research concerning the label of disability, but specifically in relation to the labels of learning difficulties and health promotion centred on a group of adult men labelled with learning difficulties. As I will explore in chapter two (page 34), there is existing empirically based literature on what learning difficulties means and in chapter three (page 52) what a critical community psychology approach concerns, which have helped me to form my arguments and the research's contribution to knowledge. In addition there is established research published by critical community psychologists or similarly connected researchers in relation to disability (Goodley and Lawthom, 2005a; Goodley and Lawthom, 2005b; Kagan et al, 2011a). However, the inter-connection between disability studies and critical community psychology is limited and there is limited work on considering men labelled with learning difficulties and health promotion. I argue that this research is of current policy relevance with its exploration of the experiences of people (men in this thesis) labelled with learning difficulties in times of austerity during the current Conservative-led Coalition government (Phillimore et al, 2010). While literature exists on men's health (see Branney, 2012), health promotion (see World Report on Disability, 2011) and learning difficulties (see Chappell, 1993 and Chappell et al, 2000), there does not include a detailed discussion of the experiences of people labelled with learning difficulties with men's health, and also health promotion as an entity drawing on a critical community psychology and disability studies approach.

My research aimed to provide a rich and contextualised account of the men's participation in the development of forty-five workshops throughout 2011. Through the qualitative, participatory approaches (see chapter four, page 89) I adopted and

applied in this thesis, I wanted to uncover the ways in which the men demonstrated their understanding of health promotion using visual methods such as art, drama, poetry, sculpture and photography. This is in contrast to previous research that has explored these concepts quantitatively (see Geary et al, 2012; Peng and Fuchs, 2014) or used qualitative methods that are mainly interview based (see Heslop et al, 2013).

Writing this thesis and using a 'story/play' as a metaphor has helped me to be reflexive throughout but writing and thinking this way has also helped me to highlight the complexity and messiness of working in the community, which often surrounds people labelled with learning difficulties (See Llewellynn, 2009). In this research, the story of the 'messy nature' of working collaboratively with organisations to facilitate activities with men labelled with learning difficulties will be narrated and explained. D'Cruz et al (2007) suggested that there is a lack of clarity about the concept of 'reflexivity' in terms of who is being exhorted to be 'reflexive', when and how. However, I believe that reflecting on myself and connecting myself to the development of this story will provide clarity and turning back and re-anchoring myself in how I have developed, helping the story make sense to the reader. In the next section, I re-state the aims and objectives of this research.

### **1.9 The research aim and objectives**

The aim of this research was to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. Three research objectives were set out to meet this aim:

- 1. To explore the experiences of the men labelled with learning difficulties, participating in a group centred around creative activities formed to promote health awareness.*
- 2. To collaborate with a group of men labelled as having learning difficulties in understanding how labels are constructed and understood.*

*3. To develop a new understanding of the ways in which a critical community psychology and disability studies perspective can be utilised for men labelled with learning difficulties.*

I met the aim and objectives of this research in the following ways:

*1. Explores the experiences of the men who participated in forty-five workshops in 2011 that centred on activities such as drama, art, photography and poetry to consider health promotion.*

*2. Explores what meanings the men applied to the label of 'learning difficulties' and how the men considered the label to be constructed, evoked through their experiences and stories evoked by different activities.*

*3. Develops a new understanding of critical community psychology and disability studies through the integration of the literature and data that emerged from this thesis, to contribute knowledge to the respective fields.*

## **1.10 Summary**

In this chapter, I have located myself back in time by reflecting on some of the influences from the past that have had an effect on the beginnings of the story of this thesis. I considered to some extent, the professional and personal experiences that have affected me, and in particular to health promotion and men's health with my work with young men. I have discussed some of the problems and successes that emerged from my experiences of working in the community with marginalised groups. In addition, I also explored health inequalities that exist for people labelled with disabilities and discussed evidence that places the problems people labelled with disabilities/learning difficulties face as being contextual. I considered men's health and made the connection between the poor state of men's health alongside the poor state of health for people labelled with disabilities. I outlined the importance of this research and its relevance, which connects to the research aim and objectives. In the next two chapters, I consider the main theoretical roots to the development of this story



grounded in disability studies (chapter two, page 34) and critical community psychology (chapter three, page 52).

## Chapter 2 – Situating the background: disability studies

***‘Is psychology a source of oppression for disabled people or a resource for enabling individual and collective empowerment?’ (Goodley and Lawthom, 2005a:135).***

***‘Psychology is up for grabs: particularly by those communities whose psychologies have been pathologised and alienated by labour markets, poor housing, welfare dependency and material poverty. Psychology is a social, cultural and political creation’ (Goodley and Lawthom, 2005a:136).***

### 2.1 Introduction

In chapter one, I rooted myself within this story by explaining some of my personal and professional experiences that contributed to the making of this thesis. I reflected on my experiences of working in the community with young men and some of the challenges that emerged from that work. I considered health promotion alongside ‘disability’ and the health of men in line with the research aim, that was to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. The next two chapters are interlinked, but are presented as two separate chapters because I want to explore what disability studies, and critical community psychology mean separately, but also to be able to tease out the overlaps, connections and similarities between the two disciplines in line with the research objectives. I will end chapter three with a synthesis of the two chapters whereby I argue that disability studies and critical community psychology can work together (chapter three, pages 65 - 68).

In this chapter, I want to situate the theoretical background of this thesis in relation to disability studies. I will consider the epistemological and ontological aspects of disability studies in line with the research aim to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. In addition, I will briefly begin to look at the tensions between disability studies and psychology and will then explore how we come to understand what we might mean by ‘learning difficulties’. This draws on the work of Edgerton (1967) and Bogdan and Taylor (1982) as well as concepts such as ‘normalisation’ (Nirje, 1976; Wolfensburger, 1977), and the social model of

disability in the United Kingdom (Oliver, 1990; 1996). I will end the chapter by giving some detail about what 'critical disability studies' has to offer to disability studies and the importance of self-advocacy. However I will begin again by drifting back in time (in the next section) to some memories that have helped me reflect on the quotes above concerning psychology and disability.

## 2.2 Playing in the community

When Goodley and Lawthom (2005a:136) say '*psychology is up for grabs*', I immediately think of trees. I think about the happy memories of me, my dog and dad, my brother Dominic and one of my sisters, Maria, and the times we use to go to Cale Green Park in Manchester to play hide and seek. Really, this activity involved me and Dominic running off and hiding in the trees, whilst the others counted to sixty before they came to hunt us down. My brother and I would grab and climb the trees to hide, but they always found us in the end. My brother and I would re-enact, in our own way war film strategies we had watched with dad to avoid being detected. Playing this game was good fun and I loved those moments because we felt free, free to run and keep running with the wind in our hair. However thinking about this memory particularly reminds me of my sister Maria. Although it is nice to remember some of the good memories, Maria had a tough time growing up and still is suffering from the adverse effects of that. For instance, whilst my dad worked five nights a week as a nurse, Maria (aged around 12 years) would be sent by our alcoholic (biological) mother to collect alcohol from our (biological) grandmother, as she waited outside a shop to hand over the alcohol. These actions, amongst other horrible actions over her young life, ensured that Maria had a very difficult time. Although, me and our other siblings went through the horrible times too<sup>3</sup>.

Maria has been sectioned, given anti-psychotic medication, has cuts all over her arms and is a very anxious and shy young woman. On the other hand, over recent years her shyness and gentleness has been supplemented with a renewed confidence, with my dad always there to offer her guidance and support and her beloved dog, Jasper who is with her too. Maria now works with a local volunteer group doing some cleaning and she is doing a National Vocational Qualification in counselling and also completed qualifications in health and beauty. This is all good

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<sup>3</sup> Maria gave permission for me to write about her personal information and experiences.

and well, but both the mental and physical scars of the past are still visible for all of our family to see. My frustrations with how Maria was handled by her care workers i.e. social workers, counsellors and mentors, still remains. For example, their quick judgments about Maria's personality and background and insistence on taking anti-psychotic medication, which I think is useless in helping Maria. My view is that Maria's resilience has developed from the support she gets from our family, and more importantly, the resilience and belief she has gained by her own determination to have a better lifestyle and not by people from outside of the family (See Unger, 2005, 2007). When I think about this personal story, it also reminds me again of the frustrations I have had with psychology, discussed in chapter one, particularly in relation to psychology's ignorance of contextual effects on marginalised groups (Orford, 1992; Kagan et al, 2011a). Next, I will explain some of the problems with psychology and disability to get a sense of why there have been problems and to prepare the context that there is hope, I feel, in what critical community psychology brings to the relationship between psychology and disability studies. I will then consider how we come to understand what the label of learning difficulties means and go on to discuss the significance of the social model of disability in the UK (Oliver, 1990).

### **2.3 Psychology and disability – some of the problems**

Disability writers have emphasised that psychology has contributed to the marginalisation of people labelled with disabilities through the pathologising and individualising of people labelled with disabilities (Oliver, 1990; Finkelstein and French, 1993; Shakespeare and Watson, 1997). In other words, from a medical model standpoint, 'disability' is considered a 'tragedy' for individuals who have '*something wrong with them*' (Boxall, et al, 2004:100-101). Goodley (2003) suggested that the normalising nature of psychology has maintained the status quo by enhancing the power and knowledge of institutions (Foucault, 1972, 1977), providing negative and disempowering experiences for people labelled with disabilities. This rejects any consideration that people labelled with disabilities know more than most about the (ab) uses of psychology – what Rose (1985, 1999) called the 'psy-complex' (Goodley, 2003:3). For example, Goodley and Lawthom (2008:191) suggested that psychology continues to adopt a form of positivism that 'privileges a view of disability as impairment'.

On the other hand, Forshaw (2007) strongly defended psychology and argued (in response to Goodley and Lawthom, 2005a) that Goodley and Lawthom's (2005a:136) assertion that 'mainstream psychology' is 'pathologising, voyeuristic and impairment-obsessed' is 'inaccurate, unhelpful and counter-productive' (Forshaw, 2007:658). Instead Forshaw (2007), for example, suggested that there is a diverse range of research methods and approaches other than just qualitative methods that may serve the best interests of people labelled with disabilities. Forshaw (2007) goes on to suggest that community psychology (to be discussed in chapter three in detail, page 52) is wrong to focus on context and ignore individuality because by doing so it suggests that people labelled with disabilities are passive recipients of a discriminatory society and that their personalities and idiosyncrasies are irrelevant to a disabling culture. In addition, Watermeyer (2012) 'defends' psychology too, but first acknowledges that psychology is regularly considered oppressive towards people labelled with disabilities (particularly by theorists of the social model of disability in the UK), because psychology is considered to be ignorant of the impact of social factors that affect people labelled with disabilities (See Oliver, 1990). However, Watermeyer (2012:162) goes on to say that despite psychology being '*limited and awkward*' in disability studies, there have been inroads of representing the 'psychological' (albeit limited) and that there is still a reluctance from disability studies scholars to incorporate ideas from psychology (although this has happened with success at times, see Goodley and Lawthom, 2005a and Goodley and Lawthom, 2005b; Kagan et al, 2011a).

Watermeyer (2012) proposed that instead of simply seeing the history of disability and psychology in terms of the 'pathological', we should instead be looking inside psychology and attempting to understand psychological concepts, to get a better idea of the issues that come with this. For example, a combination of liberation and feminist psychological traditions (Martin-Baro, 1994; Lykes and Moane, 2009) may help to understand the label of disability and the social factors related to this label more:

The discipline of disability studies must have the courage to engage directly with all aspects of human development ... Central to this project is the directive to somehow cease being afraid of psychology ... Instead of the broad brush strokes of dismissing disciplines (psychology) as 'oppressive', the intention must be, through critical engagement, to appropriate useful

constructs, and build models which illuminate the nature of oppression (Watermeyer, 2012:172).

Thus ignoring psychological approaches is potentially a mistake and these approaches instead need to form part of the critical analysis to understand oppression better and not be simply rejected. On the other hand, I advocate Goodley and Lawthom's (2005a:136) perspective because, for many people labelled with disabilities, psychology has been considered 'pathologising' and 'impairment-obsessed' (also see Aspis, 1997; Chappell et al 2000). For me, Goodley and Lawthom's (2005a) and Watermeyer's (2012) perspective is much more positive about the future of psychology and disability studies, despite the negative implications from Forshaw (2007). For example, Watermeyer and Swartz (2008:168) suggested that:

Disabled people ... are forged and steeped in an intersubjective milieu of disablism; it is in the unpacking of subjectivity and the intersubjective space that we will begin to understand the hidden micro-mechanisms of subordination.

With respect to this view point, I feel that by unpacking our understanding of the intersubjective spaces that people labelled with learning difficulties face, such as in shared spaces like care homes and day centres, to interpret everyday life and culture, that we may begin to understand the contextual problems with disability. By doing so we can then acknowledge that society, culture and politics do play a part in the development of human life. In my view, despite psychological approaches being analysed as 'limiting' for people labelled with learning difficulties and arguably psychological approaches traditionally ignore the social contexts of people (Kagan et al, 2011a), psychology has a part to play in the social, cultural and political manifestations that contextualise 'disability'. I would also argue that critical community psychology can have a strong relationship with disability studies to help to build bridges between the disciplines (Goodley and Lawthom, 2005a). However, before I discuss critical community psychology and argue that it is an approach that can add value to disability studies, I want to start to unpack what the label of 'learning difficulties' might mean, which will provide a useful context to how critical community psychology might fit into collaborating with disability studies.

## 2.4 How do we come to understand the label of learning difficulties?

One of the early attempts to understand the experiences of people labelled with learning difficulties, from the perspective of people labelled themselves, was undertaken by Edgerton (1967). Edgerton suggested that nearly all the literature in the field of 'intellectual disabilities' at that time came from the perspective of 'social workers, psychiatrists, psychologists and other medical specialists' (Edgerton, 1967:372; Klotz, 2004). Edgerton argued that this might inform the way that the people labelled in this way might behave, or are categorised and distinguished from other people (Klotz, 2004). Thus Edgerton attempted to provide insight into the day-to-day lives, from the perspective of the people labelled with learning difficulties. His landmark work 'The Cloak of Competence: Stigma in the Lives of the Mentally Retarded' (Edgerton, 1967) provided a basis to critically re-think how the label of learning difficulties is perceived.

However, Edgerton (1967) did not explore why people labelled with learning difficulties were considered to be a 'problem' in socio-cultural society and how these perceptions shape how people labelled with learning difficulties are treated (Klotz, 2004). Instead it was the work of Bogdan and Taylor (1982) who claimed that human behaviours are products of how people interpret the world they live in, that marked a shift from Edgerton's interpretations and instead saw 'mental retardation' as primarily a social construction (Bogdan and Taylor, 1982). Hence people labelled with learning difficulties become prisoners of their labels, put upon them by other people in their socio-cultural surroundings. For example, Rapley (2003), who argued that the operation of power/knowledge (Foucault, 1977) is visible at multiple levels of analysis, suggested that analysis must go beyond the pathologised individual. Moreover, Bogdan and Taylor (1982) suggested that as well as being perceived negatively, people labelled with learning difficulties were often considered intimidating and dangerous. This intensifies the negative stereotyping of people labelled with learning difficulties (also see section 3.8 in chapter three, page 56, on the effects of austerity for people labelled with disabilities from Briant et al, 2013).

Edgerton (1967) and Bogdan and Taylor's (1982) work on the negative effects of institutionalisation and labelling had a noteworthy impact on policy development globally (Klotz, 2004) and opened up new ways to think about the label of learning difficulties. In the next section, I want to consider an alternative social policy that

arguably had a bigger impact on people labelled with learning difficulties, that being the concept of '*normalisation*' (Nirje, 1976; Wolfensberger, 1977).

## 2.5 Normalisation

Nirje (1976; 1980) and Wolfensberger's (1977; 1980) alternative social policy of 'normalisation' led to widespread 'change' and influence on how we might view people labelled with learning difficulties. The central principle can be described as:

The creation, support and defence of valued social roles for people who are at risk of social devaluation (Wolfensberger, 1983:234).

The formulation of normalisation stemmed from the idea that people labelled with learning difficulties were seen as people who did not deserve to have opportunities to enjoy normal patterns of life such as the separation of work and play, an ordinary life, even within segregated services (Nirje, 1980). Therefore, normalisation was a strategy to reverse institutional models of segregation and to promote integration with 'valued' (i.e. non-disabled) individuals and institutions (Wolfensberger and Tullman, 1982). Later the normalisation principle was developed into '*social role valorisation*', which was a way of understanding the transactions between human relationships and human services (Wolfensberger, 1983). In other words, a social role valorisation considered the importance of valued social roles for people labelled with learning difficulties. For example, if a person holds valued social roles, that person is likely to gain more from living within that society (Osburn, 1998). For example, having friends or access to places in day to day life or being able to contribute to society may be recognised as valuable, which then may reduce scapegoating (Quarmby, 2011) and the loss of personal autonomy and freedom that can lead to social and relationship disjointedness and/or deindividuation (Reicher et al, 1995).

During the 1980s, normalisation dominated the agenda of services for people labelled with learning difficulties because normalisation demonstrated that anything reformist could be achieved by applying the ideas behind normalisation (Chappell, 1993; Race et al, 2005). Normalisation appeared to support the rights of people labelled with learning difficulties and, for many countries became a basis to improve the lives of people labelled with learning difficulties (Nirje, 1980). Nirje



(1980) and Wolfensberger (1980) suggested the following achievements of normalisation (Walmsley, 2001:70):

1. Teaching of skills to develop and grow – minimising the constraints of 'disability'.
2. Gaining of respect, status and dignity through the adoption of socially valued roles.
3. Creating a presence for people labelled with disabilities, to share a space with 'normal' people.
4. Within the space they can/have developed relationships within communities.
5. Freedom of choice and opportunity to gain employment and independence.

However, according to Chappell (1992), normalisation did not offer explanations for why people labelled with learning difficulties are oppressed in societies that are capitalist, with no plan to liberate people labelled with learning difficulties from this marginalisation (Chappell, 1992). Normalisation may be considered a movement that helped to integrate people labelled with learning difficulties into mainstream society. For example, the aim of normalisation was to help people labelled with learning difficulties to develop relationships with non-disabled people (Wolfensberger, 1977; Wolfensberger, 1980). Chappell (1992) explained that the problems with 'normalisation' such as the priorities of people labelled with learning difficulties using services, were dictated by the professionals, usually non-disabled people and that normalisation was idealist in its concerns about the stigma and labelling that comes with being labelled with learning difficulties.

The principle of normalisation was intended to challenge the idea that people labelled with learning difficulties were best kept apart from mainstream society (Williams and Nind, 1999; Walmsley, 2001). Normalisation initiated a 'management' of making people labelled with learning difficulties 'normal' and 'socially acceptable' (Gleason, 1994). Thus, the major problem with normalisation was that normalisation still positioned the individual as not being 'normal'.

However, Race (1999; 2006) suggested that, favourable change had happened globally to learning disability services, and individual improvement in the lives of people labelled with learning difficulties as a result of normalisation. For example,

UK de-institutionalisation from the 1980s and development of services to prevent further isolation for people labelled with learning difficulties afterwards (Race, 1999). Nevertheless, although normalisation was seen as a progressive step in continuing to challenge the marginalisation of people labelled with learning difficulties, the separation of non-disabled and people labelled with learning difficulties is problematic. This highlights Chappell's (1992) assertion that by 'managing' people labelled with learning difficulties, normalisation distinguishes between what is or is not normal.

Following the critique that encompasses normalisation, a newer focus soon emerged in how people labelled with disabilities/learning difficulties and their contexts were considered in the form of the social model of disability in the UK (Finkelstein, 1981; Oliver, 1990; Barnes, 1991). This emerged to promote the need for people with labelled with disabilities/learning difficulties to get, full economic, social and political inclusion in society and to understand the daily encounters for people labelled with disabilities/learning difficulties (See Chappell, 1993; Walmsley, 1997).

## **2.6 Social model of disability in the UK**

The social model of disability in the UK emerged from the Disability Rights Movement (1960s – 1970s) and challenged the isolation of people labelled with disabilities. This started during the Industrial Revolution, a time when people labelled with disabilities were identified as a 'social problem' (Winter, 2003), arguably leading towards a 'system of lifetime segregation for disabled people' (Chappell, 1992:51). Since then, the social model of disability in the UK has helped to develop a political and social understanding of 'disability' (Finkelstein, 1981; Oliver, 1990; Barnes, 1991; Shakespeare and Watson, 2002). In addition, the social model of disability in the UK has helped to challenge, to an extent, the meaning of 'disability' across society and may now be considered a continuous and ever changing process of new understandings instead of rigid, archaic understandings of what 'disability' means (Oliver, 1996). Instead the social model of disability in the UK places the roots of 'disability' in society's structures, which:

Turned the understanding of disability completely on its head by arguing that it was not impairment that was the main cause of the social exclusion of

disabled people but the way society responded to people with impairments (Oliver, 1996:43).

The social model of disability in the UK, which emerged from disabled people's organisations and research, considers 'disability' as a social construction (Burr, 2003) created by cultural-historical-social-economic factors, which label and stigmatise some people (Oliver, 1990; Finkelstein, 1993). The social model of disability in the UK arguably provided a way to help achieve political reform and self-identification during the 1990s (Walmsley, 1994), for example, through the creation of the Disability Discrimination Act 1995. This Act put 'disability' on the political agenda (Gooding, 1996) and legislation was later extended to include direct and indirect discrimination (The Act was later integrated into the Equality Act 2010). On the other hand, some recognised that the Act had its flaws. For example, according to Gooding (1996) and Corker (1999), the Act represented justified discrimination and the Act became a barrier to people who were isolated, under-resourced or ill-informed. For instance, you had to have a 'clinically recognised' condition and it was not necessary to look at the causes (contextual) that demonstrated that someone was 'disabled' (Sayce and Boardman, 2008).

However, the social model of disability in the UK may be considered a 'practical tool, not a theory, an idea or a concept' (Oliver, 2004:30). Therefore, the social model of disability in the UK should be considered as the starting point in disability research, without the focus on the 'problematic' individual (Goodley and Lawthom, 2005a; Goodley and Lawthom, 2005b). Nevertheless, criticism has been directed at the social model of disability in the UK including Chappell's (1992) argument that people labelled with learning difficulties are ignored by the social model of disability in the UK. For example, the disability movement comprised people with different 'physical impairments', whereas people labelled with mental illnesses/learning difficulties tended to be classed as one group, often by the medical model of disability (Rapley, 2003; Goodley, 2007a). In addition, more so than ever, society is now greater in diversity between people in terms of gender, class, race and sexuality (Beckett and Macey, 2001). Hence, the social model of disability does not just apply to people labelled with disabilities, but rather to other groups too such as women, children, the elderly and gay people who may be labelled with disabilities (See next section on 'critical disability studies', page 38).

Chappell (1993) and Morris (1998) also expressed fears of certain groups being made into 'special interest' groups (i.e. women labelled with disabilities), although Chappell (1993) suggested that people labelled with learning difficulties do not even have the status of 'special interest', arguably weakening the theoretical basis of the social model. This criticism can be considered in two ways according to Chappell (1992). First, there is not enough academic literature concerning people labelled with learning difficulties and even more so *by* people labelled with learning difficulties and secondly, the social model of disability in the UK assumes to refer to all people labelled with disabilities when analysing the literature, favouring people labelled with sensory and physical impairments. Thus, Chappell (1992) argued that disability research is favourable towards people labelled with impairments that are described as relating to the physical/the body (Chappell, 1992; Aspis, 1997), although the understanding of what 'impairment' means is also complex as the label of learning difficulties (Oliver, 1996). For instance, Oliver (1996) argued that there was terminological misunderstanding and discrepancies with definitions of impairment particularly from organisations such as the World Health Organisation. However, I align myself with Boxall's (2002) suggestion that, rather than focusing on the marginalisation of people labelled with learning difficulties within a social model of disability (UK) discussion, that the focus should instead consider the ways we can support people with the label of learning difficulties in contributing to that discussion.

In relation to sexuality, the literature tends to generalise to all people labelled with disabilities (Guldin, 2000; Taleporos and McCabe, 2003; Baxter, 2008; are examples of sexuality and physical impairment studies). Some research suggests that people labelled with learning difficulties are not expected to have a sexuality at all because they are judged not to have adult maturity (Shakespeare, 1999). Similarly, some people labelled with learning difficulties are sometimes viewed as aggressive or incapable of understanding the affectionate side of sex, or as people who are overly sexual (Cambridge, 1999; Cambridge and Mellon, 2000; Abbott and Burns, 2007). Barron et al (2002; also see Scior, 2003) suggested that people labelled with learning difficulties were not expected to have gender identities and are perceived as being non-sexual and heterosexual (Snyder and Mitchell, 2006). However, some writers have included learning difficulties in their writing about sexuality such as Shakespeare (1996) and noted the 'vulnerability' of people labelled with learning difficulties and sexual abuse. Yet it still somehow links these

people/groups with stereotypical labels associated with being overly sexualised or vulnerable.

Other writers have expressed frustrations with the social model of disability in the UK also, in terms of impairment. Thomas (2004) argued that the social model of disability denied that impairment has any relevance, which can be used to reassert individualistic approaches to disability. Nonetheless, Peters et al (2009:544) suggested that:

The social model ... has been particularly useful as a tool in that it raises awareness of oppression – a critical first step needed in order to challenge oppression through action.

In addition, Beckett (2006:750) reinforced the above that the:

Powerful articulation of the disabling practices at work in society provides an important basis from which to challenge and overcome these practices.

Hence the social model of disability in the UK can be used for people who are labelled with any kind of 'disability'. However, the social model of disability (in the UK) arguably needs to adapt and make room for other perspectives, models and interpretations such as literary, cultural (Bolt, 2009; Mallett, 2010) and queer (McRuer, 2007). Ryan and Runswick-Cole (2008) argue that parents have been placed outside of the disability movement, due to the division between impaired and non-impaired people that the social model of disability in the UK creates. For instance, parents of disabled children who are considered non-impaired may be positioned as being a contributing factor in the discrimination and disablism their children with impairments face. However, Linton (1998a) suggested that:

The question of who 'qualifies' as disabled is as answerable or as confounding as questions about any identity status. One simple response might be that you are disabled if you say you are.

Thus, despite the achievements of the social model of disability in the UK, the model has not gone without criticism and, particularly needs to adapt to understand the label of 'learning difficulties' which arguably is ignored (Walmsley,

1997). Nevertheless, the social model of disability in the UK has laid the foundations to the emergence of 'critical disability studies' (Meekosha and Shuttleworth, 2009) in recent years, which brings a different and more diverse perspective to the study of disability/label of learning difficulties. Next, I will consider some of the implications of applying critical disability studies.

## **2.7 Critical disability studies**

According to Meekosha and Shuttleworth, (2009), using the term 'critical disability studies' moves away from the dualistic understandings of disability such as social vs. medical. In addition, Meekosha and Shuttleworth (2009) argued that despite the preoccupation with disability studies being framed within a global North context, writers from the global South are also contributing to the understanding of disability too (See Ghai, 2002; Watermeyer et al, 2006; Grech, 2009, 2012). Therefore, 'critical disability studies' has 'open(ed) up spaces for rethinking the self and other' and opened up different theoretical developments (Goodley, 2011:160, also see Corker, 1999). Arguably, critical disability studies might be considered a transdisciplinary space which may potentially break down boundaries between disciplines that have historically marginalised people labelled with disabilities (Thomas, 2007) such as psychology (Olkin and Pledger, 2003; Goodley, 2011) and intersects with other philosophical perspectives including postmodernist (Corker and Shakespeare, 2002) and post-structuralist (Tremain, 2005) thinking. These developments have moved beyond the materialist dominance of the social model of disability analysis (Meekosha and Shuttleworth, 2009) and instead places emphasis on other ways to understand labels of disability from discursive, cultural and relational perspectives (For example, see Tremain, 2005; Shildrick, 2007, 2009; Roets and Goodley, 2008; Campbell, 2008). According to Shildrick (2007, in Meekosha and Shuttleworth, 2009:49):

(Critical disability studies) is broadly aligned with a post conventional theoretical approach. It seeks to extend and productively critique the achievements of working through more modernist paradigms of disability, such as the social constructionist model.

Hence, a post conventional theoretical approach could enhance the social model of disability in the UK because with the social model of disability in the UK distinguishing between 'disability' as a social system of discrimination and the label of 'impairment' as a limitation, the model received much criticism (see Shakespeare and Watson, 2002; Reeve, 2004 – also see previous section for more critique – Chappell, 1992; Aspis, 1997). For example, for some, such as Shakespeare (2006), the social model of disability in the UK had become a model against which all disability research was expected to be judged, whereby any deviance from the social model of disability risked being dismissed for not taking the political dimensions of disability seriously (Oliver, 2004; Barnes, 2012).

Using the term 'critical disability studies' arguably moves away from the binary understandings of social vs. medical, disability vs. impairment (Meekosha and Shuttleworth, 2009). Vehmas and Watson (2013) have argued that there is no evidence that the categories that are applied to people labelled with disabilities actually create a divide. Instead they argue that without binaries or categories that we would not know how to support or include people labelled with disabilities or what services to provide.

In contrast, Hosking (2008) argued for a multidimensional conceptual understanding of disability oppression, which the social model of disability helped bring to light, particularly when linked with critical theory (Parker, 2005), as it would counter any suggestions that binaries or categories are useful in understanding the multiple complexities of the oppression of disability. With the arrival of many perspectives from humanities and cultural studies, it means the study of disability is not just about social, economic and political perspectives, but also about other areas such as intimacy and sex (Paterson and Hughes, 2006; Liddiard, 2014) and discursive approaches (Rapley, 2003; Inglis and French, 2012). Meekosha and Shuttleworth (2009) suggested that critical disability studies is important because it builds on the multiple interdisciplinarity that encompass disability studies, whilst continuing to incorporate relevant aspects of the social model of disability as well as listening to work emerging from the global South (See Grech, 2012).

Overall, critical disability studies and its discursive, cultural and relational angle could be beneficial to the social model of disability in the UK. The collaboration of critical disability studies and the social model of disability in the UK makes a promising partnership to challenge the position of people labelled with learning

difficulties in society because research in this area is scarce. Yet Davis (1997: XV) warned:

As with any new discourse, disability studies must claim space in a contested area, trace its continuities and discontinuities, argue for its existence and justify its assertions.

However, what also needs to be considered is not just the challenges and problems that surround people labelled with learning difficulties, but the ways in which people labelled with learning difficulties can feel empowered to make changes themselves or to challenge the status quo. One example of this is to consider self-advocacy, which is what I will review in the next section.

## **2.8 Self-advocacy in the UK**

Although UK based self-advocacy arguably started in 1984, with the emergence of 'People First', self-advocacy has a lengthier history (Walmsley, 2002). For example, in 1972 there was the campaign for 'mentally handicapped people' (words from the campaign, not mine), getting people to speak up for themselves. In addition, the mid-1980s saw many self-advocacy groups emerge, mainly in service settings (e.g. 'Growing Voice', Crawley, 1988) and independent groups and gradually more organisations (established) began to take self-advocacy more seriously. For example, some academics (e.g. Atkinson and Williams, 1990) published papers, which emphasised people's experiences of being labelled with disabilities.

The emergence of self-advocacy attracted some important studies such as Simons' et al (1992) '*sticking up for ourselves*' (See Goodley, 2001) and self-advocacy began to take shape when it developed more credibility and permanence (Buchanan and Walmsley, 2006) such as the development of 'People First' in the 1990s. But what is self-advocacy? There are many definitions of self-advocacy by people labelled with learning difficulties, academics and service providers. However, I think a good way to start to think about what self-advocacy means is to consider the People First definition (1996 taken from Aspis, 1997:648), the only organisation run/controlled by people labelled with learning difficulties:



1. Speak for yourself.
2. Stand up for your rights.
3. Make changes, be independent.
4. Take own responsibility (for example, to lead and facilitate projects).

In Aspis's (1997:648) paper, she also alludes to Dawson and Palmer's (1993) suggestion for how self-advocates can advocate:

1. Resist oppression by challenging people in power.
2. Have the right to challenge others and be angry.
3. Challenge carers when the need arises.

Armstrong (2002) suggested that early advocacy groups were characterised by the activity of the individuals and groups, who in the past had experienced disempowerment whilst fighting for their rights (Crawley, 1988; Sutcliffe and Simons, 1993). For the first time, professionals and organisations were listening to people labelled with learning difficulties, who were demanding change to their lives. Furthermore, Morris (1991) argued that self-advocacy was a way to express the struggle people labelled with learning difficulties faced, not because of 'learning difficulties', but by prejudice, discrimination and rejection by society and political-economic circumstances they faced. For example, Williams and Shoultz (1982) emphasised the importance of acknowledging life stories and experiences of people labelled with learning difficulties. Williams and Shoultz (1982:16) stated that:

Self-advocacy means self-respect, respect by others, a new independence, assertiveness and courage. It involves seriousness, political purpose and understanding of rights, responsibilities and the democratic process.

However, self-advocacy has been criticised for being too individualistic because the recording of life stories sets it within a particular context and does not always address the wider political socio-economic contexts that people labelled with learning difficulties live within (Graby, 2012). Chappell et al (2000) also theorised that there is potential in people labelled with learning difficulties in *doing* the social

model of disability, although there are not many people labelled with learning difficulties who have been able to contribute by writing through the academic literature.

Related to this is the wider political context. For example, Buchanan and Walmsley (2006) found that the Labour Government between 1997 – 2010 in the UK funded the provision of learning disability services generously, leading to more widespread consultation with people labelled with learning difficulties following (Department of Health, 2001). This included advocacy, specific advocacy organisations and consultation. On the other hand, this obligation came with responsibilities and the need for targets and outcomes (National Health Service Health Scotland, 2004), which assimilated 'advocacy' into service structures and ignored again the People's First expectations to be able to take their own responsibility. The integration of advocacy services arguably ensured that tokenistic approaches prevailed because self-advocacy needed to meet targets.

Nevertheless, some writers labelled with disabilities have expressed their personal experiences and have provided political insights into understanding the relevance/meaning of the label of disability (i.e. Aspis, 1997). This can be related to the feminist perspective of situating the label of disability in wider political and social structures (Butler, 1990). However, Crow (1996) suggested disabling barriers can create economic and social disadvantages, but the subjective every day experiences of people labelled with learning difficulties is not often seen or understood. This is not because people labelled with learning difficulties are incapable of expressing and exploring their personal experiences, but they are less heard. On the other hand, some writers labelled with learning difficulties have published their works. For example, Simone Aspis (1997) and Jackie Downer (See Goodley, 2000). Also, in 2012 at Manchester Metropolitan University, Duncan Mitchell edited an edition of *British Journal of Learning Disabilities* whereby the articles were edited and peer reviewed by people labelled with learning difficulties (Nind and Vinha, 2012). The journal claimed it was a world first, which inspired hope that maybe a breakthrough can be made to bring more of the work of people labelled with learning difficulties to the academic arena. But like the term 'empowerment' (Ward and Mullender, 1991) advocacy can be a 'social aerosol', covering up the 'smell' of conflict and division, leading to tensions and varying ideological and political positions. In other words, empowerment may be used to

indicate participation, but with little undoing of what it means (Lawthom et al, 2007) and this could also be the case for self-advocacy.

## **2.9 Summary**

In this chapter, I discussed the background on how we might come to understand what the label of 'learning difficulties' means. I did this through exploring the problematic relationship with psychology and disability in the past and in particular the pathologising and individualising nature of psychology (Goodley and Lawthom, 2005a and Goodley and Lawthom, 2005b) and its effects. I went on to discuss the early research by Edgerton (1967) and Bogdan and Taylor (1982), which started to move away from viewing people labelled with learning difficulties as people who could not think for themselves. In addition, I explored 'normalisation' (Wolfensberger, 1983) and considered the initial positive effects this had, but also the problems that can arise from normalisation, specifically the dichotomy of what is 'normal' or 'not normal', dismissing diverse identities and difference.

I explored the significance of the social model of disability in the UK (Finkelstein, 1981; Oliver, 1990; Barnes, 1991; Shakespeare and Watson, 2002), in that the model attributes problems, which people labelled with disabilities/learning difficulties face, within the contexts that surround them. However, Chappell (1992) and Chappell et al (2000) argued that despite the progress the social model of disability in the UK made for people labelled with disabilities, the model in essence still ignores people labelled specifically with learning difficulties (Chappell, 1992; Aspis, 1997; Chappell et al, 2000). I discussed the hope that critical disability studies (Meekosha and Shuttleworth, 2009) brings, in that it considers many different aspects beyond the contexts people live in including carnal, psychological and discursive elements. I ended this chapter by considering the importance of self-advocacy (Aspis, 1997; Armstrong, 2002). Self-advocacy is essential for people who are labelled with learning difficulties to be empowered and included in all aspects of their lives. In the next chapter (chapter three, page 52), I shift the focus from disability studies, for now as a concept, and start to consider 'critical community psychology' and how it might connect to disability studies.

## Chapter 3 – Situating the background: critical community psychology

*'He popped out of my mind (Mickey Mouse) onto a drawing pad 20 years ago on a train ride from Manhattan to Hollywood at a time when the business fortunes of my brother Roy and myself were at the lowest ebb, and disaster seemed right around the corner' (Walt Disney, 1948).*

*'All we sociologists (and psychologists) have are stories. Some come from other people, some from us. What matters is to understand how and where the stories are produced, which sort of stories they are, and how we can put them to intelligent use in theorising about social life' (Silverman, 1998:111).*

### 3.1 Introduction

In chapter two, I situated disability studies in the context of this thesis by exploring how we may come to understand the label of learning difficulties. I explored the significance of the social model of disability in the UK (Oliver, 1990), in that, the model attributes problems people labelled with disabilities/learning difficulties face within the, social, cultural and political contexts that surround them. I discussed what a critical disability studies perspective brings (Meekosha and Shuttleworth, 2009) to disability studies in that it considers many different aspects beyond the contexts people live in including carnal, psychological and discursive elements (Tremain, 2005; Shildrick, 2007; Roets and Goodley, 2008; Campbell, 2008). I ended chapter two by considering the importance of self-advocacy and the values behind self-advocacy, which I feel are as relevant now as they were thirty years ago. Now, I want to turn away from disability studies specifically and broaden the theoretical lens by focusing on what 'critical community psychology' (Kagan et al, 2011a) means, and review how useful critical community psychology might be in partnership with disability studies. I do this by considering what critical community psychology means and I explore the value laden, interdisciplinary approach that encompasses critical community psychology. In other words, I will consider some of the epistemological and ontological aspects of critical community psychology. However, first, in the next section, I want to reflect on some of the stories that have had a lasting impact on me from my own personal contexts, whether they be real or not. This makes me think about the complexities that come

with growing up and understanding the world around me, but also how personal past experience can connect with the present research. Thus I continue to use the story metaphor to tell a story that is evocative and allows for creativity (Spry, 2001) and to represent the fluidity and multiplicity that accompanies any story (Sykes and Gale, 2006).

### **3.2 Watching Dad and listening to stories**

Not long after the war (just before Walt Disney reflected on how the story of Mickey Mouse was created), on the 7<sup>th</sup> March 1946, in Blaenafon, in a valley completely covered in thick snow, my dad was born. In those days, most people were born at home, but my grandmother's eighth birth was particularly concerning because my dad had bronchitis and my family could not reach the shed where the wood was stored for burning, to keep warm, because it was that thick with snow. So they had to break up a piano, to burn the wood, to keep my dad warm and alive. Related to this, is a lovely story which has been retold in my family many times, was that my dad was named after a robin that was 'bobbing along' outside, just after the birth. I always think that that was a lovely idea by my grandmother, whom I never met and of course, nearly seventy years later, I was to name my first son Robin, who incidentally is the fourth Robin in my family, with my dad being the first.

I have always admired and felt proud of my dad and it is probably one of the main reasons why I have always been passionate about the 'land of my fathers'. I admire him for how he has always been friendly with people (often complete strangers) and always likes to share a joke. He was well loved by the elderly patients he worked with in hospitals and care homes as a nurse because he knew how to build a relationship with them, and that made them feel good. This was a long way from when he was a young man, in the Welsh pits in the 1960s, in the pitch-black darkness, when maybe he had only himself to talk to at times, along with the pit ponies.

Thinking about the story of my dad and how he came to be named reminds me of the stories, both real and fantasy, which dominated my childhood and I still think about these stories from time to time. For instance, one of the family legends in Wales is that Aneurin Bevan from Tredegar, founder of the National Health Service, is a distant relative. Similarly, another legend is that of my uncle Victor, an

engineer, who was killed in Sheffield by the Irish Republican Army (IRA) because he would not allow his Irish Catholic wife to pay any money to their cause in the 1970s. This story does affect me at times because he looked like me, so it kind of fascinates me when I see pictures of him (I never met him), but also because of my own Roman Catholic upbringing and Irish influences in England.

Unsurprisingly, some in the family believe these stories to be true and others do not. But I suppose that is how stories work. Distinguishing between fact and fiction is difficult and maybe stories are never complete. Other stories I remember through my youth include being retold the story, again and again, about St Bernadette from Lourdes in France, and Mary the Mother of God appearing to her regularly. More frighteningly was seeing pictures of her preserved body on display. Later in life, I was to find it equally strange, to see dead popes gilded in bronze, displayed in the Vatican. This was scary but not as scary as when I was a child and each time the 1960s pictures of Myra Hindley and Ian Brady re-appeared on TV (news reports of this in the 1990s), I was told that if I was naughty I would be taken away too. In addition, I was made to believe that Bing Crosby was a great uncle of mine, but not sure if this is as strange as finding out that Robin's great, great uncle is David Dickinson, the over tanned antique dealer on TV (this is a true story, his mum's great uncle).

As Silverman stated in the quote at the beginning of the chapter, what matters, regardless of how strange, odd, interesting, honest or real stories you become familiar with are, it is how we can put them to use in '*theorising about social life*'. The stories above have made me think about how my identity as developed and to what extent these stories are real, fantasy, true or not. Similarly, working in the community with marginalised groups, I have witnessed people sharing stories, stories that are real or not, and it helped me to reflect on my own stories and identity too. Some of these stories were explored in this research and were analysed in chapters five – nine, in the analysis of this research. But for now, in the next section, I want to start to explore what 'critical community psychology' means.

### **3.3 Critical community psychology**

In chapter two, I discussed the different ways in which we have come to understand the label of learning difficulties (for example, through reviewing

'normalisation', Wolfensberger, 1977, see page 40). My review of this label suggested that it is difficult to pin down what the label of learning difficulties might mean because contexts are so complex, with different meanings, but similarly, critical community psychology is difficult to pin down and define, for example:

There is no consensus among the different paradigms in the discipline about a single definition for the field. The different approaches in community psychology, for example mental health, social action, ecological and organisational, and the different perspectives within these approaches... demonstrate the heterogeneous nature of community psychology (Pretorius-Heuchert and Ahmed, 2001:19).

Nevertheless, to capture the essence of 'community psychology' in this thesis, as I stated in the prologue (pages 1 - 6), I will orientate this thesis around 'critical community psychology' set out by critical community psychologists at Manchester Metropolitan University (Kagan et al, 2011a). In relation to community psychology being 'critical', Kagan et al (2011a) suggested that the most important form of being 'critical' is 'critical theory', with critical theory concerned with questioning 'culture' in relation to society. In other words, critical theory, and theorists like Fromm (1955) and Habermas (1979), applied a set of practical-theoretical tools to social phenomena to try and get a more comprehensive understanding of what can help influence social change.

This can be connected to disability studies too, for instance, Reeve (2002) suggested that disability theory has been influenced by Marxism, feminism and post modernism. However, disability studies does not just relate to a Marxist approach, but can be linked to work that seeks to redefine, re-work or give direction too. A good example of considering disability studies contextually, is the social model of disability in the UK, because it questions dominate frameworks such as the medical model of disability, in relation to 'ableist' values (Corker and Shakespeare, 2002 - also see chapter two, page 34). Here is how a group of critical community psychologists' defined critical community psychology in Manchester:

Community psychology offers a framework for working with those marginalised by the social system that leads to self-aware social change with

an emphasis on value based, participatory work and the forging of alliances. It is a way of working that is pragmatic and reflexive, whilst not wedded to any particular orthodoxy of method ... It is community psychology because it emphasises a level of analysis and intervention other than the individual and their immediate interpersonal contexts. It is community psychology because it is nevertheless concerned with how people feel, think, experience and act as they work together, resisting oppression and struggling to create a better world (Kagan et al, 2011a:24).

However, Kagan et al (2011a) also note there is much work that has been done that does not use the term 'critical community psychology', but has similar methods and values i.e. youth work, social work and community development work (also see Lawthom et al, 2007). The main idea that emerges from Kagan et al's (2011a and 2011b) definition is the importance of going beyond the individualistic perspective and instead placing emphasis on the surrounding contexts, which has parallels with the social model of disability in the UK.

One of the tenets that sets out critical community psychology to be different, when compared to other forms of psychology, is that of it being value-based. For example, Kagan (2004 in Lawthom, 2011; Kagan et al, 2011a) conceptualised critical community psychology as being focused around a set of values that underpin critical community psychology. They have distinguished between the core values of 'justice' (i.e. equal rights in sharing of resources and self-determination), 'stewardship' (i.e. duties to look after the world and help people gain a sense of belonging) and 'community' (i.e. respect diversity and be accepted for who we are).

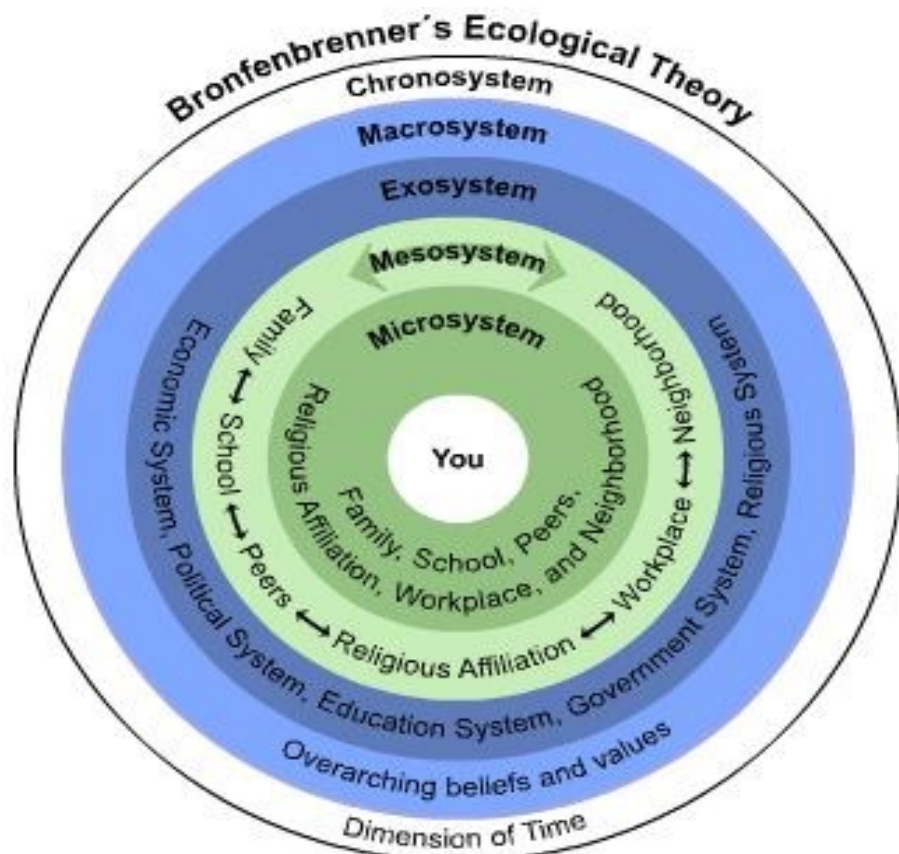
In my view, the value-laden epistemology of critical community psychology, complements the ideals set out by self-advocacy i.e. stand up for your rights, make changes, resist oppression and challenge power (Aspis, 1997). In this respect, critical community psychology in turn holds shared values of self-advocacy, and may contribute to a partnership with disability studies. In doing so, to challenge the conditions of being labelled with disabilities and to ensure that research is done with people labelled with disabilities as co-researchers (Goodley and Lawthom, 2005b). Next, I want to explore in more detail what the 'ecological metaphor' means and its connection with critical community psychology, which



provides a useful insight into understanding context, a major turning point from how psychology is traditionally understood.

### 3.4 Ecological metaphor

Critical community psychology attempts to depart from traditional approaches in psychology in that it places problems and issues individuals, groups and communities face, in their contexts and not within the individual (Rappaport, 1977; Nelson and Prilleltensky, 2005). For example, in Figure 1, Bronfenbrenner's ecological theory diagram (Source: bjspt2014.weebly.com) represents the interpersonal/micro level of the individual, who is at the centre, influenced by surrounding contexts at a local and societal level (adapted from the work of Bronfenbrenner (1979) who was a developmental psychologist):



**Figure 1 – Ecological Levels of Analysis/Nested Systems (Source: bjspt2014.weebly.com - adapted from Bronfenbrenner, 1979).**

The ecological model considers the different environments that we may encounter during our lifespan, which can influence behaviour at different times and situations. The micro system is the setting that we directly live within, which may

include influences from family, friends and neighbours. This setting is where we have direct social interactions with the people that we directly have contact with. In addition, the mesosystem considers the relationships beyond the micro system. For example, family experience, as well as school experience, may be linked and can affect how a child interacts with peers and teachers. At the micro and mesosystem level, the person at the centre plays an active role, but at the exosystem level there is a close link with the context a person may not have as much of an active role in. For example, the influences of the educational curriculum in schools that is decided by the Education Department. This in turn may be effected by the macrosystem which incorporates the actual culture, influencing overarching values and beliefs within a society. The chronosystem considers the dimension of time, in view of the impact of the transitions and shifts in one's lifespan, where the socio-historical contexts may influence the person.

In relation to this, what sets critical community psychology apart from an 'individualised' psychology is the way critical community psychologists seek explanations of social experience and taking action (Orford, 1992; Kagan et al, 2011a). Therefore, applying an ecological perspective has become an important principle of critical community psychology theory and practice, considering a person/people within the contexts that surround them, which enables critical community psychologists to develop new progressive insights (Levine and Perkins, 1997; Burton and Kagan, 2000).

Critical community psychologists mostly agree that systems analyses is required to reach understanding about people and to take action (Nelson and Prilleltensky, 2005). For example, families, welfare agencies and schools, all provide some form of support to resist oppression and celebrate identity (Kagan et al, 2011b). However, as Leonard (1975:56) stated, systems also 'carry to greater or lesser degree the marks of economic exploitation and the cultural hegemony of the ruling class'. Thus as long as critical community psychology recognises these contradictions, critical community psychology can potentially support features of these systems to help people who are marginalised (Ulrich, 1998; Midgley, 2000; Kagan et al, 2011a). Hence, in relation to people labelled with learning difficulties, critical community psychology can provide some hope that as long as it continues to recognise the interests of people (usually marginalised groups), change can occur or challenges the status quo in relation to the stereotyping, exclusion and dismissal of people labelled with learning difficulties. In chapter two, I discussed

critical disability studies and how it cuts across different perspectives and disciplines. Similarly, I argue that critical community psychology does the same and will be reviewed in brief in the next section.

### **3.5 Interdisciplinarity**

Another epistemological break from psychology by critical community psychologists was to move towards a whole systems praxis (See Franscescato, 1992; Midgley, 2000; Taket and Whyte, 2000). In other words, critical community psychology seeks to apply interdisciplinary perspectives, whereas psychology has traditionally not offered much in the way of understanding systems praxis, highlighting the need for critical community psychology praxis to become interdisciplinary (Kagan et al, 2011a). For example, Christens and Perkins (2008) proposed a comprehensive interdisciplinary framework that focused on multiple levels of analysis relating to socio-cultural, political, economic factors on oppression. Related to this is the work of Maton et al (2006) who suggested that collaborations with other disciplines helps to develop questions of social change to generate new ideas and theories to initiate change at micro and macro levels of analysis. Consequently, inter/trans disciplinary perspectives can lead to new perspectives and understanding about social problems and how to address them. Nevertheless, Maton et al (2006) also suggested that there are challenges to doing inter/trans disciplinary work. For example, disciplines differentiate in their values, levels of analysis and practices, which may be barriers to collaborate effectively. They also argue that the neoliberal emphasis in academia has pushed educational institutions to adopt a market orientation that militates against innovative research because of costs. However, the link between the social model of disability in the UK (Oliver, 1990) and disability studies (Goodley, 2011) with critical community psychology, I feel, can provide an interdisciplinary understanding of the causes of oppression, which can be a guide to take action or as a way of interrogating the problem spaces. Next, I want to explore how critical community psychologists might apply change and the resistance that often comes with change.

### 3.6 Change and resistance to change

Many of the principles set out by critical community psychologists regardless of what part of the world they are in, have 'change' as a core element. For example, to empower people/marginalised groups (Prilleltensky, 1994; Zimmerman, 2000). Whilst other forms of psychology do not approach change as desirable beyond the individual (Goodley and Lawthom, 2005a and Goodley and Lawthom, 2005b), Nelson and Prilleltensky (2005:144) distinguished between ameliorative and transformative change:

Ameliorative interventions are those that aim to promote well-being.

Transformative interventions, while also concerned with the promotion of well-being, focus on changing power relationships and striving to eliminate oppression.

Nelson and Prilleltensky (2005) go on to say that most forms of critical community psychology action is ameliorative and that although ameliorative action is good, they argue for more emphasis on transformative change to promote social justice and create long lasting, sustainable change (Kagan et al, 2011a and 2011b). My work with young people (see chapter one, pages 15 - 33) was ameliorative in that I would facilitate workshops concerning sexual health, and debate the issues associated with this and maybe challenge their views, to help them to learn new things (Richards, 2010; Kagan et al, 2011b). However, for my work to have been transformative, it would have meant that more systemic change would have been needed to be applied, to ensure that the young people had the knowledge through education earlier. In addition, with change or the proposal of change came conflict and differences of opinion, which could have prevented change from occurring. For the present research to be transformative it would need to change people's perspectives of people labelled with learning difficulties, although with lots of ameliorative change, transformative change may have occurred, it is difficult to assess. Nevertheless, Burns (2007: 144) stated:

Those with a vested interest in the status quo often mount an attack on the 'methodology' because they do not like the 'challenging' work that the group

is doing. It is often easier to attack the method than to attack the sense making that inquiry is doing.

In other words, with change or the proposal of change, inevitably there is resistance because not everyone wants change, especially if it is not in their interests i.e. not meeting funder's requirements, which can be driven by an outcomes agenda, ignoring processes (Parker, 2007). Veno and Thomas (1992:23) outlined the challenges that accompany resistance to change. For example, differences in 'value systems, social stratification and opposition to the goals of change'. Therefore, with this thesis being orientated around a critical community psychology approach, it was inevitable that it would come up against resistance because the project aimed to promote some form of change i.e. in perceptions around the label of learning difficulties. However, what might also cause resistance to change here are problems that critical community psychology might be associated with, which I will discuss in the next section.

### **3.7 Problems with critical community psychology**

So far, I have argued the case for critical community psychology being an approach within psychology that can build (and has done, see Goodley and Lawthom, 2005a; Watermeyer, 2012) a relationship with disability studies. However, critical community psychology is not without its critics. For instance, Seedat et al (2001) and Pretorius-Heuchert and Ahmed (2001) have identified limitations of community psychology in South Africa, which may overlap in other parts of the world. For example, the continued domination of white, middle class psychologists and limitations with critical theory being forced into political practice (Pretorius-Heuchert and Ahmed, 2001). Parker (2007:145) summed up community psychology from a critical psychology perspective:

Community psychology, then, often glues together the two terms 'community' and 'psychology' in such a way as to psychologise what a community is – to treat the community as something that can be conceptualised and studied by psychologists on their own terms – and then to use that psychologised image of the community to understand the individuals that comprise it.

In the same text, Parker (2007) described how critical community psychologists often work within the limitations of a funding agenda, with funders prescribing and controlling how projects work i.e. pressure on professionals/professions in the arts for health field to apply quantitative evaluation (Staricoff, 2006). In addition, Duckett (2005) questioned the extent to which interventions in critical community psychology have resulted in any meaningful resistance against for instance political violence, whilst Mitchell (1999: 33) suggested that evidence-based practice is about control. On the other hand, although psychology is still stalwartly positivist (Kral, 2014), some branches of psychology like critical community psychology have moved towards qualitative research. However, qualitative methods are still being dismissed as unempirical (Maracek, 2003) and qualitative methods is being taught in few institutions (Camic et al, 2003), which prevents a discipline like critical community psychology from developing and being influential. However, Parker (2007:146) goes on to say:

The concern with turning the dumb non-psychologists into good citizens who would be grateful to those in the discipline who have given away their knowledge is a conservative response to political problems in psychology. It not only betrays the hopes of those outside the discipline who thought that psychology would something interesting and useful to say about alienation, it also betrays the activities of those who have really tried to put politics on the agenda.

The problem I have with Parker's (2007) critique is that on the one hand, it is not very hopeful for the future and on the other, it may not reflect on how some people in the community or non-psychologists feel, certainly not in my experience. I feel that Parker (2007) rejects any kind of hope in making changes to enhance psychology, and hopes to strengthen the relationship between psychology and disability. In fact, I feel that critical community psychology is not only values based, but critical community psychology also is a reaction against the individualism of psychology (Goodley and Lawthom, 2008). Therefore, I argue that critical community psychology is a discipline that seeks to work with people within their contexts. Next, I want to provide some context to the space in which critical community psychology fits into during these times of austerity before I discuss how

disability studies and critical community psychology can come together in partnership.

### **3.8 Critical community psychology and disability in austerity**

The recent economic crisis (from 2008) has made life even worse for the most marginalised groups, particularly for people labelled with disabilities (Cross, 2013). For example, there have been increases in the number of people unemployed, which heightens fears for the future for people already living in problematic environmental and social contexts (Orford, 1992; Zani, 2003; Kagan et al, 2011a). This is important for critical community psychologists because they share an interest in the effects and the problems that surround people in their contexts, and from within these contexts the tools needed for solutions may be found (Nelson and Prilleltensky, 2005).

Given the hierarchical social contexts people live in (during austerity or not), it is likely that marginalised groups will have more health problems and gain the least from resources needed to sustain them during day-to-day life. For example, community projects are less likely to be financed (Francescato and Zani, 2010). Furthermore, community projects and critical community psychologists might struggle to find funds to develop new projects or continue to fund old ones. Thus, people labelled with learning difficulties, may find themselves marginalised in society more than ever if there are no projects available for them to attend. This is noteworthy due to the expected increase in people being labelled with learning difficulties in the coming years (Emerson and Hatton, 2008b; Emerson and Baines, 2010).

The economic crisis has also caused or is likely to cause problems academically. For example, critical community psychologists at universities are less likely to be employed because funding is increasingly given to the biotechnologies and the neurosciences (Reich et al, 2007). This is evidence of a neoliberal turn is evident, which supports capitalist markets and the Science, Technology, Engineering and Mathematics (STEM) agenda. Despite a small number of critical community psychology academics establishing community psychology theories and practices at undergraduate and post graduate levels, i.e. in the UK at Manchester Metropolitan University, Brighton (Walker et al, 2012), East London and York St John a number of those academics have been retiring

and the increase of students fees will mean it is less likely people from poorer backgrounds will attend university. Therefore, critical community psychology might well become marginalised in psychology departments before it is really established (Bergold and Seckinger, 2007). Reflecting on this potential demise, Vasquez Rivera (2010: XLIV) comments:

The extraordinary triumph of individualism is that it makes us feel unique and special, therefore, separate and different, therefore, alone and isolated, therefore, with individual and disconnected problems, therefore, 'without power' and neutralised.

In this respect, arguably, a decline or marginalisation of critical community psychology that stands against individualism and the exclusion of groups such as those who are labelled with learning difficulties, could be detrimental for those excluded groups who have benefitted from critical community psychology's collaboration with community groups and people. However, there is hope that critical community psychology will continue to have a space to work in the UK. For example, in 2010, a new community psychology section was created at the British Psychological Society (of which I am a member).

Critical community psychology of course is not the only area facing difficult times during austerity, but people labelled with learning difficulties are too. For example, Wood (2012) indicated that since the Emergency Budget in 2010, people labelled with disabilities and their carers have seen a fall in income of over £500 million. However, this will worsen because it is likely to rise to £9 billion by 2015. Additionally, by 2016, a further half a million of people labelled with disabilities are likely to lose their disability living allowance (DLA). In fact, 36% of people labelled with disabilities will not be able to claim incapacity benefit by the end of 2014, with some councils alongside this reducing support to only people with substantial needs as far as 81% (Wood, 2012).

In relation to this, Wood (2012:39-77) has criticised the present UK Government (2010 – 2015) for ignoring the effects of cuts on people and suggested four trends that will dominate the families of people labelled with disabilities and their lives over the coming years:



1. Struggle for survival - both statutory services and third sector services are being cut.
2. Less civic and social engagement - households are becoming more socially remote and reducing the amount of activities they engage in such as work and medical appointments, in contrast to the Government's vision of stronger and active communities (Big Society – see Runswick-Cole and Goodley's (2011) paper using a dismodernist critique and Runswick-Cole, 2014).
3. Declining mental health - households are increasingly experiencing anxiety, depression and fear for the future, with some relying on increased medication.
4. More informal care - informal carers are taking the strain as disabled people are losing the financial support and services they once relied on.

In addition to this, Cross (2013) suggested that replacing DLA with Personal Independence Payments (PIP) is causing concern because this change comes with other large cuts, all of which will impact disproportionately on people labelled with disabilities. Moreover, Briant et al (2013) found that since these benefit changes people labelled with disabilities have become a 'folk devil' in media coverage and found an increase articles relating to disability benefit and fraud as well as hurtful language to describe people labelled with disabilities (also see Inclusion London, 2011).

Overall, critical community psychology as a psychology is facing difficult times, but even more so are marginalised groups such as people labelled with disabilities. Therefore, in that respect, critical community psychologists and people labelled with disabilities have a common bond and it is through uniting that there may be possibilities for resistance and change. Next, I will consider the connections between critical community psychology and disability studies.

### **3.9 Disability studies and critical community psychology – the connection**

Kagan et al (2011a) argued that critical community psychology aims to address social and individual change, in conjunction with the people of a community (in this research men labelled with learning difficulties) and psychology and other similar professions (see Watermeyer, 2012). On the other hand, in relation to disability,

Finkelstein and French (1993) maintained that most people remain confused about defining disability, not least psychologists and this may affect the way in which disability is conceptualised, determining the type of interventions used by psychologists. In this respect, psychology needs to align itself collaboratively with the progress and development of the disability movement concerned with political change (Campbell and Oliver, 1996). Thus enabling psychological practice to take place outside the limitations of psychological institutions (Kagan et al in Goodley and Lawthom, 2005b) because in such contexts, people labelled with disabilities continue to be excluded from decision making about services that they receive. Consequently, the task for both disability studies and psychology is to unravel the complex social relations that intertwine how the label of disabilities is constructed.

Bringing disability studies and psychology together allows the complex dynamics between individual and social worlds to be addressed (Goodley and Lawthom, 2005a). In other words, psychology's emphasis on the individual experiences of people labelled with disabilities ignores the problems of the wider disabling world, as Goodley and Lawthom (2005a:136) state:

A discussion of community psychology in the disability studies world brings with it difficulties, not least in the use of the term 'psychology.

However, Barton (2004) advocated that as critical researchers we need to explore our theoretical perspectives and consider what our educational (psychological) institutions are for. This helps to ensure that the experience of disability can teach us about the organisation of culture and the development of our self-understanding (Titchkosky, 2003), because representations of our understanding of the label of disability are mapped out differently across societal and cultural practices and institutions (Titchkosky, 2003), therefore, psychological practice must engage with inclusion (Walmsley, 1997, 2004). This is a useful way to reflect on action or proposed action that is taken in participatory research with disability. On the next page is a table adapted from Goodley and Lawthom (2005a) that represents some of the main similarities and differences between disability studies and critical community psychology:

<b>Disability Studies (UK) (Goodley, 1998, 2000).</b>	<b>Community Psychology (Dunne et al, 1999; Kagan et al, 2000, 2001).</b>
Social models and theories of disability.	Collection of liberating theories.
Theoretical young and interdisciplinary.	Theoretical development in relation both to the discipline of psychology and other disciplines.
Emancipatory disability research agenda.	Transformative action research agenda.
Winding journey from functionalism to interpretivism to radical structuralism (questionable engagement with radical humanism).	Cyclical journey from functionalism to interpretivism to radical humanism and structuralism.
Social, economic, cultural and historical rather than individual focus.	Social, economic, cultural and historical rather than individual focus.
Against functionalism and individualisation.	Against functionalism and individualisation.
Expertise of disabled people.	Expertise of community members.
Indirect reference made to shared identities of people with learning difficulties.	Direct engagement with shared identities of community members.
Disabled people over professionals.	Critical involvement of both professionals and community members.
Celebration of insiders' perspectives.	Negotiation of co-researchers' perspectives.
Questionable engagement with psychosocial element of disability identities.	Directly engages with the psychosocial elements of community identities.

**Table 1 – A table comparing and contrasting disability studies and (critical) community psychology (adapted from Goodley and Lawthom, 2005a, pp. 147).**

Goodley and Lawthom (2005a) argued that a relationship between critical community psychology and disability studies could be 'ground-breaking', which I support. Promoting a research agenda that allows people to construct or express their own identities that is both the researcher and the participants in the research,

allows for reflection concerning the ways we have been alienated in society (Scott-Hill, 2002). This is appealing to both disciplines of disability studies and critical community psychology. In this respect, I argue that critical community psychology and disability studies are a good fit to work together to promote change and promote diversity.

### **3.10 Summary**

In this chapter, I discussed the background to critical community psychology and its meaning, and in particular what it means from the perspective of critical community psychologists in Manchester and the way critical community psychology is practised in the UK (Burton and Kagan, 2005). I did this through exploring the ecological metaphor, in other words, critical community psychologists consider problems in people's lives to be contextual. In addition, I considered the potential interdisciplinarity and values-based nature of critical community psychology, which marks it out from the traditional understandings of psychology. I considered critical community psychology's place during times of austerity and recognise that being a critical community psychologist during austerity is difficult, but not as difficult as being labelled with disabilities/learning difficulties during austerity. This means not just heightened marginalisation through the creation of new 'folk devils' (Briant et al, 2013), but a loss of resources, finances, family stress and breakdown (Cross, 2013).

In the first three chapters (chapter one, pages 15 - 33; chapter two, pages 34 - 51; chapter three, pages 52 - 69), I set out the background to the story of this thesis by considering and discussing the central concepts that being health promotion, disability studies and critical community psychology, in relation to the aim to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. The background to this thesis in the first three chapters also relates to the three research objectives:

*1. To explore the experiences of the men labelled with learning difficulties, participating in a group centred around creative activities formed to promote health awareness.*

*2. To collaborate with a group of men labelled as having learning difficulties in understanding how labels are constructed and understood.*

*3. To develop a new understanding of the ways in which a critical community psychology and disability studies perspective can be utilised for men labelled with learning difficulties.*

I have provided a context for these concepts through discussing some of the key issues and elements that make up the central concepts to the thesis in relation to the research aim and objectives. Through an exploration of past and present literature, I have identified a space and the relevance of my thesis to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. In the next chapter (chapter four, page 70), I will provide a discussion on how I situated my research within a methodological framework.

## Chapter 4 - Creating the story: approach

***'Qualitative research opens a space inside psychology to do something radically different to link human experience with social action' (Parker, 2005:1).***

***'They hurt you at home and they hit you at school.  
They hate you if you're clever and they despise a fool.  
Till you're so fucking crazy you can't follow their rules.  
A working class hero is something to be'.  
(John Lennon, 1970, 'Working Class Hero', Plastic Ono Band).***

### 4.1 Introduction

In chapters one to three, I provided a contextual, theoretical background from which I was able to explore the aim of this research, that being, the experiences of a group of men labelled with learning difficulties in participating in a health promotion project, in a city in the North West of England, UK. In chapter one (pages 15 - 33) I identified the aim and objectives of the research, and will now consider how I achieved these by addressing the methodological approach of the research and the theoretical scaffolding by discussing participatory approaches. In addition, I will discuss the autoethnographic, reflexive nature of the thesis and locate its methodological foundation. The second part of the methodology, in chapter five (pages 88 - 128), will cover how I contacted participants, ethics, methods and the chosen method of data analysis.

The research is located within a qualitative framework of inquiry. This makes sense because as discussed in the previous chapters, there have been tensions between the study of psychology and disability and have been challenged by the social model of disability in the UK (Oliver, 1990) and critical community psychologists (Kagan et al, 2011a). So as Parker (2005) stated above, a qualitative approach involves doing something different, creating a space in which human experience and action can take place.

A methodology provides the foundations and scaffolding for any research, almost like starting with a set of tools and a pile of bricks and then planning what to do with them. The concept of 'scaffolding' is connected with the socio-cultural

theory of Vygotsky (See Daniels, 1996) and can be considered as a metaphor in problem solving and finding solutions (See van de Pol et al, 2010). With this in mind, and also thinking about John Lennon's lyrics, which reminds me of growing up, I now wander back to my childhood and reminisce about the ways I use to search for scaffolding in my own way to find solutions and problem solves in challenging contexts.

#### **4.2 Scaffolding my own way to new knowledge and understanding**

In my autoethnographical reflections so far (See section 4.4 for a review on 'autoethnography', page 75), I have thought about my little Robin, my dad, brother and sister and touched on some of the problems Maria has faced. But writing this thesis in the past two years has come at a time in which I have had to face so many different new and old emotions like never before. Almost like an emotional cocktail of memories and stories that have re-emerged without warning. This came to a head in October 2013, when I reached thirty years of age, culminating in a period of deep reflexive thinking about life over the past twenty to thirty years, with the feelings that my 'youth' was coming to an end and a new chapter was to begin. This came alongside the emotional effects of the recent birth of little Robin in 2012 as well as having to watch my dad get a divorce, which brought back a lot of terrible memories as well as the good memories too. But also fears of losing our family home, the home in which I was brought up in.

Looking back in time and thinking of my childhood, I remember the things I used to do to help me through the difficult times. In particular, what was always a great relief and joy to me was my books and my eagerness to learn. For instance, I remember teaching myself the Welsh national anthem and impressing people by answering questions on *Mastermind* (on complex subjects for a 10 year old) like *the history of Westminster Abbey* or *the Tudor dynasty 1485 – 1603*. Reading books, learning about Shakespeare's plays and my passion for learning about English history still makes my mouth water now. I remember visiting the House of Lords and upstaging the tour guide, clearly annoying her because I was able to name and explain the relics, art work and statues that saturate Westminster Palace to my class mates and teachers. And I was always correct, not bad considering I had never been to London before, and was only 10 years old.

I remember going to the door of 10 Downing Street, which you could do then and seeing the then chancellor, Norman Lamont, come out of the door which was a highlight for me, knowing I knew who he was at that age. Although it would not be a highlight now because he is a Tory. I received a book award for my knowledge of English history and was presented with it in front of the whole school, which made me feel very proud. This period of time also reminds me of when I use to go to the local library and borrow books on history and other factual books, and also because I knew I would eventually take them back, I would write the books out. For example, I remember writing out a book on the profiles of fish, all their Latin names, colours, how they behaved and where you could find them. Unsurprisingly, I do not remember any of these fish or the name of the book.

However, looking back, I think books and learning new facts and figures gave me contentment and an escape into history from the troublesome, abusive present, fascinated by how people use to behave, think and feel. A contentment I got years later when I read Foucault's *'Madness and Civilisation'* (1964) and Szasz's *'The Myth of Mental Illness'* (1960). Learning new concepts and ideas and searching for new ways to think and understand was my way to survive the abuse. I look back and think that for me learning new things gave me contentment despite being in a troubling environment, but also even wanting to learn new things could go against you, hence why I think of Lennon's lyrics *'they hurt you at home and they hit you at school'*, so never felt I could be myself wherever I was.

So a complex story, a story that came with many stumbling blocks growing up, but one that describes my journey of finding ways of surviving, building resilience and developing hope out of adversity, which makes me think about the ways we look for solutions, to make things better (Hart et al, 2013; Hart and Heaven, 2013). Writing this thesis has come parallel with the past resurfacing, triggered by my dad's divorce and birth of Robin and also reaching the milestone of being thirty years old. Therefore, a time for reflection but then finding ways to understand, to cope with it, to develop hope and positivity for the future. That scaffolding and re-scaffolding in finding solutions makes me think about this chapter, in which I review how the scaffolding of this thesis was developed.

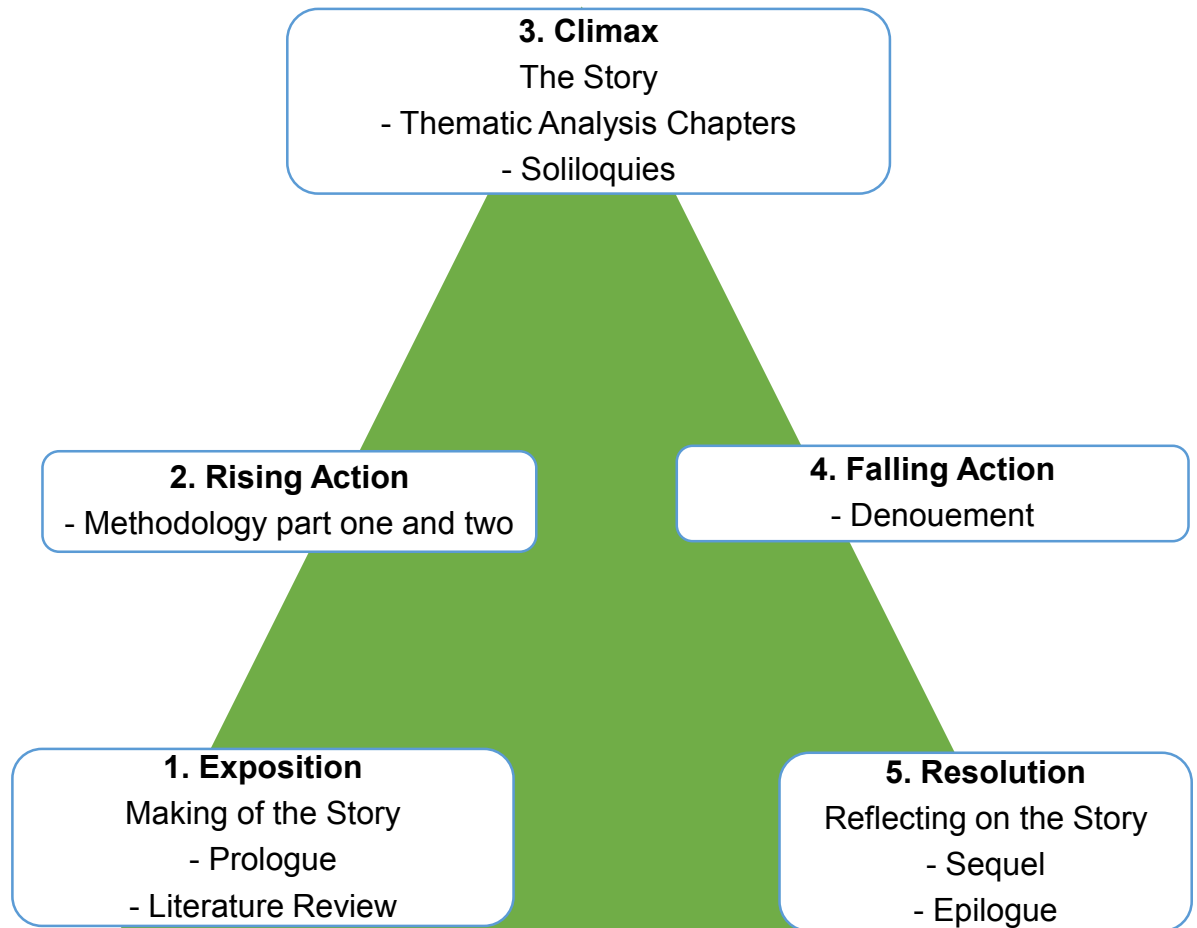
Next, before I review why I used autoethnography in this thesis, I will review how this thesis is structured and why I think about the structure in relation to a Freytagian pyramidal (1863), which was a way of analysing Shakespeare's plays, in keeping with the story/play metaphor of this thesis.



### 4.3 Structure of this thesis

In the prologue (pages 9 - 14), I set out the structure to this thesis by briefly stating what each chapter concerns. By setting out the chapters in that way, I felt that it was the most effective way in telling the story of the research, to unravel the plot. With my interests in English history and literature (reflected upon in my autoethnography in this chapter), I have always been interested in how playwrights were able to structure a story whilst maintaining the emotional intensity that comes with drama. With this in mind, an effective way to understand the structure of this thesis was to adapt Freytag's (1863) well-known approach to analysing Shakespeare's plays. Freytag introduced a five-part pyramidal structure which he believed to be the most successful format for a play and applied this to Shakespeare's plays, and to make sense and establish the meaning behind Shakespeare's plays (De Silva and Henderson, 2005). On the next page is an example of this pyramidal structure, combining the chapters and structure of this thesis.

Freytag's interpretation of how a Shakespeare play would work typically began with the exposition, which would set the scene and context to how the play/story was to unfold. Soon from this exposition, tensions would begin to rise as the plot started to scaffold, leading to the climax, the drama and excitement of the story itself. Once the drama had reached a climax, the emotions and tensions would be reviewed to make sense of the climax, leading to resolution and an end.



**Figure 2 – A Freytagian structure of a Shakespearean play presenting the structure of this thesis (Adapted from Gustav Freytag’s ‘Technik des Dramas’ 1863).**

Freytag’s pyramidal structure can be considered a tool for mapping a plot structure, which may allow the readers to visualise the key parts to the story. For example, Beaunae et al, (2011) used a similar play like structure to explore the complexities of resistance during an interview process. Writing a paper in the form of a play, Beaunae et al (2011) claimed that resistance can challenge the normativity of interviewing by opening up new spaces for interpretation. Similarly, other qualitative researchers have also used ‘play(s)’ as a form of structure or way to analyse experiences in qualitative research (see Gray, 2003; Denton and Ryder, 2009; Gale et al, 2010). In addition, thinking about the structure of this thesis, using a Freytagian approach, helped me to structure the narrative, by putting the thesis into an ordering of events. I was then able to make something of the events that unfolded in this research, to signify the people in the story in a personally and cultural coherent way (Sandelowski, 1991). As Churchill and Churchill (1982) suggested, narrative is a threshold activity that captures a

narrator's interpretation (me the writer of this thesis) linking the past, present and future in a passing moment in time. Thus applying this Freytagian structure helped me to put the story of this research together and to be able to tell the story in a coherent way that is understood by the reader. Freytag used his analysis to make sense of Shakespeare's plays and I too, have used this structure to make sense and provide coherence to the structure of this thesis, keeping with a story/play metaphor that I proposed at the beginning of this thesis.

In the next section, I will now provide a theoretical basis to the autoethnographic approach I have taken so far in this thesis.

#### **4.4 Autoethnography – turning back to my story**

When I first started to write this thesis, I was very confident that I could do so comfortably. I was used to being successful in academia and saw this process as a natural next step up from a Masters level. However, putting this thesis together has been incredibly challenging because, what I was writing, just did not seem to capture the story of this thesis very well. I was trying to find a way to encapsulate this thesis to be able to tell the story in the best possible way, but it took me some time to find the lens I wanted to use. The answer and turning point for me was to look from within and my own personal contexts and as mentioned in the previous section, the past two years of writing this thesis have come at a time of deep reflexive thinking about life. Although this thinking and writing has been difficult to do, which could relate to my own masculine identity such as reluctance to discuss problems (see chapter one, pages 15 - 33 on the discussion on men's health, Courtenay, 2000; Faramond, 2011), I realised very quickly that now was the right time to express my feelings. Indeed Noy remarked (2003:12), that writing autoethnographically may move oneself *'into emotions and actions with an intensity that surprises me'*. Richardson and St Pierre (2005:967 in Smith, 2012:962) put it nicely when they say *'writing is thinking ... writing is indeed a seductive and tangled method of discovery'*. Hence connecting my personal experiences with the themes and structure of this research and the experiences of the men in the project and in their lives, enabled me to write an evocative and meaningful thesis relevant to the aims and objectives of this research.

In this thesis, I have found some clarity in integrating my personal experiences with the research experience (Defenbaugh, 2008) as it has allowed me to 'gain

insight into the meaning of my own life (and) come to know my own story' (McAdams, 2006:11) by applying an autoethnographic approach, which Tedlock (2005:467) described as research that makes an attempt to:

Heal the split between public and private realms by connecting the autobiographical impulse (the gaze inward) with the ethnographic impulse (the gaze outward).

Similarly, Moore (2013) described in her autoethnography concerning illness, that she was both an '*insider and outsider in my own story*' (Richards, 2008:1721) for which she declared that she resided in the present, and yet the past is a part of her. Titchkosky (2003) also discussed how stories can be told in different ways through her experience of being dyslexic and her partner being blind. In addition, Moore (2013) explained that narratives concerning illness do not ask for pity (Defenbaugh, 2008), but the 'vulnerabilities' that may emerge from the narratives written are placed with the reader for their own interpretations (Ellis and Bochner, 1996). In this respect, the control is handed over to the readers, who may reconstruct their own meanings derived from their own experiences too. Spry (2001:712) stated:

Autoethnographic texts reveal the fractures, sutures, and seams of self-interacting with others in the context of researching lived experience.

Although I am not narrating research on illness or personal illness, Moore's (2013) insights help me to consider autoethnography as a methodology that can transcend boundaries and can showcase the interaction of my *self* and society (Spry, 2001). Autoethnography may also help me consider the different sociological positions in the relatively short period of time you have during a research journey (Goodley and Lawthom, 2005a). Moreover, Richardson and St. Pierre (2005) suggested that writing narratives helps us to understand the world and society around us, because by writing narratively you are locating life experience with the historical and social contexts in which you live. Therefore, autoethnography enables the writer (me) and the reader to find a deeper appreciation of the experiences within the narrative (Spry, 2001). Adams and Holman-Jones (2011:110) point out that within autoethnography, identity and

experience are 'uncertain, fluid, open to interpretation, and able to be revised'. This fluidity between cultural and personal experience can make the exploration of experience and knowledge of people important as a research method in social science research (Chang, 2008; Hanauer, 2012), which Clough (2000:290) described as a vehicle for forming 'new parameters of the social'.

However, autoethnography is not without its critics. For instance, Chang (2008) suggested that autoethnography has its drawbacks with its focus on the self and over emphasis on narration rather than analysis and cultural interpretation. Krizek (2003) goes as far as to say that autoethnography is egotistical and even vain, but he also goes on to say that no matter how personal autoethnography is, it should connect to a larger element of life. In this thesis, I am doing that by connecting some of my personal experiences with understanding the wider aspects of this research, which will be discussed in more detail in chapter eleven (the sequel chapter). In addition, my personal story highlights some of the precious, good memories you hold onto amongst the bad memories in relation to family experience. As Davis (2009) noted, there are many reasons for having silent or distorting family stories, but it is the silences that 'provide the flesh and bone—the backdrop against which meaning is established' (Denzin, 1997:38). I like the way Poulos (2006:113) suggested that even stories in our dreams should be a part of the ethnographic palette because dreams 'can cut through all the hubbub and haze and shadowy ambiguity of everyday life'. However, I feel that day-to-day life, past and present, can also be hazy and shadowy and influence how we might feel in the present, which might influence the research process. Additionally, Richardson (1994) maintained that by telling stories we validate our identity and pain, which may provide a way to developing a critical consciousness (hooks<sup>4</sup>, 2000).

Applying autoethnography to this research meant I was able to describe and analyse my personal experiences to help understand the research experience more (Ellis, 2004; Holman-Jones, 2005). Making use of autoethnography meant using tenets of autobiography and ethnography (Adams, 2005; Ellis et al, 2010). For example, autobiography is when the author writes retrospectively about personal life experiences usually with hindsight (Freeman, 2004), whereas when

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<sup>4</sup> bell hooks is the pen name for Gloria Jean Watkins, who is an American feminist and social activist. She uses lowercasing for her name to signify that the substance of her work is more important than herself as an individual.

doing ethnography, the author studies the cultural practices and shared experiences by becoming participant observers by, for instance, taking field notes of the participant's/researcher's involvement in the research process (Goodall, 2001). Therefore, when writing autoethnographies, the autoethnographer will produce evocative descriptions of personal experience (Ellis et al, 2010), but will also make personal experience more meaningful by engaging that with cultural experience in the research process (hooks, 1994; Goodall, 2006). In this thesis, I have already started to link my personal experiences with the literature review, but will continue to write autoethnographically throughout and will relate my personal experiences more to the data collected and issues discussed, combining my personal experiences to the cultural experiences of this research.

The aim of writing autoethnographically for me was to demonstrate that by re-creating my own stories of the self and identity, I can come to a better understanding of the contexts in which I participated within. But also, as Boylorn (2006) suggested, that autoethnography is a form of what hooks (2000) calls 'repositioning', which enables the writer (me) to be able to say what has not always been easy to say (Tsalach, 2013). For me, writing this thesis autoethnographically, to an extent, allowed me to break the silences of the past, in my own personal contexts and in the contexts of this research. Whilst working with men in this research, I was experiencing life-changing events like becoming a dad, which was a catalyst for me to reflect on the tougher experiences of growing up. Hence personal experiences came hand in hand with my research experiences, enabling me to 'reposition' myself to be able to say what cannot always be said (that talking about personal experiences is not easy).

In relation to the exploration of personal and cultural experiences, during this research process, I now want to consider 'reflexivity', a key concept in qualitative research.

#### **4.5 Reflexive approaches – research story**

During the past four decades, 'reflexivity', has become an important part of inquiry for the social sciences (Berger and Luckmann, 1966; Davies et al, 2004). Macbeth (2001:36) suggested that with etymological roots in critical self-reflection, the contemporary move to analytical reflexivity is marked by a '*turning back upon itself*', which links to my discussion in the previous section on autoethnography.

Reflexivity enables the researcher to ‘take up the knots of place and biography’, which can deconstruct hegemony and resistance (Macbeth, 2001:39, also see Stonach et al, 2007:39), but also, may ensure a ‘methodological rigor with a critically disciplined subjectivity’. For example, feminists sometimes employ self-reflexivity to deconstruct the unequal distribution of power (Knight et al, 2004). As a result, reflexivity can be considered a methodological tool that examines the fluidity of the researcher’s positionality and the power dynamics between research participants (Knight et al, 2004), which can be related to multiple social relations including class, gender and race (Bottero and Irwin, 2003). Parker (2005: 8) puts it well when he stated that:

Reflexivity is a way of working with subjectivity in such a way that we are able to break out of the self-referential circle that characterises most academic work.

This thesis is about some of my personal stories and the stories of the men participating in this research. These are interconnected through the relationships we built and by sharing experience of being marginalised within the contexts we live (this will emerge in the analysis and discussion chapters later). My interest in reflexivity developed when I started to study critical community psychology (see chapter one for more detail), as I realised that reflexivity was a way to ‘break out of the self-referential circle’, as described by Parker (2005:8) above, and instead I wanted to hear the voices of the people who are usually on the receiving end of our academic assumptions and predictions. Moreover, Anderson (1989) argued that reflexivity is crucial in keeping research findings openly creative in the generation of ideas, by preventing the research data from being stuck rigid within a theoretical framework (Shacklock and Smyth, 1998). Thinking in a reflexive, autoethnographical way has made me realise that there are overlaps and connections between my personal world and work as a researcher. Being reflexive acknowledges that ‘*we are always on some corner somewhere*’ (Richardson, 1992:104) and that there are no privileged views in research in relation to research problems, processes and accounts because these things are socially situated.

Both critical community psychologists and disability studies researchers have applied reflexivity to their work. For example, Kagan et al (2011a) suggested that reflecting can result in radically different understandings of our contexts (See

Lawthom et al, 2007 and their work with artists). Disability researchers have applied reflexivity to their work such as Shelley (2008) with personal assistants using reflexive ethnography and Andrews (2005) doing the same with disabled volunteers. Thus, reflexivity plays an important role not just in this research, but also in qualitative research as a whole wherever it is utilised and in critical community psychology and disability studies. Nonetheless, reflexivity can expose the power dynamics between research participants and the researcher, meaning reflexivity may require researchers to emerge from the secure barrier of anonymity and be involved (Etherington, 2007), which can create tensions with the people involved in the research (see chapter nine, pages 207 - 247, for my accounts relating to tensions, in the form of soliloquies).

I have highlighted the reflexive, autoethnographic angle this thesis takes, but in the next section, I want to consider more closely the methodological approach I took encompassing participatory approaches.

#### **4.6 Participatory approaches**

In this research, I used participatory approaches because using participatory approaches invited people (men labelled with learning difficulties) to participate and talk about themselves (Reason and Heron, 1986) and to break down the 'mystique surrounding research' (Chambers, 1997), with participatory approaches seeking to find commonalities between researchers and research participants (Mercer, 2002). These attributes of participatory approaches link well to the autoethnographic and reflexive narratives that provide connections, coherence and multiple meaning throughout this thesis:

Narrative descriptions exhibit human activity as purposeful engagement in the world. Narrative is the type of discourse that draws together diverse events, happenings and actions of human lives (Polkinghorne, 1995:5).

Applying participatory approaches in this research was useful because participatory approaches have a strong history in disability studies (Nind and Vinha, 2012). There are many examples in which participatory approaches have been used to engage with people labelled with learning difficulties (see Minkes et al, 1995; Chappell et al, 2000; Goodley and Runswick-Cole, 2013). According to



Chappell et al (2001), applying participatory approaches has been useful because they have involved consulting participants on what they want to do and how projects should be managed. By doing this, as suggested by Stalker (1998), participatory approaches challenges traditional research practices that are often objective and individualistic. Furthermore, Northway et al (2014) suggested that participatory research recognises that some voices do not get heard in the research process, leaving participants feeling powerless (a philosophy that emerged from Freire, 1972). Therefore, participatory approaches concerns building relationships between the researcher and the participants to equalise power, which I attempted to do in relation to the research aim, to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. In addition, Burke (2003) suggested that flexibility in participatory approaches is essential because of the critical evaluation that might emerge during the research process, which then links back with my reflexive, autoethnographic stance discussed in the previous sections. This enables participants (who might have very different experiences of the research), to be able to share and agree on the topics, approach and methods (Meulenberg-Buskens, 1996). Moreover, the growth of participatory approaches elucidates the range of inventive ways which people labelled with disabilities can collaborate to produce research with non-disabled people (Chappell et al, 2000), which may involve different types of communication such as using performative methods like drama (Fitzgerald, 2007). Hence, participatory approaches can link with the experience of people labelled with disabilities to the social model of disability in the UK (Goodley and Moore, 2000).

Similarly, critical community psychology employs participatory approaches (see Trickett, 2011; Kral, 2014) often under the guise of participatory action research (Kagan et al, 2011a). Participatory action research is a methodology that confronts the complexity of people's issues and seeks to be able to understand people (particularly marginalised groups), in a meaningful and changeable way (Stringer, 2007). In practice, participatory action research means that research is done with people, rather than on or for people (McTaggart, 1997; Nind, 2008). For instance, Nelson et al (2004) found that participatory action research was essential for building trusting relationships and enhancing collaboration and communication between the researcher and participants. The dialogical approach to evaluation (Guba and Lincoln, 1989; Stringer, 2007) and applying participatory action

research implies a democratic approach to research, which is the ideological basis for participatory action research. For example, Dowrick and Keys (2001) suggested community psychology work on disability issues involved action research, which must include people labelled with learning difficulties, through them having a voice. Consequently, participatory approaches aim to work with people with expertise to assist that 'voice' and create action that can lead to the empowerment of people labelled with learning difficulties.

In relation to participatory approaches, another area of study that needs to be considered is 'emancipatory disability research' (Oliver, 1992 – who first coined the term, Barnes, 2003). Mercer (2002:233, also see Barnes, 2003) suggested key principles that may encompass an emancipatory research approach. For example, adherence to the social model of the disability (in the UK); the rejection of researcher objectivity to support the political struggles of people labelled with disabilities; the rejection of hierarchical research relationships, and instead, more collaboration with people labelled with disabilities, with emphasis on using different methods and methodologies. Zarb (1992) suggested that emancipatory research focuses on the qualities of the relationships between the researcher and the researched. Similar to critical community psychology, emancipatory disability research aims to expose the social oppression of people labelled with disabilities and seeks to transform society through political action, making emancipatory disability research praxis-orientated (Mercer, 2002). Similarly, this research aimed to be subjective rather than objective, with the aim to collaborate and work together, building on relationships and using different methods.

Another important focus of my aim and objectives in this thesis was 'health promotion' (as reviewed in chapter one). The health benefits of participation in the arts, for instance, has received more attention in recent years (Hamilton et al, 2003). The arts have been used for health promotion and to tackle social exclusion and to help achieve social capital (Everitt and Hamilton, 2003), promoting social inclusion and promoting public health (NHS Health Development Agency, 2000). For example, the effectiveness of the arts in health promotion has been seen in research on dementia (Spector et al, 2002), raising self-esteem (Matarasso, 1997) and chronic mental health issues (Nicol et al, 2002). Heath (1997) suggested that arts for health should be facilitated by experienced researchers with cross-disciplinary input from other experienced professionals, such as artists, ethnographers and the participants themselves. Therefore, the arts and

participating in the arts is an intersectional way to readdressing social and health inequalities (Acheson, 1998).

However, participatory approaches have also been criticised. For example, Diamond (2004) drew attention to the ways in which consultation with participants is based on external requirements, to involve local people, but will often proceed too rapidly which in turn fails to listen to people and build relationships. This may alienate any input from local people. Thus, decision-making and participation is complex and likely to be out of the hands of marginalised groups. In addition, South et al (2011) noted that 'participation' is problematic because it is complex, dynamic and flexible in nature during its process, whereas, Morgan (2001:221) considered community participation as a '*perpetual allure, persistent challenge*' because of varied interpretations and difficulties in implementing participative work. This can affect power relations as Laverack and Wallerstein (2001:182) argued that the distinction rests on whether projects have an 'explicit agenda' around the social and political change and, caution that many participatory approaches '*do not necessarily seek emancipation or empowerment*'.

Nevertheless, Campbell and Murray (2004) noted that it is bottom up participation and collective action that is likely to have the greatest impact on both well-being and changing the material circumstances of life. With this in mind, similarly to the work I have done with young people and other adult groups (discussed in chapter one, pages 15 - 33), I felt there was a need to apply participatory approaches to create vibrant, 'safe spaces', for the participants to communicate (Nind and Vinha, 2012).

My review of participatory approaches suggests that participatory approaches are important for research with people labelled with learning difficulties (Chappell et al, 2000), hence why I applied participatory approaches in this research. But in the next section, I want to map out some of the philosophical terrain, which underpins this research.

#### **4.7 Mapping the terrain**

Research is complex, fluid and messy (Mercer, 2002) and in a similar way, writing autoethnographically may also mirror some of the complexity, fluidity and messiness that emerges in qualitative research. For example, Spry (2001) suggested that autoethnography is a form of self-narrative, reflecting and critiquing

the self in social contexts which we can make sense of our personal epistemology in opposition to an essentialist position. In addition, autoethnography is a diverse interdisciplinary praxis (Reed-Danahay, 1997) and autoethnographic writing resists grand theorising and positivist research that may decontextualise people (Spry, 2001). The resistance to grand theorising and being objective enables this present methodology to connect strongly to the values of critical community psychology and the social model of disability in the UK.

Moreover, this research focused on a group of men labelled with learning difficulties. With respect to gender/men and disability research, Robertson (2004) considered that work by feminists labelled with disabilities (Morris, 1993) has been important in highlighting how disability research/studies have been 'gender blind' and how gender has been invisible in disability research. In fact, men labelled with disabilities have been taken as representative of 'disabled' experiences in general, although little research has actually been done drawing on the experiences of men labelled with disabilities (Shakespeare, 1996; 1999). For instance, the research is rarely 'about men in a more complex, more problematised, sociological sense'; a situation all too familiar in a medical model and its approach to 'disability' research whereby research is conducted 'on' rather than 'with' participants (Oliver, 1996:72). Although Oliver's insights were written over twenty years ago, the research I reviewed in chapter one (pages 15 - 33) indicates that there is much still to be still done with men and their experiences. Being able to capture this using an autoethnographic approach has allowed me to steer this thesis into an accessible story capturing the spirit of working in the community with the men labelled with learning difficulties, in order to share their experiences (See Smith and Sparkes, 2008). To be able to do this effectively, I approached the study from an ideographic, value laden and interpretivist perspective, which connects to the meanings of the ecological metaphor (Nelson and Prilleltensky, 2005; Kagan et al, 2011a and 2011b) and social model of disability in the UK (Oliver, 1990; Goodley, 2011) discussed in chapter two (pages 26 - 43) and chapter three (pages 44 - 61).

However, can a 'non-disabled' researcher work with people labelled with learning difficulties? Goodley (2011:22) suggested the lives of people labelled with disabilities/learning difficulties have been dominated by individualising medical models historically, which has influenced research on people labelled with disabilities/learning difficulties, and often carried out by non-disabled people. However, I align myself with Barnes (1996, 2002) position in that researchers must

work with a disability organisation, to develop user-led research with and for people labelled with disabilities, regardless if you are labelled 'disabled' or not. In opposition, Oliver (1998) warns about the exploitative tendencies of researchers, who are led by the interests of capturing the experiences of people labelled with disabilities/learning difficulties, to develop their own academic careers rather than the ambitions of people labelled with disabilities/learning difficulties. Linton (1998b:537) suggested:

It is incumbent on non-disabled scholars to pay particular attention to issues of their own identity, their own privilege as non-disabled people and the relationship of these factors to their scholarship.

In relation to Linton's (1998a, also see Linton, 1998b) observations, I feel that I have tried my best to consider my own identity and 'privilege' of being a 'non-disabled' person in a disabling world through writing autoethnographically and understand that my own research could enhance my career and future earnings. However, by aligning myself with a disability organisation (will be reviewed in chapter five, pages 88 - 128) and applying participatory approaches in this research, I feel I did my best to collaborate with the men labelled with learning difficulties using the right methodology.

In chapter two (pages 34 - 51) and chapter three (pages 52 - 69), I considered the overlap between the social model of disability in the UK and the ecological metaphor adopted by critical community psychologists (Nelson and Prilleltensky, 2005) and disability scholars (Goodley and Lawthom, 2005a and Goodley and Lawthom, 2005b). Kagan et al (2011a), from a critical community psychology perspective, highlight the importance of positionality in reflexive work, and see it as something that needs to come under continuous scrutiny as it defines our ideological position in relation to what we know about others.

My position on how we might understand and relate to others is anchored in social constructionism, which is anti-essentialist and anti-realist (Burr, 2003). Social constructionism has its roots in postmodernism, which Burr (2003:4) described as the '*backcloth*' to social constructionism because postmodernism rejected modernism, which embodied the ideas that emerged from the Enlightenment on seeking 'truth' through the application of reason. In relation to social constructionism, Gergen (1973 in Burr, 2003:4) argued that:

All knowledge, including psychological knowledge, is historically and culturally specific and that we therefore must extend our enquiries beyond the individual into social, political and economic realms for a proper understanding of the evolution of present day psychology and social life.

In this respect, social constructionism has many roots including in existential-phenomenological psychology, social history and social psychology (Watzlawick 1984; Holstein and Miller 1993). Several of its themes have occurred in the writings of authors at different times and places. For example, Kant and Marx made constructionist remarks in relation to the structures that form part of society (Burr, 2003). A social constructionist orientation views data not as a more or less accurate view of the world and of the participants, but rather as an account of activities fashioned in multiple contexts of influence (Haydon-Laurelut et al, 2014).

In relation to this, the traditional research paradigms of science may claim 'truthfulness' for their findings because of the objective nature of the research. However, social constructionists reject this and instead research is considered how human life is constructed by context (Burr, 2003), which is where I stand ontologically, because for me the ideas about existence and the relationship between people and society (like social constructionists), lie in the relationships between people, not on the individual people. Furthermore, Gergen and Davis (1985) argued that it is the truth claims that emerge from empirical (i.e. experiments) research that is incompatible with a social constructionist perspective, not the methods themselves. Therefore, in relation to psychology, it may be used to address a 'problem', but problems have no objective existence because, they are always problems *for someone*, through a social constructionist perspective (Burr, 2003).

As I am underpinning this research from social constructionist perspective, viewing people subjectively in their contexts, it is important to note here my own position. Immersed in this thesis so far has been my reflexive, autoethnographic perspective on writing this research, so being a male, a father, son, a young person, academic, researcher and student, all in some way have influence on how this thesis was written and interpreted. My personal experience of working in different communities with marginalised groups and my own feelings of marginalisation in my own personal contexts, has resulted in not approaching this

research as an unknowledgeable, objective outsider (Silverman, 2000). These experiences were useful in helping to build relationships with the stakeholders and the men who participated within this project.

#### **4.8 Summary**

In this chapter, I have considered the methodological backdrop to this thesis by discussing the structure and autoethnographical approach I have taken throughout. I applied a reflexive approach because it helped me put this thesis together and to make a richly contextualised, fluid story that captured the creativity and ideas behind the research in relation to the aim, to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. In addition to this, I explored participatory approaches in the context of disability research, critical community psychology and health promotion, and further I considered the location of this research by exploring the philosophical underpinnings of the research. In the next chapter (chapter five, pages 88 - 128), I will discuss the tools and settings used in the creation of the research in this thesis, continuing my review in relation to the methodology.

## Chapter 5 - Creating the story: settings and tools

***‘There is no place for ‘subjects’ or passive co-operation ... instead everyone involved is an active participant. Ideally, the expertise and talents of everyone are utilized to the full ... the approach does not, however, reject expert knowledge or help from outside, rather it aims to make traditional research more effective and more meaningful’ (French and Swain, 2004:5).***

***‘The study of narrative forces the social sciences to develop new theories, new methods and new ways of talking about self and society’ (Denzin, 2000:3).***

### 5.1 Introduction

In chapter four (pages 70 - 87), I considered the methodological backdrop to this thesis by reviewing the autoethnographical approach I have taken and considered the importance of reflexivity and the use of participatory approaches in this thesis. This connects with how I located myself philosophically within this research. In this chapter, I discuss how I accessed locations, and describe the settings I used with Galaxy (the museum, the location of the research) and Springfields (the charity that helped me to access the men). I will review the methods that were used in this research (with which the data was collected), that enabled me to construct the story of this thesis. In addition, I provide a discussion of the practicalities of undertaking the research, including ethical considerations and outline how I analysed and presented the data. I also consider how my role as researcher was negotiated, as well as outlining how I collected the data using my reflexive diaries (containing visual and textual data). In other words, having discussed the methodological background to the research, I now want to focus on the research process itself.

The quotes above suggest, that taking action in collaboration with participants in research, is important in allowing traditional research to be more effective and meaningful, which in turn can lead to new theories and methods, used to talk about self and society. However, despite agreeing with this, I am mindful through experience, that community projects and advocating change is not easy. With this



in mind, I will now drift back to a place I love to go to when I want to reflect (which I will draw upon in the next section).

## **5.2 Having problems and making things work**

Whenever I get the chance to go down to South Wales and visit my family in Blaenafon and the surrounding areas, I like to go out of my way each time I visit to a specific place at the top of Blaenafon. Here is where I come to reflect at a place known as the 'Keeper's Pond', a natural looking reservoir in a stunning site that overlooks a large valley at the edge of the Brecon Beacons. Just to the side, the 'pond' is shadowed by black slag heaps, and just over the way from that is 'Big Pit', the place where my dad worked as a miner in 1960s. However, the additional significance of this world heritage site to me, is that it is at this 'pond', my dad likes to recall stories of himself as a child, with his friends and siblings, diving into the pond and having fun despite how freezing cold it was on top of the mountain. It always makes me think of nice images of my dad, as a child, growing up and I try to imagine what he would have been doing. I think about his own difficult journey in life and yet he still always remains positive and works hard. I think about when he was born and nearly dying from bronchitis and his own experiences of a Victorian, violent and drunk father, and his own young teenage body crawling through the seams of coal at 'Big Pit'. I think about him at 21 years of age (in 1967), a lonely stowaway, just a boy, on a train heading for York, but instead ending up getting off at Manchester and still remaining there even now. With the traditional industries declining, he wanted to find sustainable work. He was to manage factories in the 1970s, when workers consistently went on strike, and was to be a social worker in the 1980s, followed by being a nurse in the 1990s. Now aged 68 years, a care worker with the elderly, doing on average five, twelve hour shifts a week. If you throw in five children, two divorces and at times unemployment, I just think as I look at the Keeper's Pond, what an unusual, complicated life my dad has had and yet he still talks positively and is as energetic as ever.

Like my dad, I stubbornly stay positive despite adversity and always look for answers rather than 'dead ends', looking for ways to change things, often through a critical community psychology perspective. For example, I have witnessed change with the marginalised groups that I have worked with as an active

participant. Most importantly, I have seen hope and with hope you get more ideas and strength from knowing that you must be doing something right, in some way, because working with people is 'more effective and more meaningful' (French and Swain, 2004). With this in mind, in the next section, I will discuss the way in which this research started to come together, by considering how I came to work and know the men, as well as other stakeholders in this thesis to develop 'new ways of talking about self and society' (Denzin and Lincoln, 2000).

### **5.3 Accessing the field - Springfields and members forum**

In chapter one, I touched upon my interest in researching men's health promotion and the label of learning difficulties, this stemming from my experiences of working with young men. I decided to take my interests further by identifying Springfields (a local disability charity), as an organisation I wanted to collaborate with, in an area of 'Bromhead', a city in which I had previously worked in the community (see chapter one, pages 15 - 33). The location was ideal because it meant I was familiar with the resources and facilities in the area, and a place in which I had developed networks with local groups and organisations. Below is a brief overview of my interpretation of the setting and background to Springfields taken from field notes:

*Springfields is a local charity that has been based in the community since the 1970's, in a socio-economically deprived area of Bromhead. Springfields provides an advocacy project that involves volunteers working with people labelled with learning difficulties and promotes groups including a football drop in, yoga sessions as well as art and film based activities. It is based within an old building that was once a care home for people labelled with learning difficulties. It is now used as a resource centre by Springfields and another local organisation for the elderly. The building smells of boiled cabbage, with two budgerigars twittering constantly and the furniture looks worn and dated. There are lots of little rooms that were previously used bedrooms and are now used for storage. For example, in one room it is full of old wheelchairs and old sewing machines. Yet despite the negative décor and smell of the place, there always seems to be activity, particularly with the elderly members of the other organisation. The building does have some well-kept gardens and is within reaching distance of the local shopping*

*centre and bus station. Springfields has many members on the 'books', but generally has about forty regular members attending their groups. Springfields are self-funded and get donations through charity events and donations. However, they were also in receipt of funding from the local council for their advocacy project. Springfields has three paid workers and a small hierarchal structure with a board of trustees. Springfields relies mostly on volunteers to facilitate their projects.*

### **Vignette 2 – An overview of Springfields.**

I approached Springfields by email in the early spring of 2010, having seen Springfields being advertised on their website via their volunteer coordinator (Jim) in early 2010, who I thought would be a good gatekeeper (Hammersley and Atkinson, 1997) in accessing the men I wanted to work with. I recognised from earlier work that gatekeeping is an unavoidable step in gaining access to the data needed (Hornsby-Smith, 1993). I felt comfortable and hopeful about this meeting because I felt I could convince Jim that my ideas could add value to the experiences of their members and to the organisation, having had much success and experience in negotiating with local projects in my work with young men. For example, developing groups that men felt comfortable to talk about their health and other personal issues (discussed in chapter one). When I met Jim at Springfields location, he was positive about what I was proposing, that being to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. Jim even suggested that I could deliver some training to his volunteers about working in the community, so that volunteers could learn from my experiences of working in the community with marginalised groups. Jim also proposed that he could talk to other staff and the trustees about my work and inform me of the outcomes. I felt positive about this reaction, which is contrasted to some researchers' experiences, that when you first access projects gatekeepers they may attempt to use '*blocking tactics*' or be '*channelled in line*' to close off certain avenues of inquiry (Hammersley and Atkinson, 1997:75), whereas I did not experience any problems at this stage.

Later in the spring of 2010, I met with a trustee, Susan and two male members of Springfields, Joseph and Gareth (Joseph and Gareth were later to be members of this research project). Their role was to work with me in developing the men's group, which Springfields became keen to do, advising on what the men's group

may involve in terms of activities, and discussed the kind of activities they wanted to do. At the meeting (I invited the people at this meeting to attend and I arranged this to be held in a local community space), it was discussed that we should put on an event, a 'members forum', to be able to speak to members of Springfields, to ask what they wanted Springfields to provide and this event was an opportunity for me to discuss my research. I thought this was a great idea because I believed the forum could act as a sort of 'pilot study' (Van Teijlingen and Hundley, 2002; Peat et al, 2002) to judge how a men's group might work and what it would involve. Staff at Springfields sent out letters and emails to all members on their books. Attached to the letter was a basic questionnaire to send back if they could not attend the event concerning what members would like to do, in what kind of locations and to provide any other ideas they might want to add (Appendix 1, pages 335 - 338). Springfields received some replies from people who could attend, others just sent back the questionnaire unable to attend the event, but most people did not respond. I received 16 responses out of approximately 300 members, although about 50 – 70 members regularly participated in Springfields initiatives such as football groups, yoga and swimming). We felt disappointed that only so few replied, wanting to get involved, but for Springfields it did highlight that despite the many members on their 'books', the relationship they had with members was maybe not so good and it highlighted that there could be support issues on literacy around the need to help members to complete the questionnaire.

However, the members forum still took place in the summer of 2010 and a mixture of Springfields staff, trustees, some carers, seven members, all men, attended the event. Although having seven people turn up was a good group number to do the activities and invite discussion (because people in the audience are more likely to engage with fewer people), seven people turning up was also disappointing. If more members (including women members) had turned up, I am sure more ideas would have emerged to add value to the event and any subsequent project or group that developed from the event. However, the event was engaging in that there was lots of discussion, and interest in the project I was proposing to Springfields and its members. For example, the members of Springfields discussed how they wanted to do more arts-based activities and were interested in health related topics such as 'diet' and 'exercise'. In particular, the idea was put to them about whether they wanted a men's group or a mixed group.

The men were all in full agreement that they would like a group specifically for men. This was very convenient for the research I was proposing, to work with men. If Springfields members had wanted a mixed group, I am sure this would have developed, which might have meant a group developing within Springfields without me doing the research I was proposing with them. Alternatively, I might have contacted other members of Springfields who did not attend the event, who did want a men's group.

Overall, the event worked out well for me because the men I wanted to work with also wanted to develop a men's group. This event made me feel good because I felt that the research I was proposing was starting to take off. Next, I will consider how Springfields and I formed a connection with Galaxy.

#### **5.4 Accessing the field: Galaxy**

Once Springfields (trustees and George) and I had gained some insight into what a men's group might involve such as the members who attended the forum (i.e. Stephen) wanting to do arts-based activities, a key decision upon commencing the research was identifying a location to be able to facilitate a group. Once the 'member's forum' took place, whilst we had some ideas about what a men's group might involve (such as participating in arts-based activities), we had no specific location to be able to facilitate a group. I did contact a few local churches to see if we could use their facilities and we got some supportive feedback, in that their halls were available but always at an expense. Trying to get somewhere free was important because Springfields did not have money to sustain a group that involved costs and, although Springfields suggested that the men could pay a contribution to the costs, I wanted to avoid this, knowing that marginalised groups, in my experience, do not have spare money to be able to spend on attending groups or travelling to locations.

In the autumn of 2010 (October), I met again with staff from Springfields at their base. The meeting included, George, Gareth and Joseph. The meeting was about where we could develop a project for a men's group and which members we should approach and ask, and how they would access transport and what activities they might want to do. For example, Gareth recommended we speak to his parish priest, and Joseph wanted to do some tenpin bowling. George, a worker at Springfields and a filmmaker, suggested that he would contact the men to see

who wanted to be involved and would arrange any transport that might be needed. Earlier in the discussion, George suggested that we approach Galaxy, because he had previously run a community project there and that there might be room to discuss with them another project (Galaxy is a museum in the North West of England). Everyone in the room thought this sounded like a good idea and Galaxy was contacted and a meeting was arranged (within about ten minutes) for the following week. I was excited about this because before the meeting, it never crossed my mind that I could be facilitating a project in a museum I had not visited since I was a child. Gareth and Joseph were also excited, and were looking forward to visiting the museum with me and George. Below is my perspective of Galaxy and its context taken from my field notes:

*Galaxy is based at the heart of Bromhead, near a major road into the city. Galaxy is adjacent to a key railway bridge, in Victorian brick style, with a canal intertwining underneath with some popular cafes and restaurants. But the old structures from Victorian times are surrounded by newer buildings, encased by glass and silver looking panels. In the centre of Galaxy, we had our first meeting with a community worker (who was responsible for getting community groups to access Galaxy), called Janet. We had the meeting in Galaxy's 'learning centre', which was to end up being the room in which the project (forty-five workshops) took place. I loved the feel of the room straight away. When you first entered, there were windows from the ceiling to the floor and you entered a room, with a back wall of Victorian brick, which matched the viaduct outside. The ceiling was wooden beamed in a style that reminded me of the interiors of an old church you might find at an Oxford University college. There were tables and chairs in the room, but what dominated the room was a bricked alcove in the centre, which partially separated the room into two separate spaces. Immediately I saw the potential for doing different activities and running mini groups within this space. It made me feel that this was a 'safe space', which could help the men (Bryant et al, 2011) to encounter other people with similar experiences and be able to share their experiences. Although Galaxy is a public space, here I was presented with a 'shelter' within to come away from the negative aspects of a full public space (Parr et al, 2004).*

**Vignette 3 – An overview of Galaxy.**

George, Gareth, Joseph and myself met with Janet (community development worker) from Galaxy and had some tea. The meeting with Janet was successful because Janet was impressed with the ideas from the research proposal and the idea of working with Springfields and myself in developing a men's group. Subsequently, we planned an initial five-month project, with a possible extension, which would cover the whole year. This was more than enough time to collect data and build relationships with the men and other stakeholders. Galaxy also suggested that we might want to do a community exhibition too and we thought this could be a good way to sustain the new project and be beneficial to everyone involved including the members of the group. This fitted in with Galaxy's agenda of making their organisation accessible to local groups within Bromhead, forming part of their mission statement, and having funds to work with local groups to create a community exhibition. As mentioned earlier, George's role in representing Springfields was to identify the men who might be interested. George contacted a local care home and other partner Springfields organisations near to Bromhead. There were no rules on age, ethnicity, locality or experience of the men to be able to attend, and other than they are men who had been identified as being labelled with learning difficulties, either by themselves or by other organisations or families. In addition, George arranged a local bus service to pick up the men attending Galaxy, although some men were able to travel by public transport alone or with family/carers. Overall, in a short space of time, this research project was starting to develop into a sustainable project.

Towards the end of 2010 (November), more meetings took place with Galaxy about how the project would work and how we would work together. For example, discussions on what resources might be needed, such as art materials. Galaxy was willing to pay for any resources we needed, which was part of the funding they had for community groups who participated in making a community exhibition for the museum. Galaxy was gaining through our presence, because we were to create an exhibition, but we were gaining by being able to do the project there with all the local amenities we needed such as restaurants, shops, transport including a train and bus stop. These meetings always involved Gareth and Joseph, but we were later joined in this process by Stephen, who was to become another member of the research project once it started. Galaxy asked us to deliver some training and to complete risk assessments at Galaxy itself. Both training and the completion of risk assessments were undertaken by Springfields, Gareth,

Stephen, Joseph and myself. The risk assessments were based on documents from Springfields and considered health and safety relating to physical accessibility of rooms and whether there were lifts available for the men to be able to access all areas of Galaxy. The training involved talking about what the label of 'learning difficulties' might mean (or not mean) and addressing how a critical community psychology project might work. The men who attended the training provided anecdotes about their experiences of being labelled with learning difficulties and how they expected people to treat them. Essentially, it was a way to build relationships and a rapport with everyone, values of which stem from participatory approaches discussed in chapter four. Members of staff from Galaxy including Janet who attended the training, which lasted around two hours.

In December 2010, a month before the project was due to start (January 2011), Galaxy were provided with a semi-structured timetable of potential activities with the group, created by Gareth, Joseph, Stephen and myself (based on the information that was collected from the questionnaire – see appendix 2 to view the semi-structured timetable, page 339). At this point I was excited and imagined all the activities we could do at Galaxy, but it did put me under some degree of pressure because in a short space of time, what seemed like what was going to be a small men's group (possibly in a local hall or church), was suddenly catapulted into a bigger men's project (with over ten men), in a larger organisation with the expectations of creating a community exhibition.

The initial plan was that the group were to attend every other week to take part in filming and other activities within Galaxy. The alternate week would involve being out in the community doing activities or being based at other locations (suggested by members in the questionnaire from the forum) and ideas from the present group about to be formed. However, soon after the project started the men wanted to keep attending Galaxy rather than be in different locations all the time and Galaxy had suggested that because the work the men created would form part of an exhibition, the project should remain there for the whole of 2011, therefore, attending each week. Consequently, the structured timetable did not work and instead the forty-five workshops were planned week by week rather than weeks in advance, which made it easier for activities to be based on what the men wanted to do and this fitted in with the values of participatory approaches in enhancing collaboration and communication between myself (the researcher) and participants (Nelson et al, 2004, discussed further in chapter four, pages 70 - 87).



This was to cause some tension later on during the project and will be explored in the analysis chapters (chapter nine, pages 207 - 247). Next, I will consider the characters that took part in making this project, and how they came to join the project.

## 5.5 Getting to know the men and other stakeholders

The men in this research were introduced to the project in different ways. However, it was George's role as a development worker at Springfields to identify the men who might be interested in being involved with the research. For ethical reasons, this was more appropriate because Springfields had files on the men. For example, Springfields, who worked with the men in their advocacy projects, had access to private data (i.e. contact details) and I did not have this information and did not seek to get permission to be able to view this private data (see British Psychological Society guidelines, 2009). George identified some men from projects run by Springfields, but also others in care homes and alternative partner organisations connected to Springfields. Most of the men lived within five/six miles of Galaxy and a local bus service was organised for them to attend the workshops each week. Some men were able to get to Galaxy on their own. The men paid a small fee to the bus service they used, and other men would use their free bus and train passes to attend. The men who lived in care homes, or needed assistance to access the transport system or buildings, came with carers or support workers. Below are brief biographies of the participants involved including the men, volunteers and organisational workers:

### 5.5.1 The men

Name (pseudonyms).	Details.	Brief Biography.
Gareth	Male, white participant	Gareth was a 64-year-old man and lived alone with his dog. Gareth used the bus service provided to attend. Gareth delivered training and completed risk assessments before the project commenced.

Stephen	Male, white participant	Stephen was a 46-year-old man and lived with his brother and sister in law. Stephen used the bus service provided to attend the workshops and like Gareth helped to deliver the training and complete risk assessments.
Joseph	Male, black Caribbean participant	Joseph was a 56-year-old man and lived with his carer and her family, but had lived independently for most of his life. Joseph attended the project independently from home by bus.
Jeffrey	Male, black mixed participant	Jeffrey was a 42-year-old man and lived in a care home with other men and would use the bus service provided each week.
James	Male, black Caribbean participant	James was a 45-year-old man and lived with his wife independently, but received regular care for himself and his wife at home. James came independently by bus and tram for the first part of the project and his wife started to attend later in the project.
Callum	Male, white participant	Callum was a 42-year-old man and lived with other men in a care home. Callum attended each week with a carer and would come to the project using a bus.
Jack	Male, white participant	Jack was a 32-year-old man and came to the project by train. Jack was the only man who would travel from outside Bromhead to get to the project.
Terence	Male, white participant	Terence was a 54-year-old man and lived within a semi-independent house with other men and attended each week with a carer.
Martin	Male, white	Martin was a 44-year-old man who lived

	participant	in a care home with other men. He attended by using the bus service provided.
Richard	Male, white participant	Richard was a 43-year-old man and lived in a care home with other men in the group. He attended by using the bus service provided.
Jason	Male, black mixed participant	Jason was a 38-year-old man and lived in a care home with other men in the group. He attended by using the bus service provided.
William	Male, white participant	William was a 26-year-old man who and lived with his parents at the family home. He attended by using the bus service provided.
Tony	Male, white participant	Tony was a 48-year-old man and lived in a care home with other men in the group. He attended by using the bus service provided.
Winston	Male, white participant	Winston was a 56-year-old man and lived in a care home with other men in the group. He attended by using the bus service provided.
David	Male, white participant	Derek was a 65-year-old man who and lived in a care home with other men in the group. He attended by using the bus service provided.
Scott	Male, white participant	Scott was a 58-year-old man and lived in a care home with other men in the group. He attended by using the bus service provided.

**Table 2 – The male participants and brief biographies.**

## 5.5.2 Volunteers

<b>Name.</b>	<b>Role.</b>	<b>Brief Biography.</b>
Terry	Volunteer	Terry was a volunteer provided by Galaxy to support the workshops. Terry was a retired special school teacher and an artist. He was a part of the group until the end and inspired some of the sessions and exhibits through his skill and expertise (sculpture, low relief and comic strips).
Matthew	Volunteer	Matthew was a student who came to Galaxy to volunteer. He came for the first 6 months and supported the men in their activities. He returned for the launch of the exhibition.
Adrian	Volunteer	Adrian came for a few workshops, but was best remembered for a workshop in which he brought in a number of different animals for the men to hold, explore and take pictures. For example, frogs, snakes, rats, lizards and giant millipedes.

**Table 3 – The main volunteers and brief biographies.**

## 5.5.3 Organisational staff

<b>Name</b>	<b>Role</b>	<b>Brief Biography</b>
George	Development worker and filmmaker at Springfields	George was the development worker (paid worker) at Springfields. George identified Galaxy as a potential location, identified the men who took part, set up the bus service and filmed/edited scenes for the exhibition. George helped to

		complete the risk assessments and deliver the training.
Janet	Community officer at Galaxy	Janet was the community development worker (paid worker) at Galaxy. We initially approached Janet to start the project. Through Janet we arranged for resources to be provided such as materials for art and sculpture. Janet prepared the refreshments each week, called for meetings and made sure we completed work for the exhibition.
Ryan, Gary, Louise, Alice (See chapter nine, pages 207 – 247, for analysis concerning tensions about female support workers attending a male group)	Paid carers/Support workers working with the men	The project had a variety of carers over the course of the project, who would rarely take part in activities, but stayed in the room and assisted men during the breaks and sometimes in activities if the men needed help.
Others	Galaxy and Springfields staff who occasionally came and supported the project	Occasionally, the project had other people who assisted in some way, but not regularly/consistently such as the chief executive officer at Springfields, other volunteers – who came once and never came back and Galaxy staff.

**Table 4 – Organisational staff (Springfields and Galaxy), other people and brief biographies.**

Next, I want to provide more context to this research by locating this research in the geographic area that we were based within.

## **5.6 Location of the project**

In order to apply good ethical practice and to ensure the anonymity of the organisations and people involved, I have applied pseudonyms throughout (Savage, 2000; Gordan and Wolder-Levin, 2007). In addition, I have applied a pseudonym to the area in which Galaxy is located called 'Bromhead'. Bromhead is a city located in the North of England and like many cities during the Industrial Revolution, unplanned mass urbanisation brought a boom to the local industries and the city of Bromhead prospered. However, after World War Two (1939-1945), the city's fortunes decreased due to deindustrialisation, leading to an increase in the levels of poverty, unemployment and poor health, but in the past twenty years the city has seen much financial investment which has led to widespread regeneration. Now at the heart of Bromhead, there are many expensive retail outlets, with restaurants and banks. Nearby is a train station, numerous bridges and a canal, marks left from the height of Industrialisation, which can be found in many cities in the UK. With Bromhead being a city, it meant that residential homes, such as the men's homes, were quite far away, but the bus routes were reliable and were located right outside Galaxy, which is in the centre of Bromhead.

Now that I have provided some context on locality and how the organisations involved were accessed, I want to consider an important part of any research, that being, the importance of ethics, particularly in relation to working with adults labelled with learning difficulties, which I will discuss in the next section.

## **5.7 Ethics – working with adults labelled with learning difficulties**

This research considered the importance of the rights of participants such as the right to privacy and respect (Murphy and Dingwall, 2007), aiming to avoid treating participants as a means to an end (Atkinson et al, 2000). Similarly, psychology researchers are obliged to consider the needs, feelings and emotions of who we are working with, not just placing emphasis on collecting data. For example, Swain et al (1998) suggested that the more control participants have in the research, the less likely the rights of people labelled with learning difficulties would be infringed during the research process. In relation to ethics, below is a summary of how psychologists should begin to think about the right conduct towards participants, set out by the British Psychological Society Code of Ethics (2009:6):

Thinking about ethics should pervade all professional activity. Ethics can be defined as the science of morals or rules of behaviour ... (whilst) ethics and psychology are distinct, there is nevertheless an overlap as both are concerned with behaviour. Before embarking on professional work, the ethical implications should be considered as part of the work context together with legal, professional and other frameworks.

The British Psychological Society's ethical code (2009) is based on principles that help to ensure that participants have a safe (enjoyable) time, but working to legal and moral requirements. The ethical code set out by the British Psychological Society is based on four ethical values including competence, responsibility, respect and integrity. With these principles in mind, before this research commenced, it was subject to scrutiny by the Manchester Metropolitan University Department of Psychology's Ethics Panel (see Appendix 3, pages 340, to view the ethics form and consent form).

As discussed in chapter one, the inclusion and participation of people labelled with learning difficulties is important in addressing health inequalities (Shogren et al, 2009). However, communication problems can make it difficult for people (in this case adults aged 24 to 65 years) labelled with learning difficulties to express their own health needs and this can be worsened when they have to interact with staff who they do not know very well or at all (van Schrojenstein, 2005). Furthermore, Tozer et al (2013) suggested that preparation is important when setting up a project, but what is also important is gathering information from those who know the participants best, particularly finding out the best ways to communicate with them. Carers and family may provide valuable input by the information they provide. In relation to this, I worked with the carers and support workers of the men to communicate with the men concerning the collection of data and how their data was to be used. I went through the ethics form and consent form with each individual (Appendix 3, pages 340) and I applied accessible language principles in creating the consent form (based on the principles set out by Mencap, 2002 - guidelines for accessible writing). I informed participants of the confidential nature of their participation within the study. Whenever I interacted with the men, I asked their permission to write down any information that they told me and always asked if they were happy for me to take pictures of their

interactions. Sometimes they did not want their picture to be taken and they would let me know verbally or non-verbally. I also assured them that all names and personal information would be anonymised in the final thesis, as well as any other public presentations or publications.

In relation to ongoing consent, Morris (1998) suggested that participation in research is a process that needs to be ongoing and should not be something established only at the beginning of the research. Hence I ensured that at different intervals during the process, I re-confirmed that I had consent to use the men's data by asking the men (sometimes in collaboration with their support workers or carers), that the data I was collecting was allowed to be used for research purposes. The men/support or care workers were also aware that they could withdraw at any time from the research. For example, making them aware that I was talking at conferences about the data I collected. I would ask them directly and the men who could not communicate verbally would put their thumb up. This was confirmed by carers/support workers that this meant 'yes'. I also discussed my experiences at conferences and similar events the following week, as a sort of 'debrief'. At no point did I ask for personal information such as medical background and addresses, because I did not need this information. Personal information like that was known only by the men, Springfields and any carer/support worker connected to the individual men.

Gaining consent is a central ethic in all research, but obtaining consent to participate in research is a challenge (Cameron and Murphy, 2007) particularly in how ethics forms may construct someone as 'vulnerable', or not. For example, Devakumer et al (2013) found that participants placed importance on being able to provide consent when photographs were taken, and that getting consent was challenging but that getting consent is acceptable through different methods (including in writing, verbal or non-verbal). However, I did not find getting consent particularly difficult at any point during the research. I believe that consent was obtained because the men possessed sufficient information, understood the information that was given and were able to communicate a choice voluntarily, being free from any obvious pressure (Dean et al, 1998). Also, the use of pseudonyms and altering non-relevant details was important (Savage, 2000; Gordan and Wolder-Levin, 2007), although the overt nature of a community exhibition and being in a public space disrupted the use of anonymity and even when anonymity is preserved beyond the setting, members are likely to identify



themselves through photographs, films and art work (Ellis, 2004). Moreover, Wiles et al (2007) suggested that signed consent forms can put at risk confidentiality, making personal autonomy difficult to ensure, therefore, gaining consent in this way may depend on the moral sense of the researcher. I felt comfortable that throughout the research process, I was always honest about my role and engaged with the stakeholders in the project, in conversation and took part in activities. In this respect, I felt like I was a participant within this research, having been a participant in many community projects, I know the importance of being able to own my own data and information.

In this research, I ensured that all information concerning the participants was anonymised and kept confidential throughout the study and the subsequent writing of this thesis. For example, names were replaced with pseudonyms (Savage, 2000; Gordan and Wolder-Levin, 2007). In addition, despite much of the data in the analysis chapters having been presented in the community exhibition, meaning that the men consented to have their names and physical identity being presented in the public domain, I have placed a circle of anonymity where the faces of the men or participants may be recognised. This ensures that the people who have consented to take part in this research will remain anonymous beyond the completion of this research. In relation to some of the methods used (particularly film), footage was not analysed or presented in this thesis (i.e. via a CD) because I could not guarantee anonymity including the names of the organisations involved and the identities of the men. Additionally, my reflexive diaries (to be discussed later in this chapter, page 112) were kept in a locked filing cabinet at Manchester Metropolitan University and an electronic version on my computer was password protected. I felt that my background in community work (with the professional training I have received and my awareness of the values of working in communities), and these experiences provided me with a scaffold for developing my research role. In relation to this, in the next section, I will review the complexities that came with my role in facilitating this research.

## **5.8 Negotiating my role – the complexity of roles**

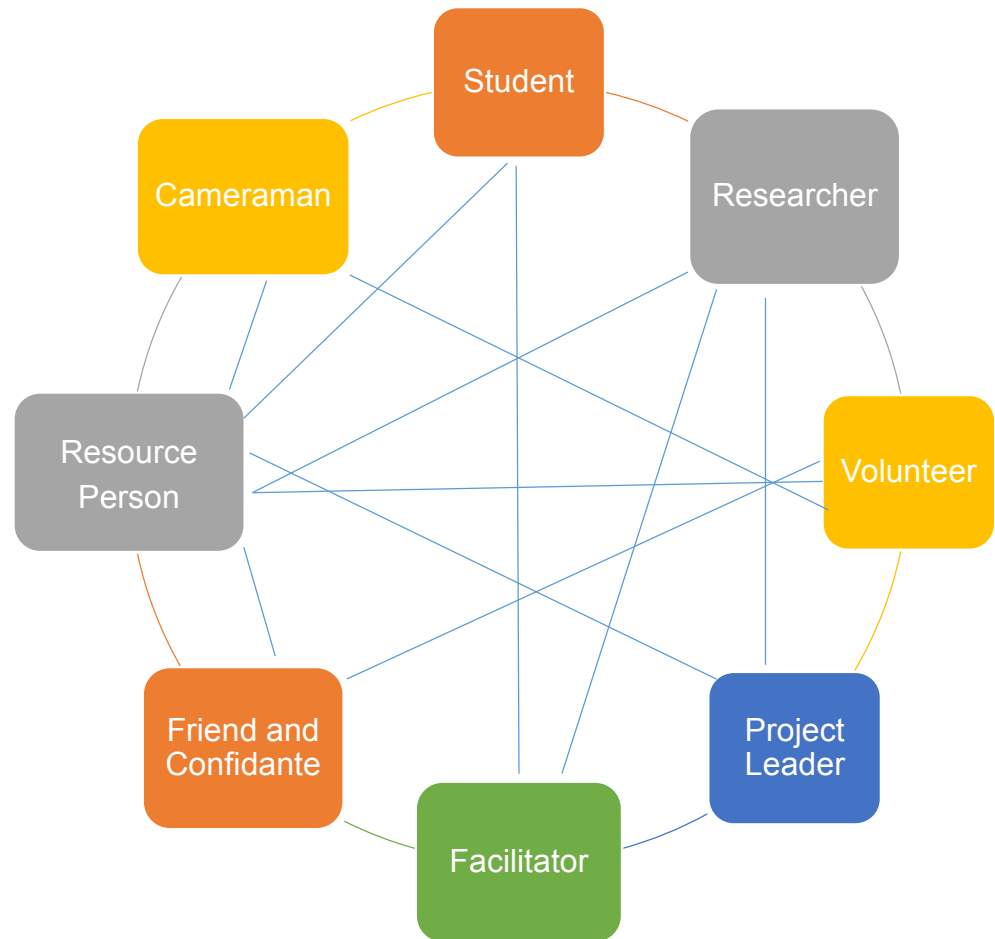
Negotiating my role in this research process was initially fluid and easy despite being an 'outsider' i.e. not being a member of Springfields and Galaxy. Bartunek (2008) and Ritchie et al (2009) suggested that the positions of insiders and

outsiders within participative research approaches can be viewed as existing on a continuum, on which the positions of individuals (like my own position) can alter during the course of the research. I felt that as the research developed, my position was placed on a continuum in which my role was regularly re-negotiated, continuous and changeable (also see Kelman, 1980 and Fahim and Helmer, 1980). As Naples (1996) identified, the fluidity of these positions often stems from social and cultural processes within the context of the study, therefore resulting in the multiple repositioning of relationships (hooks, 1994).

When I first approached Springfields, I went there as an experienced community worker, but essentially I was there to be a researcher and student. I explained this from the beginning and this was reinforced by providing the ethics form stating that my university had given ethical approval (Appendix 3, pages 340). This was important because:

Role clarification at the beginning of the process, identifying areas of expertise and establishing guidelines for the team process will mediate power and control issues (Ward and Trigler, 2001:58).

However, once the project had started, my role began to change, which caused some tensions (to be analysed in chapter nine, pages 207 - 247). Figure 3, on the next page, highlights the different roles I took on at different times, and I represent this in the diagram as a cycle, because these roles were continuous and sometimes these positions would be happening all at one time or separately:



**Figure 3 - The changing roles and positions I experienced throughout the research process.**

The diagram presents the complex, varied roles that require different skills and responsibilities. For example, if I was facilitating an art and craft activity, I would also usually be acting as a support worker for some of the men such as helping them to make a cup of tea, whilst also trying to be a researcher by collecting data. Kagan et al (2005) suggested that roles of a critical community psychologist are different to other psychology roles. For example, roles include facilitation, education, representation and technical roles, so a critical community psychologist can expect to be taking on different roles at one time and that it is important to recognise that different roles may well occur simultaneously, these roles are not mutually exclusive. In the next section, I will consider the ways in which the men participated and the methods that were used to aid participation.

## 5.9 Finding creative ways to participate

In chapter four, I discussed the importance and usefulness of applying participatory approaches to research (See Mercer, 2002 and Nelson et al, 2004). To apply and facilitate participatory approaches, I needed 'tools'/methods'. Initially, I was thinking in a rather generic qualitative way of doing this research that was to use semi-structured interviews and questionnaires, alongside applying methods I had used in previous community work including photography, filming, art and poetry. However, this was soon to change because I felt that the visual methods (i.e. photography) being used enabled more participation and collaboration between the participants (See Heath, 1997 and Northway et al, 2014), so these methods became an integral part of this research, especially in the development of the community exhibition (to be reviewed later in this chapter). For example, Silverman (1998) argued that qualitative researchers should resist becoming excessively attached to any single research technique, therefore using the variety of methods, was also useful in meeting the aim and objectives of this research, to explore the experiences of a group of men labelled with learning difficulties in *participating* in a health promotion project. However, before I review the methods that were used to collect data that was analysed in this thesis, I want to review and provide some justification for using visual methods.

In the social sciences, visual research has grown considerably over the past decade (Prosser, 2006; Pink, 2007; Reavey, 2012). For example, social networking sites such as Facebook and Twitter, have made it more accessible to more people to be able to use visual methods to capture experience i.e. Instagram pictures. One example of using visual methods in this research was a form of 'Photovoice', which has been widely used with marginalised groups including people labelled with disabilities (Booth and Booth, 2003). Photovoice can be defined as 'photography as a means of accessing other people's worlds and making those worlds accessible to others' (Booth and Booth, 2003:431). Hence, the process here of using photography can encourage people to use technology to represent their identity and emotions. Booth and Booth (2003) described Photovoice as giving people labelled with learning difficulties cameras to take pictures that capture their life in society. In other words, Photovoice puts people labelled with learning difficulties in control of how they represent themselves, which I feel is really important for working with marginalised groups, in line with the

participatory approaches applied in this research (see chapter four, pages 70 - 87). For example, Rose (2007) suggested that the 'visual' can act as a trigger for memories and thoughts, which is a powerful way to capture experiences in life. Furthermore, Photovoice sets out to convey the perspective of the person using the camera, allowing them to think about their contexts and share the story of the pictures they take (Booth and Booth, 2003). This links in with Freire's (1972) work on critical consciousness raising (Carlson et al, 2006) and with the values set out by critical community psychologists on social justice (Kagan et al, 2011a). Using Photovoice can be a revealing form of data (Hodgetts et al, 2011) and using camcorders and art and craft, can be used to represent how identity is represented in society and to share stories about life.

Applying visual methods to research is increasing in the social sciences and in psychology (Reavey and Johnson, 2008), although psychology has used visual methods for a long time (for example, in comparative psychology, Richards, 2002; psychopathology, Jackson, 1995; social psychology, Zimbardo et al, 2000). However, the polysemic nature of visualising (Ruby, 2005), which offers different perspectives on the experience of everyday life, has not been fully explored and is still relatively under-reported in psychology (Reavey, 2012). This is surprising considering that society is visually inundated with different opportunities to capture the world around us (Mirzeoff, 1999), particularly through personal technology such as mobile phones and Ipads, in what some authors have described as a 'visual turn' in late modernity (Jay, 1994; Mitchell, 1994); for example, through the use of the Internet, which is visually saturated with information. Therefore, the malleability of digital and personal technology allows the simultaneous experience of visual, audio and verbal data, which is fluid and easily manipulated, whatever kind of technology might be used (Spencer, 2011).

Visual research is important because it throws up issues of subjectivity (Warren, 1982), reflexivity (Reavey, 2012) and brings interpretation into sharper focus, which is in line with my interpretative and ideographic positioning in this research discussed in chapter four (pages 70 - 87). Visual data is perceived and interpreted by others indicating that people will evaluate visual messages differently based on complex differences and commonalities between their experience of the social and cultural contexts (Spencer, 2011; Reavey, 2012). Additionally, researchers have cultural and social experiences that comes with working with participants in research to. Pink (2007) pointed out that the subjectivity of the researcher can

shade his/her understanding of reality, but this can turn into a negotiated version of reality with the participants being researched (in this case the men in this research). However, Banks (2000:2) suggested that researchers should '*let images breath*' – in other words, an image can have long term effects on how other research data is construed as the visuals may reveal unforeseen meaning. Thus, visual methods may record as well as preserve and provide deeper meaning to the activities and feelings expressed, specifically for the men in this research, in a way that is interpreted by the men themselves as well as being interpreted by the researcher.

In relation to the use of visual methods, in the next sections, I will consider the methods that were used to collect data that was analysed and presented in this thesis.

### **5.9.1 Photography**

I previously mentioned the use of Photovoice and its usefulness to previous and present research, with photography being a familiar occupation for people with increasing accessibility for participants in research (Bryant et al, 2010). Although photography has been a useful tool for psychologists for a long time (for example, Bandura and the bobo doll in 1961 and 1963), Banks (2000) suggested that to fully understand the image and ways of constructing meaning, analysis requires a debate of the context in which imagery is used and in its representations in culturally bounded ways. The explicitness of the image is powerful and persuasive and for this reason, images have been consistently used in the sciences, politics and commercial worlds, for example:

Images are no more transparent than written accounts and while film, video and photography do stand in an indexical relationship to that which they represent they are still representations of reality, not a direct encoding of it. As representations they are therefore subject to the influences of their social, cultural and historical contexts of production and consumption (Banks, 2000:178).

Hence, the use of photography/Photovoice was useful for the participants to explore their own cultural, social and historical contexts, which fitted in with the

philosophical backdrop to this thesis from the perspective of the social model of disability in the UK and the ecological metaphor. Gauntlett (2007) emphasised the benefits of using visual methods for an embodied experience, as a worthwhile alternative to traditional interviews and focus groups. I agree, but would also argue that the use of the arts is another viable alternative to capture experience, which I refer to in the next section.

### **5.9.2 Arts (including drama, art and craft, sculpture)**

Health providers are increasingly looking for more innovative ways to deliver services and reach health targets (I touched upon this in chapter one, pages 15 - 33, in relation to my work relating to teenage pregnancy). Also health providers have explored a range of approaches that might help meet those objectives, especially with hard-to-reach groups (Cowling, 2004; Kilroy et al, 2007). In healthcare, the arts are progressively being seen to have roles in enhancing processes of care and acting as a medium for socio-cultural change, in other words concepts of health are becoming more holistic (Abbott and Avins, 2006; McPherson, 2006; Coholic and LeBreton, 2007). One way to consider this is to consider 'arts for health', which can be defined as:

Arts based activities that aim to improve individual and community health and healthcare delivery and which enhance the healthcare environment by providing art work or performance (Smith, 2003:5).

When people think of 'art', it makes people think about many things, which could range from painting to music and drama. In fact, art/the arts is a form of expression, highlighting values or communicating feelings, responses to the social and cultural settings a person/people live within. For example, Nietzsche (1872, in Kaufman, 1967:43) suggested that humans have always felt the need to represent their lives not simply as a reflection or to communicate, but as a way of celebrating existence influenced by the world around them:

An impulse which calls art into being, as the complement and consummation of existence, seducing one to a construction of life.

In this project, different forms of art were used including art and craft, sculpture and comic strips. In addition, drama and improvisation were used depicting stories or debates/discussions about the men's lives, because drama is a technique that is increasingly being used to engage people within research (Christensen and James, 2000) as a way of engaging and expressing feelings and thoughts, with facilitators supporting research participants to be the performers (Fitzgerald, 2007). These types of arts were used because the men wanted to use them (with most of the men having asked to do arts based activities), but also in using these artistic methods it was anticipated they would be presented in the community exhibition at the end of the project.

In my review of the methods that were used in this research, I have discussed the usefulness of visual methods including photography and the arts. Next I want to consider how I personally captured some of the experiences and stories that have emerged from the research process, through the use of reflexive diaries (containing both textual and visual data).

### **5.10 Capturing the experiences and stories**

Recording data using reflexive diaries can be considered a tool for recording observational research findings (Emerson et al, 1995). For example, field notes form representations and is a way of reducing solely observed events, with field notes being preserved in forms of text or visual data that then can be reviewed and considered many times (Emerson et al, 2001). However, field notes are selective because the researcher writes about things that seem 'significant', which could ignore other matters, so do not necessarily provide a complete record (Atkinson, 2002). When I recorded my notes in a workshop, because of the pressures of facilitating and the other roles I undertook, I often recorded what I perceived to be the most meaningful moments (in relation to the aims and objectives of this research), such as events, the fun moments and interesting debate. However, I was unable to record everything. Nevertheless, field notes reflect particular purposes and involves processes of interpretation such as accounts of people, scenes and dialogue as well as personal reactions and experiences (Emerson et al, 1995), which helps with the development and interpretation of the analysis of the findings.



I recorded my reflections after each workshop in detail, so I relied on my memory to write up my reflexive diaries alongside the brief notes I made in the workshops. This was aided by taking pictures during the workshops, which then helped me to reflect on the workshops that took place (I took pictures in line with the ethical considerations concerning the taking of pictures in section 5.7, page 102). I collected visual data using a camera, which often captured the interactions of the men, the activities we participated in, tensions as well as the exciting parts. Harper (2002) suggested that there is collaborative potential of a conversation about a photograph, developing 'photo-elicitation' – variations including 'reflexive photography'. In this respect, my reflexive diaries (which also contained photographs), were a kind of reflexive photography. In relation to this, as I stated in chapter four, applying an autoethnographic approach has helped me to make sense of the data that I have collected and although I kept my reflexive diaries and the observations within them separate at the time from my personal autoethnographies, both have merged together in this thesis (Foley, 2002). For me using reflexive diaries in text and visual form helped me to capture the key moments in this research that will be analysed in the analysis chapters (see chapters six, seven, eight and nine).

I have considered how I managed data collected in visual and textual forms, but I now turn to how I analysed and interpreted the data collected.

## **5.11 Analysing the research findings**

Looking back at my time with this project, including the nine months leading up to the start and the subsequent forty-five workshops over the course of 2011, I feel proud of what we created here (See page 131 for a vignette on a how a typical workshop worked). However, once the community exhibition was opened to the public, I began the long task of sifting through the data collected using the methods discussed, which needed to be conceptualised into this thesis. I want to discuss how I did this using thematic analysis and narrative analysis.

### **5.11.1 Thematic analysis**

Approaches to qualitative research are numerous ranging from diverse epistemological, theoretical and disciplinary perspectives as discussed in chapter

four (pages 70 – 87, for example see Burr, 2003). Yet Braun and Clarke (2006: 79) suggested that thematic analysis should be the ‘foundational method for qualitative analysis’ because thematic analysis provides skills that are useful for many forms of qualitative analysis (Holloway and Todres, 2003; Braun and Clarke, 2006).

Braun and Clarke (2006: 79) defined thematic analysis as:

Identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic.

Here thematic analysis was suitable for the large amounts of data I analysed because it helped me to identify patterns within the textual and visual data that was collected and I was then able to organise the data, which further enabled me to analyse the data. Similarly, Gleeson (2012 in Reavey, 2012) suggested that using thematic analysis, particularly for visual data, helped to identify repetitive features in the data that enabled patterns to come into view. On the other hand, some researchers i.e. Attride-Stirling (2001) and Tuckett (2005), have argued that there is much debate on what thematic analysis actually is or how thematic analysis should be used. In this respect, using thematic analysis may present ethical issues. For example, in relation to using visual data there may be limitations for the analysis of photographs such as ethical issues relating to privacy (Wang, 2001; Meo, 2010). In addition, Spencer (2011:66) suggested that most social research in which visual data is collected can lead to further marginalisation for excluded groups because the focus is usually on the powerless and this marginalisation can propagate a ‘victimist gaze’. This can make the analysis of visual data and organising it into data sets, problematic because without the involvement of the men (in this research) in organising these data sets, I may too perpetuate a ‘victimist gaze’.

However, thematic analysis is flexible and open to a wide range of pattern types for both textual and visual data (Ponnam and Dawra, 2013). For example, thematic analysis can apply meaning with the coding to contexts (Yardley, 2004) meaning that patterns found in the text can also be found in visual data and can potentially provide enhanced meaning to the interpretation of data. Consequently, thematic analysis can work with many frameworks (including textual and visual), and is not stuck on a particular established framework, which means thematic

analysis can work in a way that explores the experiences of individuals in a wide range of discourses (Braun and Clarke, 2006). Furthermore, thematic analysis differs from other analytic methods such as grounded theory and interpretative phenomenological analysis. For example, according to Smith and Ragan (1999), interpretative phenomenological analysis and grounded theory are theoretically restricted despite seeking patterns in the data. Interpretative phenomenological analysis is about understanding a person's everyday experiences in reality (McLeod, 2001). On the other hand, grounded theory comes in diverse versions (Charmaz, 2002) and generates theory from the data (McLeod, 2001). Thematic analysis can accommodate both, and therefore in my view, thematic analysis was the best form of analysis for my data as it is flexible enough to capture a person's everyday experience (like interpretative phenomenological analysis) and yet can still be grounded in the data (like grounded theory) using both textual and visual data.

Before I analysed the data, I felt it was useful to understand what a 'theme' meant. According to Braun and Clarke (2006), themes need to be connected to the meaning within the data and the research aims and objectives. As a result, the themes that have been conceptualised relate to the project's main aim, to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. How these themes develop can be understood using Braun and Clarke's (2006) 'guide' to thematic analysis, which outlines six phases of analysis. Conversely, Braun and Clarke (2006) suggested that these are not 'rules' and may require flexibility to suit the aims of the research (Patton, 1990). Nevertheless, Ely et al (1996) suggested that applying a thematic analysis is an analysis that involves going backwards and forwards through the phases and is not linear. Below are the six phases set out by Braun and Clarke (2006) of how to apply a thematic analysis, which I used initially in the analysis of the data:

Phase	Action
1	<b>Becoming familiar with the data</b> - Immerse into the data sets, 'repeated reading' to get familiar with the depth of the data.
2	<b>Generating initial codes</b> - Initial list of ideas from the data, organising data into meaningful groups.

3	<b>Searching for themes</b> - List of ideas, refocuses relevant codes to the broader themes of the project.
4	<b>Reviewing themes</b> - Decide what themes are relevant and refining what is relevant.
5	<b>Defining and naming themes</b> - Define and further refine the themes that are to be presented for analysis and analyse the data within them.
6	<b>Producing the report</b> - Fully worked out themes and involves final analysis of the report.

**Table 5 - Six phases of thematic analysis (adapted from Braun and Clarke, 2006).**

LeCompte and Schensul (1999) suggested that ‘analysis’ is a process needed to reduce data into a story that makes sense according to the aims and objectives of the research, which can be organised into codes and themes, using thematic analysis. I did this by using both textual data and visual data taken from the community exhibition, pictures I had taken (photographs of the content) and my reflexive diaries. Initially, I printed off the pictures I had collected and scattered the pictures, alongside my reflexive diaries, on a table, to think about how I was going to make sense of the data that was collected. I moved back and forward through the data, a complex action (Merriam, 1998), to be able to organise and efficiently handle the data in the best way possible, understanding that often the problem with qualitative research is having too much data rather than not enough (Wolcott, 1999). On page 119, my thematic analysis is presented and it highlights an overview of the initial codes that were formed before being put into meaningful groups. The initial coding was difficult because of the vast amounts of data. Therefore, to help me do this, and to be able to analyse the data more efficiently, I considered Boyatzis’s (1998) ideas on how to code and develop themes along with Braun and Clarke’s (2006) work. Braun and Clarke’s (2006) approach I felt gave me an initial basis of how to approach the thematic analysis, but Boyatzis’ (1998) five steps helped me to focus the lens more in aiding me to form codes, sub-themes and eventually the themes. Boyatzis (1998:10-11) stated that a good code has five steps:

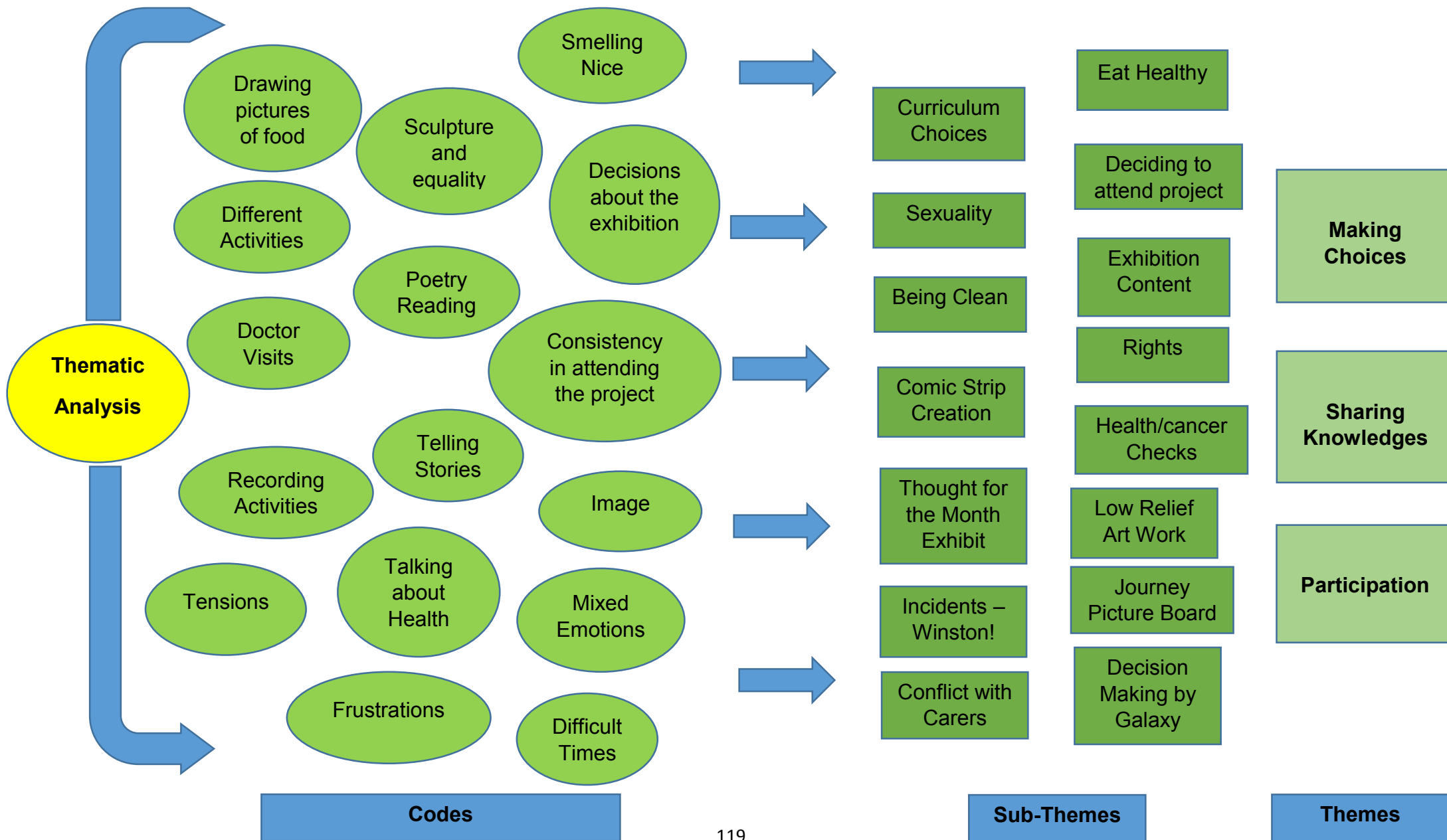
1. A definition of what the theme concerns.
2. A description of how to know when the theme occurs – those aspects that let you know to code a unit for that theme.
3. A description of any qualifications or exclusionary to the identification of the theme.
4. A list of examples.
5. A label.

With Boyatzis's (1998) five-step process in mind, I analysed the data I collected. The diagram of the thematic analysis that was undertaken demonstrates how I linked the codes to sub themes, which subsequently formed the main themes. This involved a lot of swapping and changing around of the data with different labels being applied to the data to form codes. Whilst forming the codes I considered the aim and objectives to the research in relation to health promotion and the label of learning difficulty, which made it easier to form the sub themes and themes. I have presented the detailed outcomes by using this five-step process with theme one (page 120) being labelled as 'making choices', theme two (page 121) being labelled as 'sharing knowledges' and theme three (page 122) being labelled as 'participation'. These main themes will be analysed fully in chapters six, seven and eight.

The analysis of research is subject to the researcher's interpretations of, and selection from the findings, in line with the research aims and objectives (Skegg, 2007). In this respect, due to the rich, in depth and large amount of data that was collected, using all data collected in this research was impractical. Hence, to be able to manage this data, my thematic analysis cut through the data collected. I specifically considered photographs and notes taken by myself (in my reflexive diaries) and the men's work presented in the community exhibition, which was a selection of exhibits that encompassed the variety of visual methods used, including sculpture and arts and craft (reviewed earlier in this chapter). Additionally, despite this research being participatory (Reason and Heron, 1986; Chambers, 1997; Mercer, 2002; Nind and Vinha, 2012), I did not involve the participants in the analysis of this research (see Crang and Cook, 2007). Nearly three years have elapsed, with most of the men moving on into other projects and living in different locations. Thus I have not had contact with the majority of participants in this research since then, so it would be impractical and difficult to

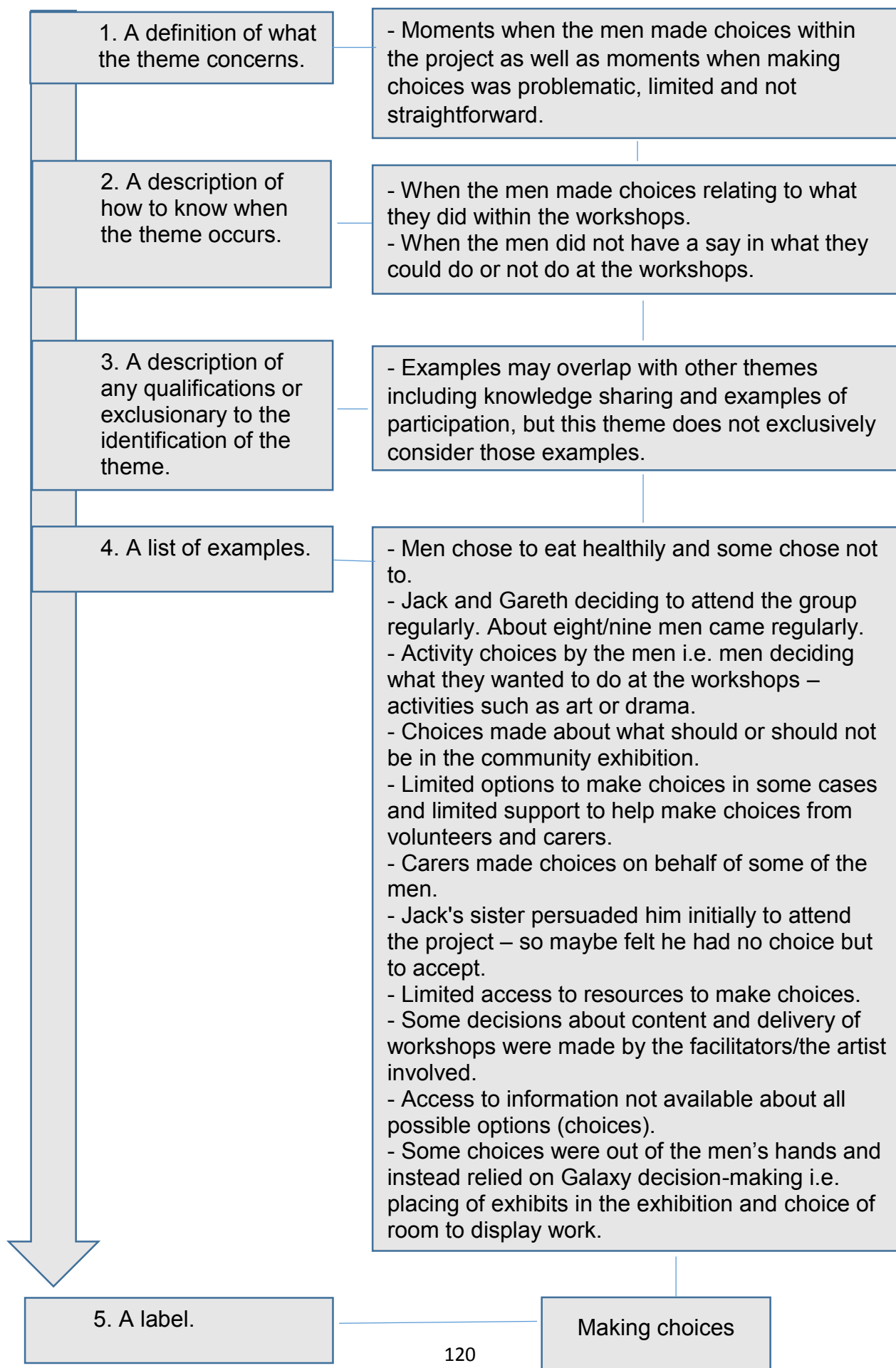
locate the men, searching and expecting disclosure of personal information of the men's whereabouts may not be ethical (British Psychological Society Code of Ethics, 2009). However, this is a learning curve for me as I could have thought about involving the men in the analysis as the study progressed, so although this is a limitation, it is also a learning point for myself in future research.

In this section, I have considered thematic analysis as an analysis that helped me to break down the large amount of data collected into organised, manageable chunks. In the next section (page 123), I will consider 'narrative analysis', which is a form of analysis that helped me to zoom in on more intricate details of the data collected, using textual and visual data.



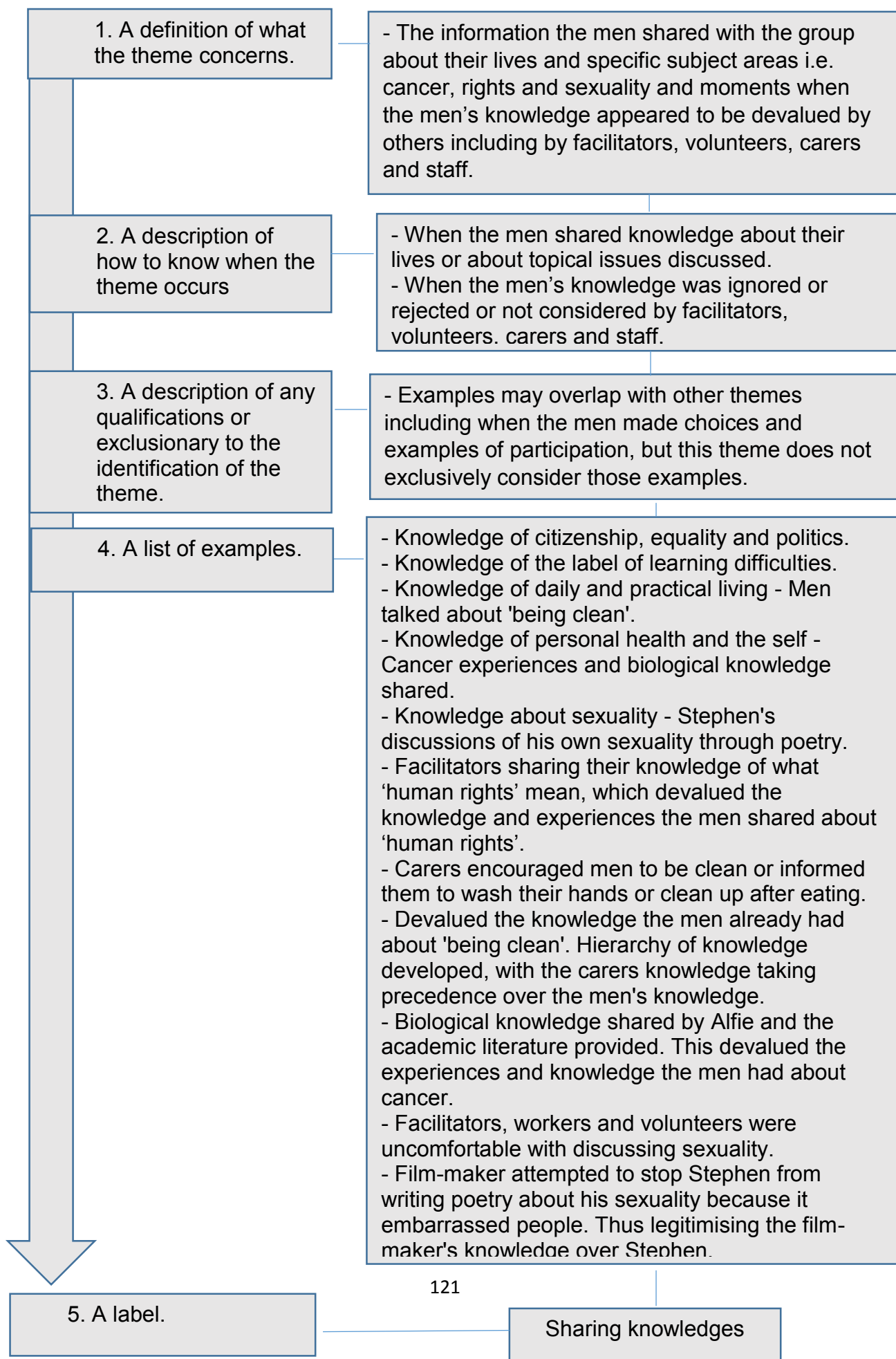
**Figure 4 - The thematic analysis that was undertaken linking the codes and sub themes to form the main themes.**

**Figure 5 – A diagram representing how the first theme, ‘making choice’ was formed using Boyatzis’s (1998) ideas on how to code and develop themes.**

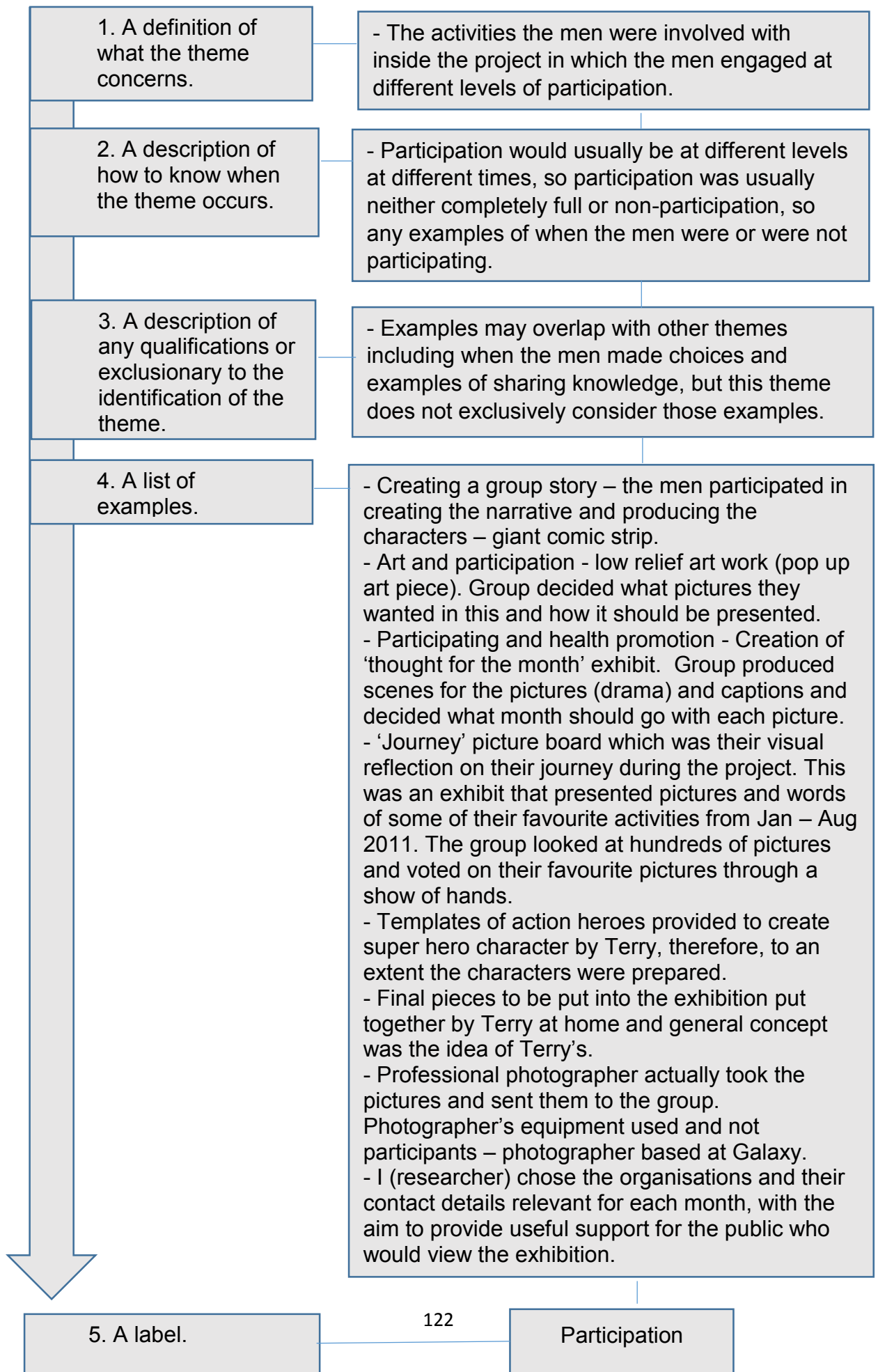




**Figure 6 – A diagram representing how the second theme, ‘sharing knowledges’, was formed using Boyatzis’s (1998) ideas on how to code and develop themes.**



**Figure 7 – A diagram representing how the third theme, ‘participation’, was formed using Boyatzis’s (1998) ideas on how to code and develop themes.**



### 5.11.2 Narrative analysis

In the previous section, I discussed how and why I applied thematic analysis to the themes that emerged, which are analysed in chapters six, seven and eight. But to get a better sense of the tensions as well as positive moments through this research process, I felt I needed to use another analysis to complement the use of thematic analysis to provide a more intricate and detailed insight into the men's experiences in this research. For me that was narrative analysis (Goodley, 2004; Smith and Sparkes, 2006).

Despite the use of narratives being criticised for being fictional (Spencer, 2011), visual and textual narratives can still be the starting point to build a context in which the story telling can become meaningful. In other words, despite the construction of visual narratives, for instance these being complex, with many meanings, narratives always link to much broader narratives (Spencer, 2011). Hinchman and Hinchman (1997) defined narrative analysis as:

Narratives (stories) in the human sciences should be defined provisionally as discourse with a clear sequential order that connect events in a meaningful way for a definite audience and thus offer insights about the world or people's experiences of it.

Narrating can be considered an interactive process of constructing and interpreting experience with others (Cortazzi, 1993, 2001 and Squire et al, 2008), so narrative analysis is potentially a means of exploring participant roles in constructing narrative accounts and in conveying perspectives (Edwards, 1997). In addition, narrative inquiry calls for multiple perspectives, with varied philosophical assumptions and methods (Smith and Sparkes, 2006). Consequently, applying narrative analysis to textual and visual data in this research does not just complement thematic analysis, but narrative analysis may also help to add more meaning and understanding to the data sets.

Epistemologically, narratives (whether visual or textual) can be a way of writing/capturing aspects of our lives and a way of finding out more about our lives (Richardson, 2000). For example, exploring narrative may be useful for providing insights in understanding identity, with its multiple guises and contexts (Smith and Sparkes, 2006) because narratives may help to the structures that mould and divide human beings (Goodley et al, 2004), which can be the same for both textual

and visual data. Moreover, accounts of how to analyse narrative data such as, in interpretative phenomenological analysis, are not common (Squire et al, 2008) and, does not offer overall 'rules' about the best way to study stories. Hence, using narrative and thematic analysis to analyse the textual and visual data that was collected, provided multiple meanings and interpretations rather than, rigid, inflexible meanings abiding to a set of rules.

Parker (2003) pointed out that the emergence of narrative social research, immersed in post-structuralist (Barthes, 1975; Culler, 2002), postmodernist (Foucault, 1972) and deconstructionist (Derrida, 1977) thinking, made an impact on social research because narrative provided in roads and interest in story structure and context. In this respect, narrative social research became concerned with the unconscious and conscious meanings and power within narratives (Parker, 2003). In other words, multiple, complex subjectivities are involved in the construction of narratives, rather than singular storytellers (Squire et al, 2008). Furthermore, Phoenix (2008) considered narrative analysis as advantageous, because, it permitted the study of identity (Bamberg, 2006), which may focus on particular times and places. Thus, narrative/analysis attends to how stories are told and how they are formed, but also narratives can be focused on episodes, a synthesis between biographical and contextual approaches rather than neatly placed as a, beginning, middle and end like you might expect with a story (Phoenix, 2008).

In this thesis, I used aspects of narrative analysis to discuss some of the tensions and perspectives of the stakeholders, particularly the men who were involved with this process. Braun and Clarke (2006) suggested that thematic analysis has no rules per se and is flexible and non-linear (Patton, 1990; Ely et al, 1996). However, thematic analysis does, to an extent, apply a degree of structure through the creation of themes and sub themes, whereas narrative analysis does not have a set way to of conducting analysis (Squire et al, 2008). Richardson (1994) suggested that there were various creative analytic practices including the use of poetry, ethnodrama and fictional representations, another being autoethnography, that may be used when applying narrative analysis. As discussed in chapter four, writing in a narrative format like autoethnography, can encourage connection and empathy (Sparkes, 2002). Therefore, writing in a narrative autoethnographic way allows the researcher to open up possibilities to help the researcher convey a thought provoking and accessible text for the reader

to engage with, which is what narrative analysis attempts to do. For example, I applied a comic strip structure in chapters six, seven and eight with some of the photographs that were collected during the project, to help re-tell some of the stories that occurred, doing so using downloadable comic strip templates. I selected pictures taken by myself and the men and put them together to arrange a story using Microsoft Word, and then applied speech bubbles to capture the men's thoughts and emotions, and also to capture what the men were doing in line with the theme they represented (see chapter six pages 132 - 153; chapter seven pages 154 - 185 and chapter eight pages 186 - 206). Using a comic strip structure helped me to interpret some of the activities/stories that emerged during the workshops, a form of narrative and storytelling. Similarly to Greenstein (2013:76), by using comic strips it felt that it gave a '*much fuller representation of the actual group activity*'.

I have reviewed how and why I used narrative analysis to analyse the data that was analysed. However, another way of using narrative analysis that helped to capture these tensions, problems and good moments in this research, and further to capture the multiple subjectivities that are involved in the production of narratives (Squire et al, 2008) was through the use of soliloquies.

Following on from other authors who have used soliloquies in different ways to present their own emotions whilst engaging in research (Smith, 1999; Saldana, 2003), I too created and applied soliloquies to capture the imagined emotions of some of the key stakeholders in this research. For example, using memory and field notes and reflections about himself, Smith (1999) drew on his relationship with his past, present and future selves as a form of narrative (Athens, 1994; Smith, 1999). I too drew upon my reflexive diaries and my memory to unpack the tensions, positives and difficulties that emerged during the research to create the soliloquies. I created the soliloquies myself, so the words are not the words of the stakeholders (who will be speaking), but my interpretation of how I think these stakeholders were feeling at different points of the research process, based upon the data I collected and the reflections I recorded about the research. Although these soliloquies are 'creative fictions', Smith's (2000:53) words on the next page are encouraging because although the thematic analysis has helped to break down the large amount of data collected into manageable chunks to analyse, what thematic analysis does not do is communicate fully the array of emotions, attitudes and behaviours that formed part of this research process:

In the very moment that they have to be more creative than they would have imagined in order to communicate. It's the very moment that they have to dig deeper than the surface to find words.

The soliloquies, I feel, helped me to not just be a storyteller but a story-reteller (Saldana, 2003) in which I could imaginatively 'restory' my narratives of the key stakeholders, who represent the main groups in the research, this then helped me to 'reconstruct the details of what had been hazy or incomplete memories' (Jago, 1996, pp. 499). For example, I used four stakeholders to present the soliloquies including myself, as the main facilitator; George, who was the main link to Springfields (and was the film-maker); Janet, who was the key contact at Galaxy, as well as Stephen, who was one of the men who attended almost all the workshops and worked with me after the project had ended. Therefore, Stephen had participated in almost everything that was analysed or discussed in this thesis (See chapter nine, pages 207 - 247 for more explanation of why I used soliloquies).

Overall, I felt that using thematic analysis and narrative analysis were the best forms of analyses to use in making sense of the large amount of data that I collected. Thematic analysis helped me to organise and identify patterns in the visual and textual data and I identified repetitive features in the data that enabled the themes to emerge. Narrative analysis helped me to build context in which the storytelling became more meaningful. In other words, despite the construction of narratives being complex, with many meanings, narratives always link to broader far reaching narratives. Thus, applying narrative analysis to textual and visual data in this research did not just complement thematic analysis, narrative analysis also helped to add more meaning and understanding to the data set. Hence, using both narrative analysis and thematic analysis combined to analyse the textual and visual data provided multiple meanings and interpretations.

Before I move on to the next chapters of this thesis, in which I present the analysis of the data, I want to briefly consider how the story was shared during and after the completion of the project.

## **5.12 Sharing the story**

Earlier in this chapter, I mentioned that a part of the negotiations with Galaxy involved the development of a community exhibition. The community exhibition was a part of Galaxy's agenda to reach out to local groups in Bromhead, to get groups and people to access, and engage with what Galaxy has to offer. The aim of the community exhibition was to highlight a specific group and their experiences living within Bromhead. For example, a previous exhibition displayed Chinese migrant workers' experiences in Bromhead. The community exhibition lasts for six-months, with the potential of thousands of visitors seeing this. For example, in 2010, they welcomed 100,000 visitors to Galaxy, so potentially the exhibition could have had thousands of visits including tourists, school children, community groups and people of all ages and ethnic groups. When the idea of a community exhibition was first mentioned, we all thought that this was a great idea because it meant a degree of sustainability over the course of the year, and the potential to do many different activities and really get to know one another. The thought of seeing the men's work on display at Galaxy did excite me and I felt it would be a great way to keep a legacy of the work we would do throughout 2011.

In addition to sharing the work of the men through a community exhibition, I was able to share the project's work through many conferences during 2011 and in one case, Gareth presented with me to share the work we did including through film and photography. In 2012, the physical community exhibition was digitally recorded with some of the men to be able to keep the exhibition 'alive' for years to come. In consultation with others, I opted not to analyse the community exhibition because there was already much data that had been collected.

## **5.13 Summary**

In this chapter, I have considered the settings and tools that encapsulated the making of this thesis. I discussed how and why I accessed Springfields and explored the processes that led towards the journey to the beginning of the actual project. Equally I discussed the process of negotiation with all stakeholders in order to plot how a men's group might work at Galaxy.

I considered the importance of the ethical implications of working with adults labelled with learning difficulties, particularly in relation to informed consent,

communication and anonymity. I then went on to discuss the different methods that were used within the project and how I collected the data to be analysed. Towards the end of the chapter, I explored why I applied thematic analysis and narrative analysis, as ways to interpret the data, and considered how I/we shared the experiences of our time at Galaxy through a community exhibition.

The first part of this thesis has considered how the theory, studies and personal experiences relevant to this thesis. The next part of this thesis will consider the data itself, which was collected and then analysed using thematic and narrative analysis and this will be presented in chapters six, seven, eight and nine. Before I present chapter six and the analysis, on the next page, I have presented a 'cast list' (Beaunae et al, 2011), providing a snapshot of the stakeholders who were involved with the project, and, those who are presented at different moments in the analysis chapters. I have also presented a vignette, which provides a general narrative of how a typical workshop worked, keeping with the story/play metaphor discussed in chapter four (page 70).





# Manpower

## The Story

### Cast List

#### Narrator and Facilitator

Michael ----- PhD researcher and  
facilitator of  
workshops

#### The Men

Gareth ----- Male participant  
Stephen ----- Male participant  
Joseph ----- Male participant  
Jeffrey ----- Male participant  
James ----- Male participant  
Callam ----- Male participant  
Jack ----- Male participant  
Terence ----- Male participant  
Martin ----- Male participant  
Richard ----- Male participant  
Jason ----- Male participant  
William ----- Male participant  
Tony ----- Male participant  
Winston ----- Male participant  
David ----- Male participant  
Scott ----- Male participant

#### The Volunteers

Terry ----- Artist and former  
SEN teacher  
Matthew ----- Student  
Adrian ----- Project worker

**The Workers**

George ----- Development worker at Springfields

Janet ----- Community project worker at Galaxy

**The Carers**

Ryan ----- Carer/support worker

Gary ----- Carer/support worker

Louise ----- Carer/support worker

Alice ----- Carer/support worker

**Others** ----- Galaxy Volunteers

(Also see Beaunae et al, 2011 in which a cast list is used).

## *Once upon a time .....*

**B**efore the men arrived at Galaxy, each week at one o'clock every Thursday, tea, coffee and biscuits and any materials we needed for that workshop were made available to use for the activities the group would participate in. Before the men arrived I would talk to the volunteers at Galaxy about the kind of potential activities we would participate in on that day. For example, if the theme was 'happy memories', we discussed how this could be integrated into an activity whether it be through drama, art or debate. The theme itself would often be based on the suggestions from the previous week made by the men and the methods i.e. film, art or poetry would be implemented in such a way that it would maximise participation around that theme.

The room itself was different than the usual day centres some of the men were used too. Here you did not get the ultra-clean, primary school looking toilets and taps and signs saying 'danger' or 'please wash your hands' (which some of the men may not have understood anyway, if they could not read). Instead, one half of the room was brick and the other side had down to the floor glass windows. The roof was wooden beamed and dusty, but different to the surroundings the men or I were used too. In the middle of the room was a large red-bricked alcove which divided the room into two. Both sides had seats and tables. Over time, the alcove was used as a divide where one part of the room was used for activities and the other space for when we had a break. The room sometimes felt like a fishbowl because whilst we worked, members of the public would walk on by and stare in or enter the room thinking there were exhibits to look at.

Some of the men would arrive early and I would sit and chat with them, over a cup of tea and talk about topics that had been on the news or what the men or I had been doing throughout the previous week. When the rest of the men arrived, we discussed if they still wanted to do the activity suggested, which more often than not they would agree to. We would spend the first hour participating in the activity. For example, if the activity involved drawing we would sit together as a group and draw and talk at the same time. The volunteers would help the men who needed it to use materials such as scissors to cut things or move the furniture to create some space to move about.

At break time, we would all help each other make some tea or coffee and sometimes there would be squabbles over how many biscuits some of the men had or not. This would soon disintegrate and we would talk more about the activity or themes or about life in general. The atmosphere around the group was usually very relaxed and informal. The carers would often separate themselves to the other half of the room rather than join in, which really stood out in a fairly enclosed space.

In the second half, we would usually participate in a different activity such as drama or walk around Galaxy. We ended by talking about what we might do next week, usually at about four o'clock. Putting the furniture back would take ages to do, but time was sometimes delayed because the men seemed to want to stay and keep chatting even when they had to go. One man always refused to leave his seat and only when the room was clear of people and we started to walk away would he then run out of the room.

### **Vignette 4 – A typical workshop.**

## Chapter 6 - Act one: making choices

***'Uncle Remus: Once upon a time – not your time, nor yet my time, but one time – I was goin' fishin' and I was just thinking how the flowers and critters was curious things. They can look into your heart and tell when it sings, if it's whistling a tune or singing a song and they all say howdy when you come along' ('Song of the South', 1946, Directed by Harve and Foster).***

***'Like stories themselves, narrative inquiry supports and calls for multiple perspectives. It might, therefore, best be considered an umbrella term for a mosaic of research efforts, with varied principles, philosophical assumptions, theoretical musings, methods and/or empirical groundings all revolving around an interest in narrative as a distinctive form of discourse' (Smith and Sparkes, 2006:17).***

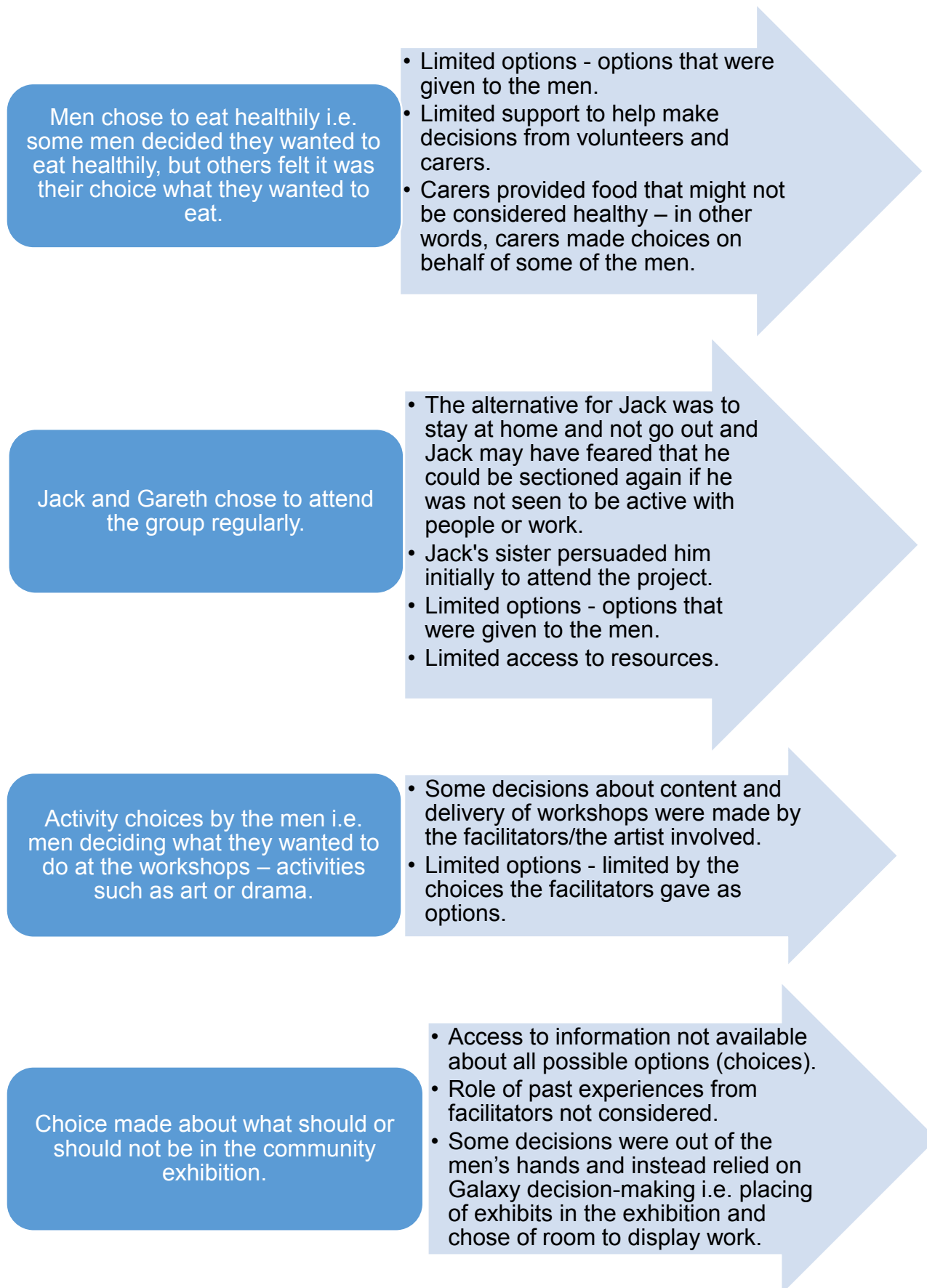
### 6.1 Introduction

In the first five chapters of this thesis, I discussed the theoretical and methodological background to the research. I also discussed why I have immersed myself autoethnographically throughout this thesis, which has helped me to narrate and write how the research was made. Now it is time to tell the story of this research and to bring to life how the story unfolded, hence why I think of Uncle Remus and how he creatively told his stories in the *'Song of the South'*. I also think about the narrative as a 'mosaic of research efforts', which makes me think of the various methods and principles that encompassed this research. However, it is not just about being creative in telling a story, but about the theoretical musings and multiple perspectives that embraces narrative inquiry (Parker, 2003; Squire et al, 2008).

In this chapter, as well as in chapters seven (pages 154 - 185) and eight (pages 186 - 206) to come, I will interpret the findings from the thematic analysis and provide visual and textual evidence in support of the themes and sub themes that have emerged. I will also use vignettes and 'scenes', which will be a more detailed look into how, for instance, a drama scene unravelled or how a discussion or debate, was rolled out during a workshop.

In chapter five (pages 88 - 128), I considered Boyatzis's (1998) ideas on how to code and develop themes along with Braun and Clarke's (2006) work on thematic

analysis. I used this framework to help develop themes and to consider what they mean, and how they have emerged from the data sets (see thematic analysis diagram, page 119). Therefore, in line with Boyatzis's (1998) ideas on how to code and develop themes, the first theme, 'making choices' emerged (see chapter five, page 120 for a diagram on how this theme was conceptualised). This theme considered when the men made choices relating to what they did within the workshops, but this theme also highlighted that, when the men did not have a say in what they could, or could not do at the workshops, demonstrating that 'making choices' for people labelled with learning difficulties is highly problematic with multiple challenges (see Rabiee and Glendinning, 2010). For example, on the next page is a diagram which highlights some of the examples of the choices the men made, but the diagram also highlights that even when the men appeared to be making choices, choices were often limited, complex and not straightforward. I will now analyse each example of choice the men made and the limitations that came with making these choices.



**Figure 8 – A diagram that represents some of the choices the men made accompanied with examples of the complexities and limitations that came with making choices.**

However, before I interpret these choices in more detail, I want to reflect on my own struggles to gain control and choice at times in my own life, which I reflect upon in the next section.

## **6.2 Fighting for control and choice for myself**

I remember having a conversation with Jason from the group about how he liked to hold his paintbrush in a way that was different than how Terry (volunteer and artist in this project) was trying to get Jason to hold the paintbrush. This conversation took me back to my childhood, to the time when people have tried to make me do things, good and bad, that prevented me from making my own choices, which always frustrated me as by doing so I felt they were taking a part of me without permission. I remember when I was in year four of primary school, and my head teacher came around the class and tried to teach me how to hold my pen. I was told to hold my two fingers and my thumb on my right hand, and to hold the pen tight and then write. However, I stubbornly did not like doing this, and instead, I held my pen like an artist might hold a brush, so that my hand was more loose and relaxed. In that context, the head teacher was meant to teach, and the learner (me) was supposed to learn, but it was not the way I wanted to do it because, the head teacher's way did not help me and I have written in my own way ever since with much success. Although I do not doubt that the head teacher was trying to be helpful and do his job, it does in a small way indicate that, choice is complex, and not always straightforward.

Speaking to Jason also helped me to remember a PE teacher at my secondary school (who was nothing less than a bully in my view), a man who wanted to control like bullies do. When he talked, he would send spit into your face, as he screamed in his Liverpudlian accent, and I always felt he was an unreasonable man unless you agreed with everything he said. The PE teacher always demanded that I play for his sports teams, because I was a fast sprinter, he wanted me to compete for the school and claimed that I could 'earn millions'. However, I did not like his attitude and was very polite in saying that I did not want to get involved. I felt participating in this way, to win at all costs, always brought out the worst in me despite being the best (i.e. being more aggressive to win more) and this teacher simply never forgave me for it over the five years I was

there. He nicknamed me 'Forest Gump' because of how fast I could run, but really, it was an insult because Forest Gump was seen as a character deemed to be 'odd'. If I am being honest, I look back at him and think of him as a bully who did not get his own way, despite difficulty and pressure, I was able to make my choices and stick with them and stand up to this bully. However, again, it highlights that making choices can be limiting. Despite choice being important to me, even at such a young age and even when I was given a choice to compete or not, the backlash was very difficult to take as a young boy. Therefore, working with a group of men labelled with learning difficulties, in which their lives are controlled in so many ways, where they have options rather than choices is something I struggle to imagine, because I have been able to prevent the control over me, but at the same time, I empathise with the struggle to gain personal autonomy. With my conversation with Jason, and my own personal reflections in mind, the next section will start to tell the story of the men in this research, in relation to the theme 'making choices'.

### 6.3 Making decisions about health

Below is a scene which provides an example of how a choice/choices were sometimes made during an activity in a workshop:

*The men had just finished their tea and biscuits and having sat down to do some art and craft, the group decided that it would be good to do some drama. Martin shouted out that he wanted to be Ken Barlow from Coronation Street<sup>5</sup>, which decided the scene in effect. The scene would be the men's depiction of how a scene in Coronation Street might be portrayed. I asked the group which characters they wanted to be. Some of the men chose to be the male characters, but I asked who wanted to be Deidre Barlow and they started to laugh and were saying 'no, no, no'. The men were adamant that they did not want to be Deidre because she was a woman. In the end, Gareth said with a smile that he would be Deidre and when the scene had started he attempted to speak in a feminine voice, which made everyone laugh. Before the scene began, the men on 'set' discussed between them and practised what the scene would be about. The scripts were*

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<sup>5</sup> Coronation Street is a popular television soap opera (1960 – present). 'Ken Barlow' and 'Deidre Barlow' are popular characters from the soap.



*improvised by the men themselves. The scenes would last as long as they wanted them too, which would normally be about 1 – 2 minutes. The small group would then perform the scene and we all chatted about it afterwards, discussing what it meant. The men created the scene between each other with some drama and comedy based on their interpretation of TV characters.*

### **Scene 1 – An example of ‘choice’ within the project.**

Making choices concerned making decisions, so to talk about choice, what needs to be considered is what decisions the men in this project made. An example of ‘choice’ can be related to the debates the group had about healthy eating. For example, members of the group enjoyed participating in drama scenes because it was an opportunity for them to talk about their views and to think together and to challenge one another. In one drama scene, ‘choice’ was the topic of conversation, described in the extract below:

Some of the group members did a drama scene called ‘in the deep end’. The idea came from Stephen, who thought of the title. The group then started to think about what they wanted to do, which got the men thinking about healthy food. The men gathered around, and sat in the room we were based in at Galaxy, and collectively discussed what they wanted to talk about and how it could be portrayed in a drama scene. The men who did not use speech, such as Callum and James would indicate their approval or not using hand gestures. For example, if it was a ‘no’, James would shake his finger/arm left to right, whilst doing so with his head. If Callum agreed he’d put his thumb up or down. What I particularly liked was when Stephen specifically and strongly putting forward the argument that ‘choice’ is more important than change. For example, Stephen stated that it did not matter whether you wanted to eat oranges (healthy) or biscuits (unhealthy), and that it is the choice of the person and whether they should have it or not. Afterwards, the group also had a ‘judge and jury’ session, that got them all discussing the importance of healthy food... they created the scenes and discussions as they went along about healthy food and discussed different food items, which, were then deemed by the men to be healthy or not. The scenes were improvised and performed for the whole group (Reflexive diary, 03.02.11).

In other words, one man in the group, Stephen, labelled by society as 'learning disabled' (specifically by social services, by his family and people who do not know him), demonstrated that he can make an argument. Not just by indicating that he knows the difference between what might be deemed as healthy or not but how having the freedom to make a 'choice' in the first place is even more important *'It doesn't matter whether it's oranges or biscuits, it's your choice what you want to do'* (Stephen, 03.02.11). Hence, Stephen had an awareness of what might make a healthy diet and an awareness that he should be able to choose whether he wants to eat healthily or not. However, Stephen was constrained by the options that were available to him because if only healthy food or only unhealthy food was available, Stephen would feel that he would have to make do with what was provided rather than having the choice to decide whether he wanted to eat healthily or not. In addition, despite Stephen's argument that choice was more important than whether food was healthy or not, choice was limited because if the carers or volunteers offered 'unhealthy food' such as biscuits to the men, the men felt obliged to eat it, and not ask if there was an alternative. In other words, the carers and volunteers would make choices on behalf of some of the men, limiting the making of choices.

Furthermore, one set of workshops the group participated in was the creation of 'a thought for the month', an exhibit that attempted to get the public who would see this exhibit in the community exhibition to think about a particular health theme each month. This involved selecting twelve themes on the most important areas of 'health' in the men's lives, which corresponded with each month of the year, in which the men applied a caption to encourage themselves and others to think about their health. The group captured this in photograph 1, on the next page, where the 'thought for the month' pictures and captions were displayed in the community exhibition, pictures they chose to be displayed (community exhibition referred to in the preface and in chapter five). Above the displays of the pictures, a selection of Stephen's poem can be read and the television was on display presenting some of the films the group produced in 2011. The men made the decision to choose the health themes collectively in the group through a discussion and voting system, with a majority decision taken for each theme they chose. If the men did not get what they voted for, they were accepting that a majority vote helped make the decision. On the other hand, this voting system also limited the choices the men made because some men would have voted for other options

which did not prevail for them. Thus making choices in this project, in this respect, was limited by the options provided and the decisions other people in the group were making and therefore, individual choices made by the men were limited.



**Photograph 1 - 'Thought for the month' pictures and captions, displayed at a community exhibition.**

Each photograph in the 'thought for the month' was based on the discussions, activities and actions the group had undertaken each week throughout 2011. The order and the captions were discussed and decided upon by the group when the exhibition was put together.



**Photograph 2 – March 2012 – ‘We cook and clean, to be healthy and gleam’.**

For example, in photograph 2, Joseph, James, Jeffrey and Callum are taking part in different activities that the group felt meant living a daily healthy life. Joseph pretending to do the washing, Jeffrey was pretending to make smoothies, James was pretending to cook and Callum pretended he was doing the cleaning. The group felt these activities helped lead to a healthier life and it was the men who thought of these ideas and wanted these ideas to be portrayed in this activity/exhibit. For example, *‘Cleaning is really important to me, especially before I cook my wife some dinner’* (James, 10.02.11).

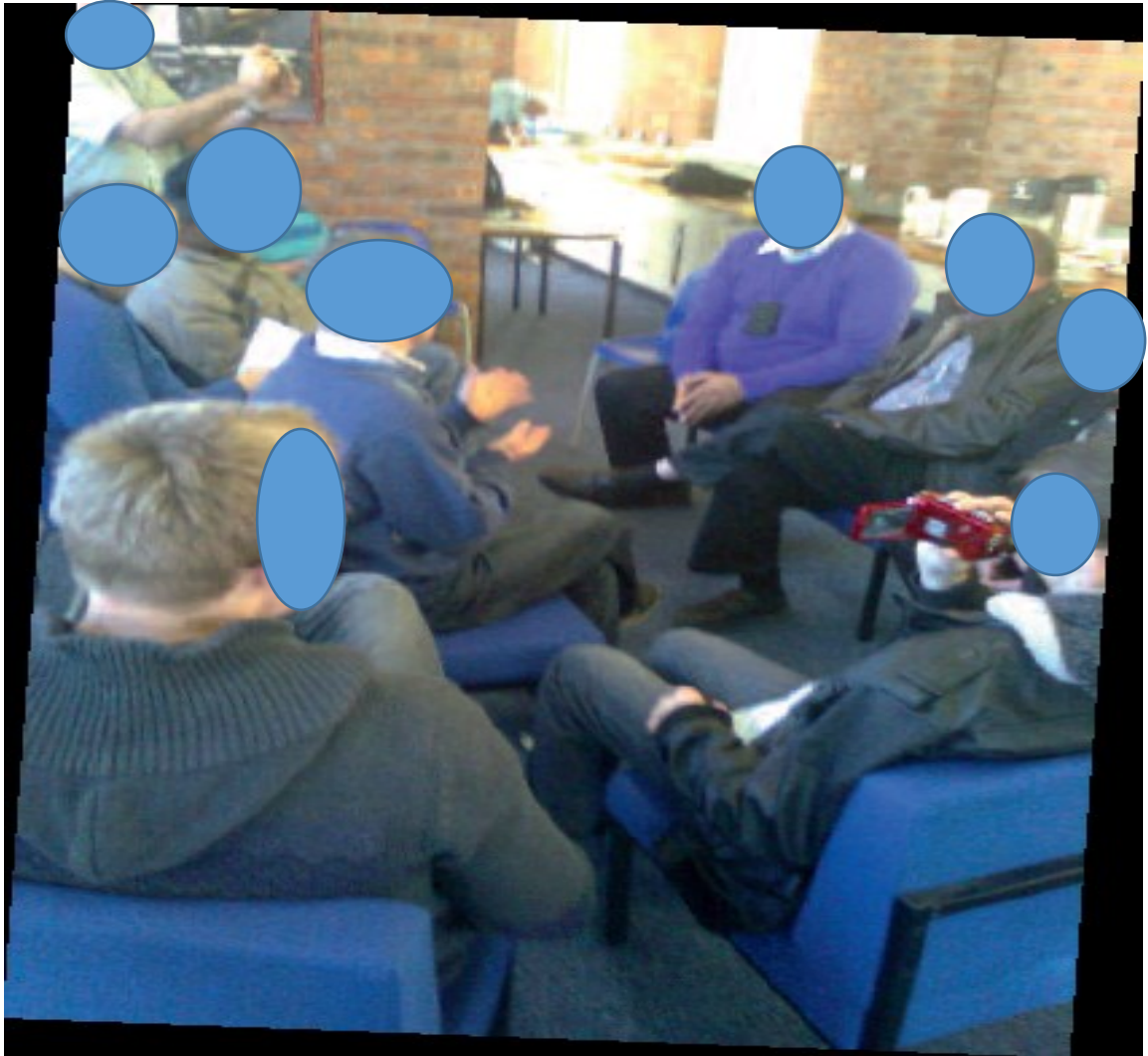
Witnessing the men do these ‘healthy’ activities and making the choice to depict this health theme in that way suggested that making choices that represented their perspectives was important to the men. The group chose this picture in a group and voted on their favourites, although the choices that were made were co-produced and not an individual model of choice. I asked the group what the pictures should be called and the men shouted out their views. For the men who did not talk they would paint or draw their views, which would merge with the choices of the men who could verbally communicate. In addition, the men did not just enjoy the freedom to express themselves, but had fun doing so. In fact,

despite cleaning/cooking/the laundry being seen by most as mundane jobs, they can actually be fun to do. For example, *'I enjoy cleaning. It keeps me busy... focused on doing something'* (William, 09.06.11). Nevertheless, the merging of choices with the men who could not verbally communicate and the men who could talk, highlighted again that there were limited options for the men. For the men who could not verbally communicate, although they looked like they were having fun and could indicate with hand signals whether they wanted to do something or not, this may have made it more difficult to make a choice in a group that was dominated by verbal discussion and debate.

Moreover, the men made the choice to participate in art related activities concerning healthy eating, which captured their thoughts about what foods and drinks are healthy or not. In photograph 3, there is an example of an art piece that distinguished between what food the men liked and did not like, which was followed up with discussion (photograph 4, on the next page) about what food they liked was actually considered to be healthy. Next, I consider Jack and Gareth's choices in attending the project.



**Photograph 3 – Art about food.**



**Photograph 4 – Men debating healthy diets.**

#### **6.4 Individual choices**

One of the men, Jack, lived outside Bromhead and would attend for almost the whole project, by travelling to Galaxy each week by train. Jack came to the project through a recommendation made by a member of staff from Galaxy, who was his sister. When Jack first came to the project he was anxious, and had recently been released from being sectioned. Jack was also concerned that his cerebral palsy (which affected his speech), would alienate him from the rest of the group. After the first workshop, Jack informed me that he would not be coming back because he felt nobody was listening to him. However, I felt that Jack needed to give the project some time and from that his confidence would build. After speaking to his sister, Jack was persuaded to come back and give the project another go and rarely missed a workshop thereafter. Jack lacked confidence and simply wanted to

be liked and listened to and, 'to do things'. With 'Manpower' (name of the project and pseudonym) he found what he wanted because the men spoke to him, even when they did not understand him, they showed patience and listened, which Jack was not used to experiencing. The confidence he gained inspired Jack to buy his own film and camera equipment and Jack became the 'official' photographer and filmmaker in the group. Jack chose to buy this equipment because he wanted to pursue his new-found hobby. Using this equipment empowered him because he felt there was 'something to do', which he felt in control of as well as making choices.

However, the alternative for Jack if he had not have attended the project was to stay at home with his family and stay at home throughout the day. Jack had a fear of being sectioned again, which limits the choices someone who is sectioned can make. Hence, Jack may have had no choice but to attend to demonstrate that he was being active and doing something 'positive' to ensure that he was not taken away to hospital again, limiting the choices he could make. In addition, it was his sister who asked if Jack could become a member of the group and I negotiated with his sister to persuade him to come back, so these discussions, although done with the best of intentions, ensured that Jack did not make any choices about these discussions. On the other hand, each week Jack started to take pictures and film scenes and workshops. Jack really enjoyed this and learned to edit his work (photograph 5, on the next page) and despite hating art, he wanted to take part in art activities (photograph 6, on the next page) because the rest of the group did it and consequently felt part of a team (although this limits choice again), which he had not experienced with his then recent experiences in hospital, which were not positive. For example, *'I didn't like it (being sectioned), I didn't feel like myself'* (Jack).



**Photograph 5 - Jack editing his photographs.**



**Photograph 6 - Jack's super hero – 'Strong man'.**



Another good example of one of the men appearing to choose to attend regularly and make or influence choices in the project was Gareth. Gareth was one of the initial men I worked with when negotiating with Galaxy and Springfields to set up 'Manpower' (pseudonym for the project's name). Gareth was also one of the men who named the project 'Manpower' alongside Joseph. With Stephen, Gareth came to almost every workshop throughout 2011. Gareth lived alone with his dog and was very active in the community and community projects, and was asked if he wanted to join this project without the need to ask any intermediaries, such as carers or support workers.

One of the important contributions Gareth made to the group and subsequently for himself was to talk about his experiences about having health checks. Initially, Gareth was reluctant to talk to the group about, what for him, were intimate and private experiences i.e. penis and anus checks. This could have been related to his 'male pride', but Gareth did admit that it was his lack of knowledge and experience of having health checks, *'I'd never done it (had health checks) before'* (Gareth, 24.11.11). Nevertheless, Gareth informed me that through coming to the group he decided to have these checks and the checks had come back all clear, which does not suggest that someone who is labelled with learning difficulties are less likely to act upon health information. Gareth decided to make his own choice to have these checks because he wanted to look after his own health. In addition, when the group participated in a workshop to discuss male health checks, Gareth decided that he wanted to talk about his experiences. Subsequently, other men in the group, had also been through similar checks, decided to talk about their experiences too, such as James and Joseph. Gareth did not just talk and inspire others to talk about their health experiences. He also supported them by giving them a hug or by sitting next to them if they felt emotional (see photograph 7, on the next page). Gareth would support the other men spontaneously whether we were talking about health checks or not.



**Photograph 7 – Gareth choosing to support other members of the group.**

One of the main reasons why Gareth wanted to attend was to take part in activities that involved art and craft, which was something he had done in other local projects. Each week the group participated in activities that would reflect on a theme that the group or facilitators decided to do. For example, one workshop considered the theme of 'favourite places'. Gareth's favourite place was Lourdes in France. Gareth visited each year with his local church. Photograph 8 and 9 (on the next page) show Gareth presenting his artistic impression of Lourdes. For Gareth this was important because at other similar projects he used the materials to draw, paint and create what was prescribed to him. Gareth did not like this and enjoyed this project's approach of coming together, and for himself to make use of the materials around him, in his own way. For example, *'I want to do things because I want to do them'* (Gareth, 07.04.11). On the other hand, despite the joy Gareth got out of doing this art work, other men in the group did not like doing art, so choice was limited in what they individually wanted to do. Also, Gareth was doing what he loved to do, and although he was not told what to do, in how to paint and draw the picture, the resources that were available to him may have limited the extent to

which he could artistically express his ideas, demonstrating that making choices is complex.



**Photograph 8 – Gareth choosing to present his art work.**



**Photograph 9 – Gareth's artistic viewpoint of Lourdes, France.**

With some of the other participants (Stephen, James, Joseph), Gareth particularly loved expressing himself through drama, whether it was in group scenes or one to one dialogues. Photograph 10 saw Gareth being filmed talking to the camera about his experiences at Lourdes. Gareth showed confidence and always made jokes to the camera and to the people in a particular scene with him. For example, in one drama scene, Gareth suggested doing a scene about a local football club he supported, who had won a game at the weekend from being 3 – 2 down. This scene concerned the men being a football team, losing at half time, and they are in the dressing room. Gareth played the ‘angry manager’ and berated them and told them not to make any more mistakes. However, when he tried to be angry he laughed and the rest of the group laughed with him too. This provided a sense of togetherness that the group had created amongst themselves. However, again, others in the group did not like drama and may have felt that they needed to be involved to keep coming to the project, limiting individual choices for some. Next, I consider more closely how the men made choices in relation to the activities they participated in.



**Photograph 10 – Gareth being filmed.**

## **6.5 Workshop activity choices**

Each week at each workshop, the group would participate in different activities relating to different themes and using different methods such as drama, poetry and art. Each workshop would orientate around the activities and themes the men wanted to think about. For example, drama scenes and scripts were entirely improvised by the men. On the next page is a comic strip, showing how a typical drama scene would function between the men:

# TYPICAL

# WORKSHOP



Comic Strip 1 – A drama scene developed by the men for filming.

In comic strip 1, the men were preparing and performing in a scene about 'healthy food'. The men were asking questions to one another, and to the director about what they wanted to say in the scene. A drama scene would be created by the men and they would choose what to say, and how they wanted to perform the scene. The filming was done by a professional film-maker and also by Jack. Some of these scenes and films were placed in the community exhibition. On the other hand, making choices could be also problematic because although the men would improvise what they wanted to say, the film-maker would regularly cut in and provide some verbal text to add to their scripts in a scene, so the men's words would be essentially edited whilst they were performing a scene. In addition, what made choices more complex was that the experience of the film-maker. In making films with other community groups and the experience he picked up from this, this experience may have influenced how he directed and edited the scenes, therefore, the film-maker's experiences may have affected the extent the men could make choices.

'Making choices' was important when deciding what work they wanted to display in the community exhibition. For example, the exhibits that can be seen in photograph 11 and 12 (on the next page), contain work that the men did not just produce, but they labelled it with their own views and titles and chose what specific art pieces (out of over 100) they wanted to share with the public, which they decided through the voting system (described earlier in the chapter). On the other hand, many decisions that were made regarding what way the exhibits should be presented was taken by Galaxy and not by the men, Springfields or myself. For example, where the actual exhibits had been placed was not chosen by the men. Although where the exhibits were presented was based on the experience of Galaxy when involved with other community projects and the men were happy when they saw their work exhibited, the men may have chosen to present their own work differently, in a way that they wanted to present their work. The actual room was not chosen by the men to present this exhibition, but was chosen by Galaxy, which caused tensions (see chapter nine, pages 207 - 247, for more detail on the issues raised in changing the exhibition room).



**Photograph 11 – The community exhibition showing photographs, the comic strip, objects and materials the men felt should be in the exhibition.**



**Photograph 12 – The community exhibition showing the art the men chose and part of the poem the men agreed should be on display.**



## 6.6 Summary

In summary, the men within this project were able to make choices/decisions about what they wanted to do and how they wanted to express their feelings about specific issues, although to a limiting extent. The men discussed and debated the importance of choice in relation to what they preferred to eat whether it was healthy or not. In addition, some men made important decisions and choices that would affect their time at the project. For example, Jack made the decision to come back and to participate despite going through some tough times in his personal life. Jack went on to buy his own equipment and become the main photographer/film maker within the group. The project itself was based on the ideas and methods the men suggested. This is reflected in the community exhibition in which the men chose which pieces of work they wanted in the exhibition and how it should be titled. Nevertheless, my analysis within the theme of 'making choices' also highlighted that making choices is highly problematic and complex for men (in this research) labelled with learning difficulties because despite the 'choices' the men appeared to make, these choices were also limited. For example, the options that were available to the men in making choices about what they wanted to do in the workshops were limited by the facilitators, so the men had to choose from the options available. In some instances, the men had limited support to make choices from carers and volunteers such as when making choices about what the men wanted to eat. For Jack, the alternative was to stay at home and live in fear of being sectioned again, so maybe he had no choice but to keep coming to the project with his sister persuading him to attend the project. Moreover, resources were limited so that the men could express themselves artistically, but again to an extent and the role of the film-maker ensured that making choices were not straightforward because how the filming/drama was directed was based on his experience, not the experience of the men. The decisions that were made by Galaxy concerning how the exhibition should be presented was never in the men's hands to make choices about.

Overall, the analysis of this theme in this chapter highlighted the complexity and problematic nature of making choices for people (the men) labelled with learning difficulties. In the next chapter, I will continue to analyse the findings from the thematic analysis and consider the next main theme that emerged relating to 'sharing knowledges'.

## Chapter 7 - Act two: sharing knowledges

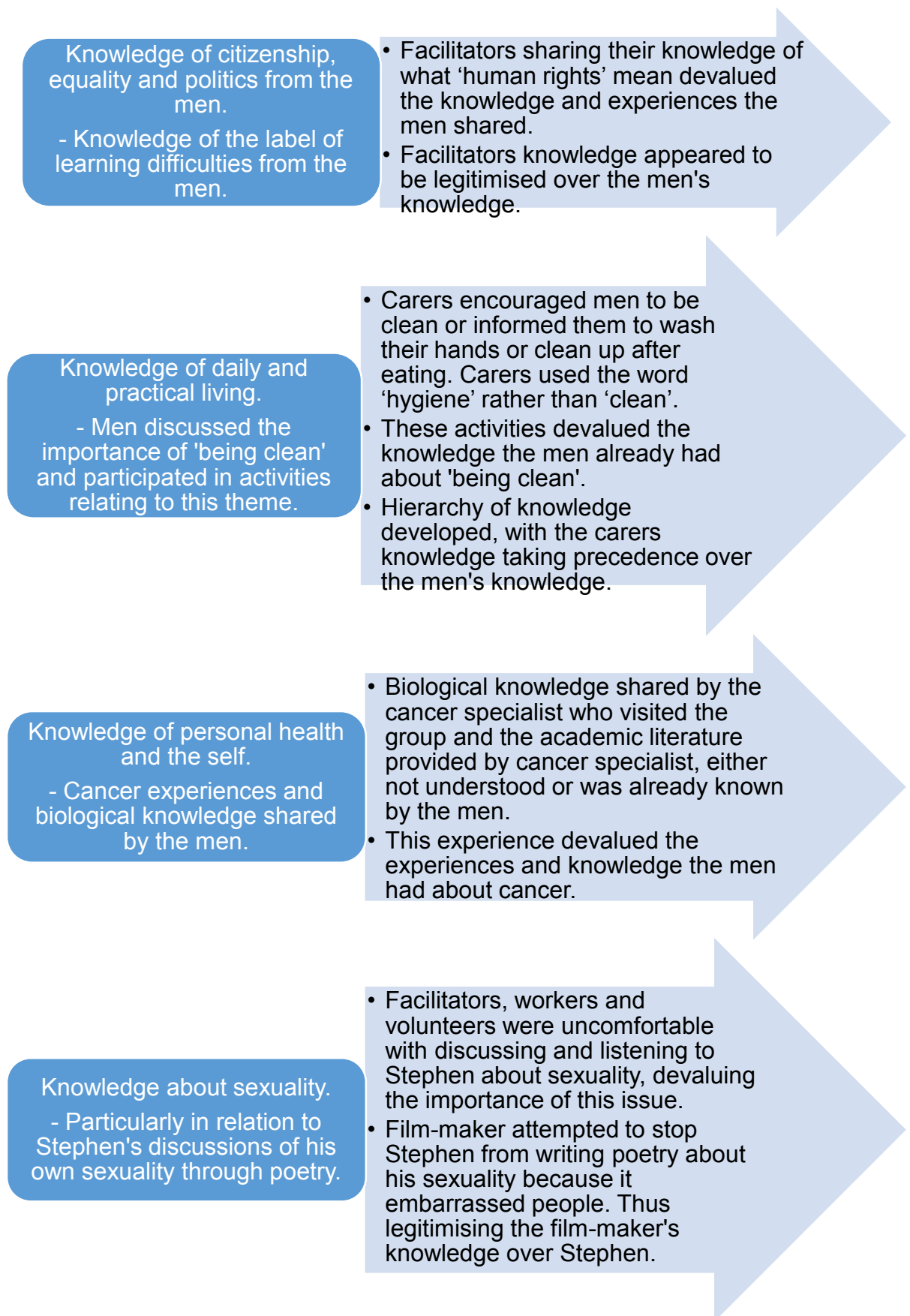
***‘People know what they do; frequently they know why they do what they do; but what they don’t know is what what they do does’ (Foucault – Madness and Civilisation, 1964:59).***

***‘The conception of knowledge as a ‘mirror of reality’ is replaced by the conception of the ‘social construction of reality’ where the focus is on the interpretation and negotiation of the meaning of the social world’ (Kvale, 1996:41).***

### 7.1 Introduction

In chapter six, I used Boyatzis’s (1998) ideas on how to code and develop themes to conceptualise the theme ‘making choices’. In this chapter, I will analyse the next main theme that emerged, ‘sharing knowledges’ (see chapter five, page 121 for how this theme was conceptualised). This theme can be defined as the information the men shared with the group about their lives and specific subject areas i.e. cancer, rights and sexuality, but this theme also highlighted when the men’s knowledge was devalued by other influences within the group from facilitators, volunteers, carers and staff, which is an important issue for people labelled with learning difficulties (See Fisher, 2007). This fits in with Kvale’s (1996:41) quote above concerning the ‘social construction of reality’ and how we interpret the meaning of the social world around us, which the sharing of knowledge enables.

On the next page is a diagram which highlights the examples of when the men shared knowledge and examples of when the men’s knowledge appeared to be devalued. I will now analyse each example of ‘knowledge sharing’ from the men and analyse the moments when this knowledge was devalued by the knowledge sharing of others including facilitators, volunteers, carers and staff.



**Figure 9 - A diagram that represents some of the knowledge the men shared within the project accompanied with examples of when the men's knowledge appeared to be devalued.**

However, before I consider these themes in more detail in this chapter, I will now reflect on some of my experiences, and the expectations that have and are placed on me because of my 'knowledge'.

## **7.2 You're 'intelligent', a 'genius', 'knowledgeable' Michael**

Throughout 2011, there were a number of occasions within the workshops in which the topic of 'intelligence' came up, and discussions about what it meant to the men. I remember on one occasion when Tony talked about how he felt 'intelligent' when he had to do a presentation at another community project because he got to speak about his life. This took me back in time and reminded me of the pressure that was put on me from an early age to be some sort of Oxford University don. The problem with this was that I was expected to be great at everything. In other words, you are expected to be great in a way that suits how people view you to be great, or as I have been described, which I feel embarrassed by, as a 'genius' or 'intelligent' or 'amazing'. Although, when I was young, these compliments made me feel good it was when these compliments were then turned into insults, because I was not meeting these standards of 'intelligence' that I become marginalised or disliked, whether by family, friends, employers or school. For example, I remember in year seven, of secondary school, as part of our English classes, we were expected to do individual presentations. Most pupils did their presentations on football or witches or a TV programme. In my case, I did my presentation on Albert Einstein and the theory of relativity. Apparently, I was the talk of the staff room, according to the teachers and people were talking about it in the playground. I followed this up in year eight and nine with 'the life and times of Charles the first' and 'the Good Friday Peace Process 1998'. I did not want to do some ordinary, silly presentation on a football team or music, but something interesting to me and what I knew about, regardless of the jokes and laughter and, often remarked upon as not 'cool' to do this at that age. Consequently, I was often described as being like Ken Barlow or Roy Cropper<sup>6</sup> from Coronation Street, maybe because those characters are a mixture of naivety, knowledge and social awkwardness as well as also being well liked, but in a pitying type of way. However, you are put into this high level category of 'intelligence' and your identity is constructed by the perception of others, when

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<sup>6</sup> Another well-known character from the soap opera 'Coronation Street'.

your own perception of your own identity can be quite different. For example, later in school life, I was happy to go out with my friends, have a few drinks and meet girls, all dressed up like the modern Danny Zukos<sup>7</sup>. The problem with this is that, this did not match with being 'intelligent' and clashed with people's perceptions of my identity, whereas I felt having fun and learning as well as being successful could go together. On the other hand, the norm did not allow that, so you are either a 'geek' or 'naughty' in that context, making identity development very difficult as a young person.

In my view, seeing 'intelligence' and identity in this way is too simplistic. This thought has become more apparent to me in recent years, not just by working in the community and speaking to Tony and the other men, but by lecturing at university too. I aim to make my lectures or seminars participative and engaging, in which students and I can share experiences and 'knowledge' together. Yet there is still this overriding sense that I am the one who has the 'knowledge' and the students are there to learn, so my approach does not match up to this traditional expectation of learning, therefore, tensions sometimes emerge. My reflections here make me think overall that identity and knowledge are linked, but it is a complex partnership. Thinking of 'knowledge' and my experiences, I now start to explore and interpret the 'knowledges' that the men shared during the making of this research.

### **7.3 Knowledge of citizenship, equality and politics**

Before I start to analyse the findings of the thematic analysis in relation to the theme 'sharing knowledges', I want to set the scene more vividly with a scene in which the men shared their knowledge:

*Today we were in the 'collections' part of Galaxy, where items from the past were stored away and with gloved hands you could go down to the basement and pick them up. For example, old cameras and metal teapots. Going down to the basement felt like going into a secure unit in a top-secret zone, where we had to*

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<sup>7</sup> 'Danny Zuko' is a character from the American musical, romantic comedy film 'Grease', directed by Randal Kleiser. Danny Zuko was a character who hanged about with a gang of boys who would rather race cars and meet girls and have a good time rather than do school work. He always tried to look his best and be 'cool' in front of his friends.

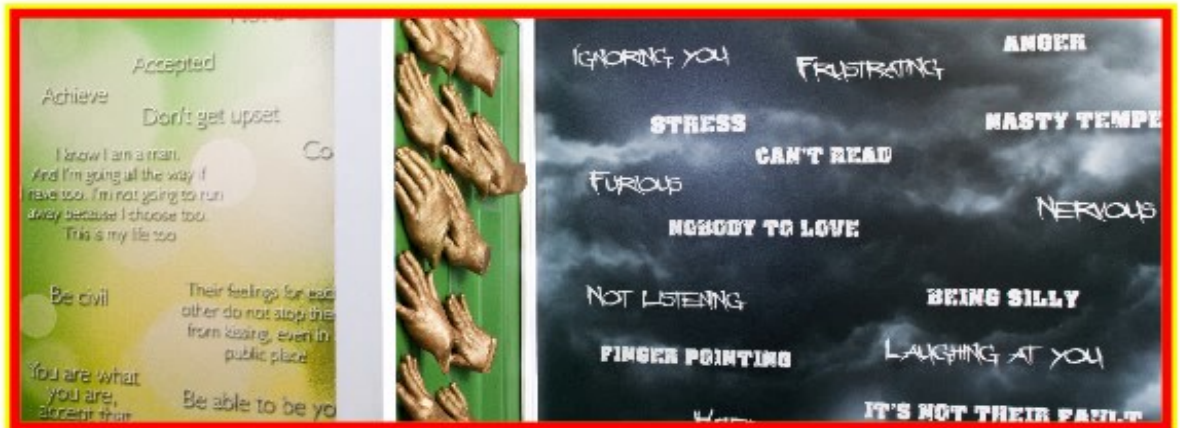
*have a card to access each door, a few doors, just to get to the end of a corridor. The corridor itself was clinical and white and smelt clean, with the air conditioning blowing in your face. Finally, the group got to sit down around a huge, long table with lots of small plastic chairs around it, opposite a small library relating to the items stored down there. On the shelves next to the table were objects they could pick up out of the boxes. Everyone went to the shelves and explored which items they liked best and which items evoked memories that were funny or represented their past or items that they just wanted to explore and see what it did. Despite being in a different location than usual, the men felt comfortable to talk about what meaning their item had for them. For example, Terence's main hobby was taking photographs and used a digital camera to take pictures of the group. In the collections, he chose a camera dating back 70 – 80 years, which was big, light brown and bulky and could only take one picture at a time. Terence shared his knowledge with the group of the differences between his camera and the old camera. This mini presentation invoked other members to share their memories of using similar old cameras when they were younger or seeing them and unable to use them. Similarly, Gareth chose some mining equipment including a lamp and tin hat. Gareth shared with the group how these would be used in the mines, a knowledge he learned from his uncle who was a miner. The same process happened with other men in the group, sharing stories or memories. For instance, Jeffrey enjoyed feeling and touching a calculator that looked very old and he kept pressing the buttons and doing sums. Jeffrey did not say what it meant to him, he may have just simply liked it and wanted to have fun with it, but in his silence he still shared with the group his pleasure at using the calculator by continuously tapping the buttons. Also William chose some old irons and hoovers that looked like they dated from the 1970's and he particularly liked them because he also said how much he enjoyed cleaning at home, although cleaning products such as irons were more easier to use now he felt.*

**Scene 2 – An example within the project of how the men shared knowledge about their lives and memories.**

This scene is one example of when the men shared knowledge about their lives and memories, usually memories that reflected on what they liked to do, including cleaning and using cameras. The type of knowledge that emerged from the men engaging with each other was stimulated by using items from Galaxy. Similar to

the exhibit, the 'thought for the month' (analysed in chapter six), the group wanted to portray how they had been prevented from expressing their views in their lives. Terry, a volunteer from Galaxy, who was an artist, suggested the group could create a sculpture to represent these feelings of marginalisation. On the next page is a comic strip of the process of creating sculpture. Essentially, the men created plaster casts of their hands, which were attached to a door, symbolising a barrier between the bad they have faced in life, trying to break down the door to greet their hopes and desires. The 'bad' reflected the many reasons why their mental or physical health had not always been good for them and the reasons why, their well-being may have been affected. Words and statements such as 'rejected', 'hated', 'finger pointing', 'not able to get a job' and 'nobody to love' are the words of the men, which suggested their knowledge had been undervalued. The comments and actions described words attributed to people or institutions they have come across in life such as family, friends, care workers, teachers, schools and places of work. Thus the men shared their knowledge about the injustices they had experienced in life, and considered these problems to have been attributed to them. In other words, they are experts in knowing about marginalisation. On the next page is a comic strip of the making of this sculpture:

# THE MEN'S RIGHTS



**Comic strip 2 - Process of designing and creating the sculpture allowing different knowledges to emerge.**



The development of the sculpture and the meaning the men applied to the sculpture, suggested that the men collectively felt that their rights had been infringed during their lives and is subsequently expressed through words and sculpture. In addition, the men's knowledge of having rights to 'have sex', be 'accepted', not getting 'upset' or wanting people to 'be civil', suggests that the men wanted society to be more aware of their responsibility to behave respectfully and equally towards people, in this case with people labelled with 'learning difficulties', in 'the way we (the men), want to feel and to be fully accepted as the people we want to be'. These examples are words/actions the men wanted to experience, but are depicted beyond the green door, out of reach. On the other hand, despite the men expressing their views on citizenship, equality and human rights, the men's knowledge was still devalued. For example, Galaxy did not want the word 'sex' on the sculpture because they considered the word to be obscene for children who may visit and observe the exhibit. This devalued the significance the men placed on not 'having sex' and wanting to have sex and legitimatised the knowledge of Galaxy over the men in that the issue of sex and the men's knowledge of this subject was less important than Galaxy's knowledge on the appropriateness of using the word 'sex'. Hence, a hierarchy of knowledge was formed because Galaxy's knowledge, of the appropriateness of displaying the word 'sex', was more important than the issue the men were raising in this exhibit. Next, I consider the men's knowledge concerning the label of 'learning difficulties'.

#### **7.4 Knowledge of the label of learning difficulties**

The topic of what 'learning difficulties' meant to the men emerged from the sculpture too, and can be connected to the men's knowledge of what the label of learning difficulties means or does not mean. For example, the men viewed 'learning difficulties' to be the labels/attitudes/behaviours that they stated on the 'dark side' of the sculpture, whereas, on the other side of the 'door of hope' they state what they regard as what they want to be or are, which are not usually attached to the label of learning difficulties. I asked the men if they considered themselves to be people with learning difficulties and almost everyone did not consider themselves people labelled with 'learning difficulties' (asked as a group). Instead the men spoke about the effects of the label, which are reflected on the 'dark side' of the sculpture. The men recognised that it was others who described

the men as learning disabled and recognised that it was others who used that language, whilst the men did not view themselves that way. Thus it demonstrated that knowledge is complex and knowledge reflects upon experience of people. For example, Terence spoke about being bullied because of his 'cerebral palsy':

Terence had some heartfelt words today in that he said he never forgets, on a daily basis, how he was bullied has a youth ... because I could not speak clearly (Reflexive diary, 30.06.11).

In addition, Martin got very angry whilst talking about his frustration concerning his carers considering him has some one with 'learning difficulties', *'I am not disabled, I just need some help'* (Martin, 30.06.11). On the other hand, James stated very clearly that he did consider himself to be 'disabled':

James said he had Asperger's Syndrome (as a result from 'autism at birth'). I asked why he felt he had this and what makes him have 'Aspergers' (syndrome). His response was that he can come to the men's group (what an interesting response) ... In other words, he was 'disabled' and if he wasn't he would not have come to the group, viewing this project as a 'disability' project, a project that was meant to challenge the label of learning difficulties ... the project itself made him feel disabled (Reflexive diary, 16.06.11).

James indicated that if he was not 'disabled' he would not have been illegible to attend the project. Therefore, it was the group itself that made James 'disabled', not his own 'impairments'. This 'hierarchy of knowledge' of being placed in a 'disability' group, in which the men were not asked their opinion about what they 'have' (label/symptoms), demonstrated that knowledge was imposed on them about what others (usually non-disabled people) think 'disability' is (myself, volunteers, carers, Galaxy and Springfields). The construction of a project that was specifically for men with the label of learning difficulties meant labelling the group as disabled, which contradicts the point of it trying to reject the label of 'learning difficulties'. Consequently, this demonstrated that James as well as Terence and Martin had knowledge about what it means, or not to be 'disabled', and related it to their rights that had been taken away whether through bullying, labelling by carers or by simply attending this project. The men shared knowledge about their

experiences of being labelled with learning difficulties and this knowledge was mostly negative and frustrating for the men, particularly because the men also had knowledge of how they would like to be seen, and what they would like to experience. For example, to 'have sex', be 'accepted', not getting 'upset or wanting people to 'be civil'. Thus, the men had knowledge of a sense of inequality and marginalisation and what learning difficulties may mean, but knowledge also of equality and inclusion too. People labelled with learning difficulties are not expected to understand because the knowledge of others (myself, volunteers, carers, Galaxy and Springfields) is legitimatised over the men's knowledge. Next, I will analyse another discourse of knowledge that emerged from the thematic analysis that being the men's knowledge of 'daily and practical living'.

### **7.5 Knowledge of daily and practical living**

One of the most topical themes within the project was discussion on 'being clean' (Gareth). For example, on the next page, James is seen washing his hands (photograph 13) after he had been to the toilet, which was a scene depicted for display in the exhibition.



**Photograph 13 – July 2012 – ‘Be seen to be clean instead of being spotty like a teen’.**

The tag line that the men chose to apply to the picture, ‘be seen to be clean instead of being spotty like a teen’ refers to the importance of ‘being clean’, but also to ‘be seen’ to be clean. For some of the men, cleanliness was important to them, for example, having regular showers, brushing their teeth, washing their clothes and smelling nice. For example:

Being clean means I smell better (Gareth, 24.03.11).

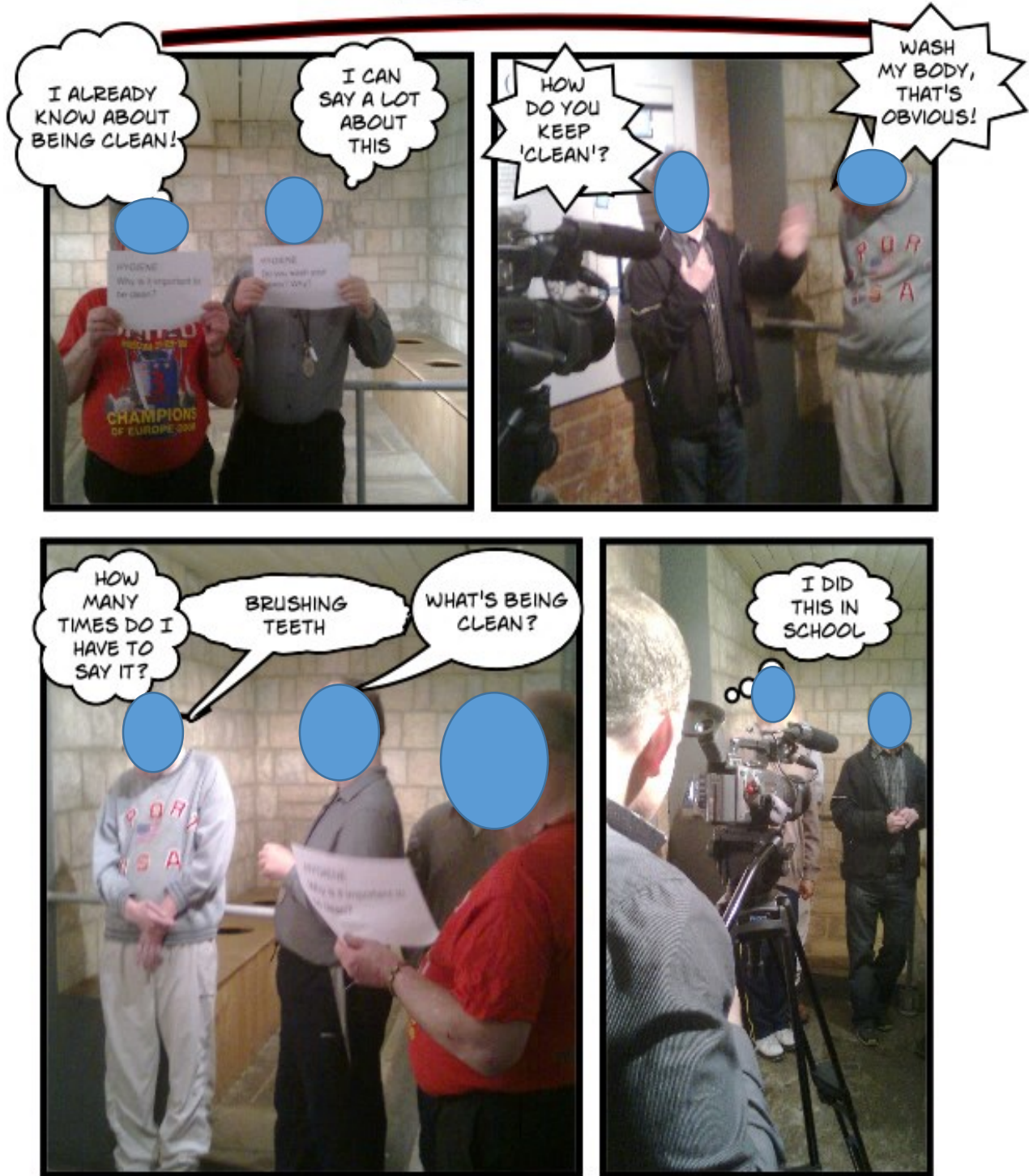
I don’t want to pong (James, 24.03.11).

I brush my teeth, I have showers, so I can kiss a girl (Joseph, 24.03.11).

The group discussed the issues that related to ‘being clean’, for instance, in their view, not being clean could affect, potential personal relationships or alienate people they work with in a job. The men shared knowledge by talking about ‘being clean’ and shared this knowledge about being clean on film and camera,

particularly about their personal experiences and demonstrated their knowledge of why it is important to be clean and the effects on their lives and personal relationships if they were not clean. How this was directed was based solely on the men choosing to take part in discussions in a pretend sewer at Galaxy because the smelly, dirty nature of sewers were the complete opposite of what they wanted to talk about. On the next page is a comic strip of the men discussing on film about their thoughts on 'being clean'.

# Being Clean



**Comic Strip 3 – Men in the sewers talking about ‘being clean’.**

In comic strip 3, the men rehearsed what they wanted to discuss about 'being clean'. The film director, George, facilitated this activity and regularly used the theme of 'hygiene' or 'cleanliness' in his drama scenes, nonetheless specific reasons for this were never explained. However, the discussion in the comic strip suggested that the men already knew about how to be 'clean' and there is some frustration despite going along with the scene. This highlighted that the knowledge of the director took precedence over the men's knowledge, the knowledge they already had about what 'being clean' meant to them, devaluing the knowledge and experience of the men. 'Being clean', was a topic area that the men did have much knowledge about because the men were able to share a fair amount of specific knowledge and experience relating to this i.e. brushing your teeth if you want to kiss a girl. The last picture sees Jeffrey remembering that he had already done this kind of activity about being clean in school.

The men clearly had much knowledge to share about 'being clean'. For example, some of the men improvised what they do to stay clean. For example, Jeffrey mimed brushing his teeth, thus he was sharing knowledge (presumed not to have that knowledge), with the group even without verbally communicating, but by talking about 'being clean', encouraged by the facilitators, carers and volunteers. It suggested that the men did not have this knowledge in the first place, and therefore, the knowledge and experience the men had was not just devalued but ignored in the first place. Next, I will consider 'personal health', which considers the men's perspectives specifically on male cancers such as penis and prostate cancer.

## **7.6 Knowledge of personal health**

Later in the project (November 2011), the group had the opportunity to listen to a practitioner in male cancers called Alfie. Alfie facilitated an activity in which he relayed information relating to specific male cancers (including testicular and penis cancer). However, despite being the 'expert' who came to deliver 'knowledge' about cancer, he was not able to answer all their questions in which some of the men asked about the subject. For example:

James asked a 'burning wee' question (what happens if you feel burning when you wee?) and studied the literature strongly about cancer provided by

Alfie. I love the fact the men were engaged and asked great questions, demonstrating they have valid, intelligent opinions that Alfie struggled to answer. James's burning wee question completely threw Alfie, it was clear to see with his stumbling words and looking to me for help that he did not know how to answer James and did not expect him to ask this question (Reflexive diary, 24.11.12).

Essentially, Alfie was the 'expert' who was there to deliver information about cancer and for the men to learn, but the men already had the knowledge because of their experiences with medical checks. For example, this is portrayed in photograph 14, in which Joseph and Gareth played the role of 'doctor and patient'.



**Photograph 14 – November 2012 – ‘Have an annual health check or risk hitting the deck’.**

Joseph and Gareth spoke to the group about their experiences of having prostate and penis cancer checks, for example:

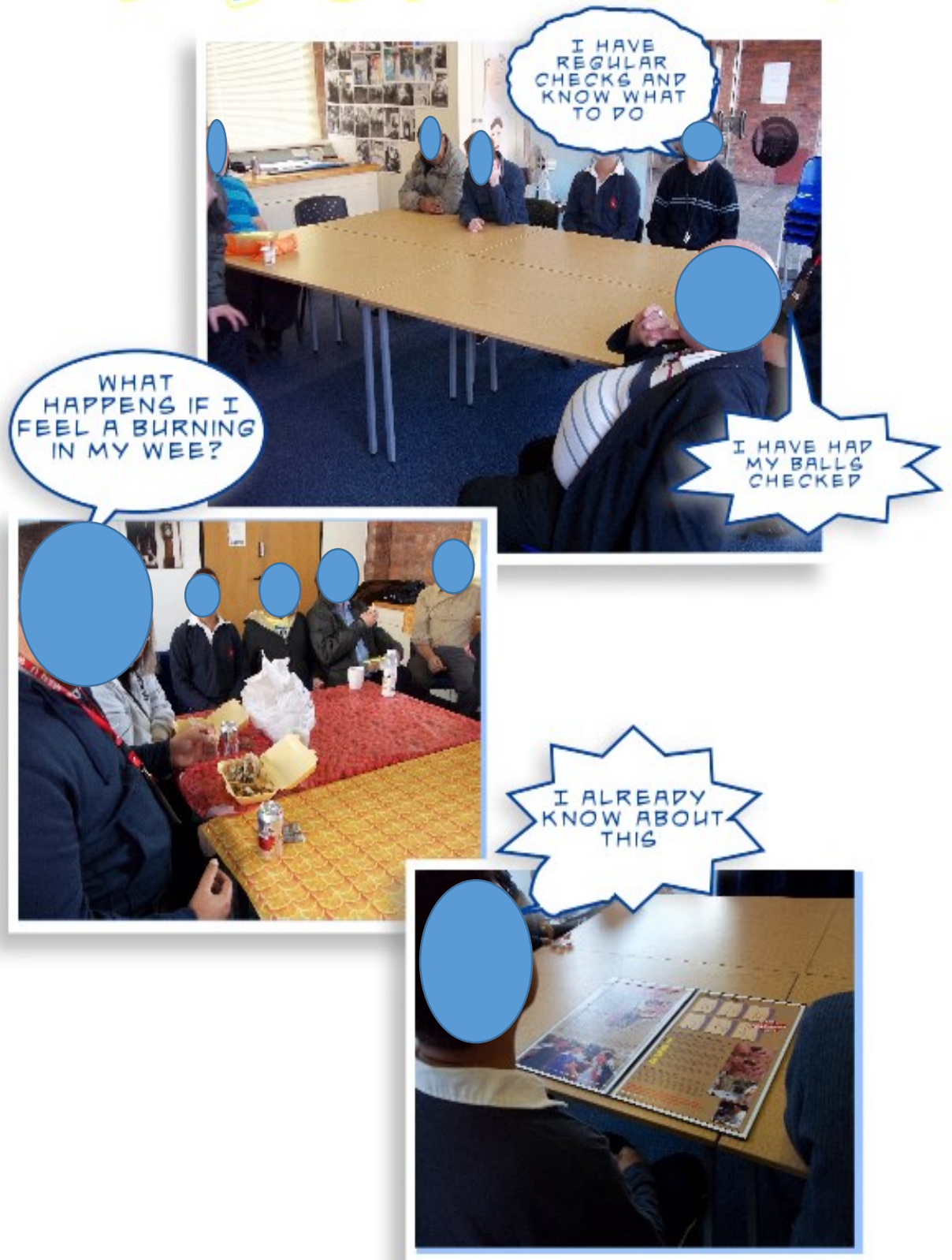


For the cancer session, Joseph was full of humour/laughter at the mention of balls and willies. Nevertheless, despite having a laugh, he also revealed his personal experiences of cancer checks such as PET scans. He too took pictures of the testicles and joked with Gareth about 'not touching' the plastic testicles (Reflexive diary, 24.11.11).

I asked his (Gareth) permission to talk about his cancer experiences and he refused, which I respected. However, during the session, he revealed this information himself to the group, so by his own choice. He joked about his situation, 'needle in his penis', 'camera up his bum' and shared the laughter/emotions with the group, but especially Joseph. I admired their courage and putting humour to it ... Lots of penis jokes with Joseph, which made me laugh and 'balls' jokes (Reflexive diary, 24.11.11).

Thus, Joseph and Gareth had knowledge about health checks and the rest of the group were more intrigued by the knowledge they had to share, rather than the knowledge Alfie had to share. This could also be due to Alfie only being in attendance for no more than thirty minutes, which limited the building of relationships and wanting to share personal experiences. Gareth and Joseph did not initially feel comfortable about talking about this subject (having had checks for cancers), but eventually felt compelled to speak about their cancer experiences, in a blunt way, but a way in which everyone understood. Hence, the biological knowledge shared by Alfie and the academic literature that he provided, was knowledge Alfie considered to be legitimate and more important than the experience the men had. However, the men's experiences of cancer, cancer checks and details of different cancers was more powerful in getting the men in the group to consider, talk and understand more about cancer. Nevertheless, Alfie's presence ensured that a hierarchy of biological/medical knowledge took precedence initially over the men's knowledge and experiences, therefore, devaluing the men's knowledge. On the next page is a comic strip of the men discussing and telling stories of their experiences of cancer with each other. In the first picture, the men are sharing the fact that some of them know what cancer checks are about and have experienced these checks i.e. Gareth having had testicular checks. In addition, James is seen asking a question, which further suggests he already had knowledge about health checks:

# TALKING CANCER



**Comic Strip 4 – The group discussing male cancers.**

Next, I will consider the men's perspectives on talking about their own identities and feelings through debate and discussion, which formed part of most workshops that took place, particularly on issues relating to mental health.

### **7.7 Knowledge about the self**

One of the most engaging parts of the project was the discussions and debates about many subjects, but particularly discussions concerning the men's personal stories and reflections on their identity. In photograph 15, the group came together and discussed face to face the work they had been doing that day.



**Photograph 15 – April 2012 – ‘Talk about your emotions, it saves a lot of bad commotions’.**

For the men, most felt that they never had the opportunity to talk about specific issues relating to themselves, or about life in general. Therefore, the group wanted other people to feel inspired and comfortable about talking about their emotions and share their knowledge of how to talk about the feelings. For example, Joseph

stated *'It is good to talk; I like talking ... can't talk at home'* (*Reflexive diary, 13.10.11*).

Despite the enthusiasm to talk about their emotions and any subject they wanted, some men did not verbally communicate (such as Jeffrey and Callum). However, Jeffrey and Callum listened and would indicate with facial expressions, hand gestures and body movement about how they felt. On the other hand, this meant that within the group itself a hierarchy of knowledge formed, because some of the men spoke a lot and were able to fully express their views and share knowledge on personal experiences, whereas the men who did not talk, only expressed their knowledge to an extent. The comic strip on the next page is an example of this, with group members who are able to talk confidently like James and Gareth and others using alternative means i.e. hand gestures and facial expressions such as Callum and Jeffrey, doing a group evaluation of the project at the half way mark (June, 2011). Some of the men had scripts, but essentially the men were sharing knowledge of what they thought about the project at that particular point in time. Hence, the men shared knowledge about their perspectives and about how they wanted a project to be, to suit them and to suit their identities. However, the extent to which the men who did not talk, could share their knowledge, may have devalued the knowledge over other men.

# Sharing Knowledge



**Comic strip 5 – Group debates and evaluations about the project.**

Throughout the project, we regularly had group discussions about what the men thought of the activities, its location and how the project could be improved. The discussions were often started by myself, but the men soon took over and dominated these discussions. When the group came together to evaluate or debate, the men would share their perspectives on issues or topics in their lives similar to the scenes in comic strip five (most workshops had an element of debate and discussion). For example, the men shared their viewpoints about the project with opinions such as:

Yeah I like doing this (coming to the project) (Stephen).

I want to eat more fruit ... not biscuits again (Jack).

I think we should go out more often (Gareth).

In addition, photograph 16 (on the next page) was a scene in which the men wanted to portray that men take risks with their health. The group decided that the caption should be 'actions speak louder than words'. In other words, they are saying do not take risks like Jeffrey, by walking on the train track but seek help or guidance to improve your health. The men shared their knowledge of health risks and creatively shared this knowledge through drama, improvisation, photography and words. Therefore, in terms of knowledge, words were not always the priority, but instead actions/behaviours are a better way to express knowledge about the self.



**Photograph 16 – May 2012 – ‘Actions speak louder than words’.**

The scene was a tongue in cheek way to raise awareness about going to see a doctor or health care provider to check on personal health. The drama scene is exaggerated with the train and tracks, but in a creative way, the men expressed their views in a positive, fun way, thus presenting they have knowledge they wish to share, as one person stated who visited the community exhibition, *‘Informative, thought provoking, fun’* (anonymous, February 2012).



**Photograph 17 – August 2012 – ‘We are who we are, with you on a level par’.**

Earlier in the chapter, I discussed how the men talked about their rights and wanting equality and the men expressed this through the use of sculpture, but also through other methods. The kind of activities that the group participated in, such as debate, art and drama, often reflected their views on particular themes relating to their lives. For example, their ‘favourite place’, in which they painted or drew pictures of their favourite holiday locations or places of interest like local parks. Another theme, ‘favourite memories’, the men talked about or painted an event in their life, such as when they were at school, home or work. In addition, the men enjoyed discussing their ‘family trees’, where they thought about their families, including who they see or do not see or who had died. Reflecting on who the men are and what their identity meant to them, helped some members of the group feel more at ease with their identity and thus sharing their experience and knowledge helped to create a relaxed feel for knowledge sharing (see photograph 17). For example, Joseph revealed to the group some personal information he had never shared before in this context. For example, *‘I have family in Barbados. My dad was a minister, but they’re dead now ... it makes me cry sometimes’* (Joseph, 10.11.11). This is very personal information that most people would not openly talk



about because it is sad and for a man to admit that he cries for his parents was gutsy. Joseph's experiences may also have highlighted that in other contexts i.e. home or college, that his personal experiences are not valued as much as they were at this project.

In photograph 17, the men are seen exploring and talking about objects from Galaxy that relate to their lives. For example, although it is not clear in this photograph, Jack is exploring a 'tape desk', which made him think about using one when he was a child to collect his favourite music. Jack was particularly fond of this and took photographs of this and chose it to go on display in the community exhibition. Another example is of Terence who was a photographer in the group and he was particularly keen on an old Victorian camera and how it worked. Below is an extract of James, and how he used objects he found at Galaxy to inspire/evoke his feelings and to share with the group:

James spoke about 1976, when he played his music on the tape desk and spoke about his dad being a skater and that he showered to keep himself 'young and fresh', which made us giggle. Talked about having no money to get by and revealed that James was labelled with 'autism caused by premature birth'. During the poetry, he got everyone involved. James talked sadly about his toy train set that he had to sell. Why? Because he thought he was too old – initially funny answer, but could be related to money (poor family) (Reflexive diary, 07.04.11).

James seemed comfortable in expressing himself, in the way James chose to do it, how he shared his personal knowledge and experiences. In addition, Jeffrey shared his knowledge about his life, not through debates and discussions, but mainly through art. For example, in photograph 18 (on the next page), Jeffrey depicted himself brushing his teeth and the items he would use to do so. Here Jeffrey is sharing his knowledge through art that he knows the importance of brushing his teeth, but similar to the 'being clean' examples earlier in this chapter, Jeffrey already had this knowledge and had no need to demonstrate that he had this knowledge because it was assumed, Jeffrey, like the other men had no knowledge of 'being clean'. In this respect, Jeffrey's knowledge and experience was ignored and devalued. Additionally, Jeffrey shared his knowledge about a boating trip he went on, detailing the cars around the lake and the bus that picked

him up (photograph 19, on the next page). Jeffrey is visually sharing his memory about a trip he enjoyed, and something that meant something to him. Therefore, Jeffrey shared knowledge no one else knew about in the project, an experience he had enjoyed, whereas the 'being clean' examples were examples all the men were familiar with prior to this project.



**Photograph 18 – Jeffrey's art work depicting himself brushing his teeth.**



**Photograph 19 – Jeffrey’s depiction of his boating trip.**

In chapter six, I analysed the complexity of being able to make choices as an individual, particularly relating to Jack and Gareth, but one of the most well discussed topics throughout the project from an individual was Stephen’s decision to ‘come out’ as gay, and his explanations on what his sexuality meant to him in poetic form, which will be analysed more in the next section.

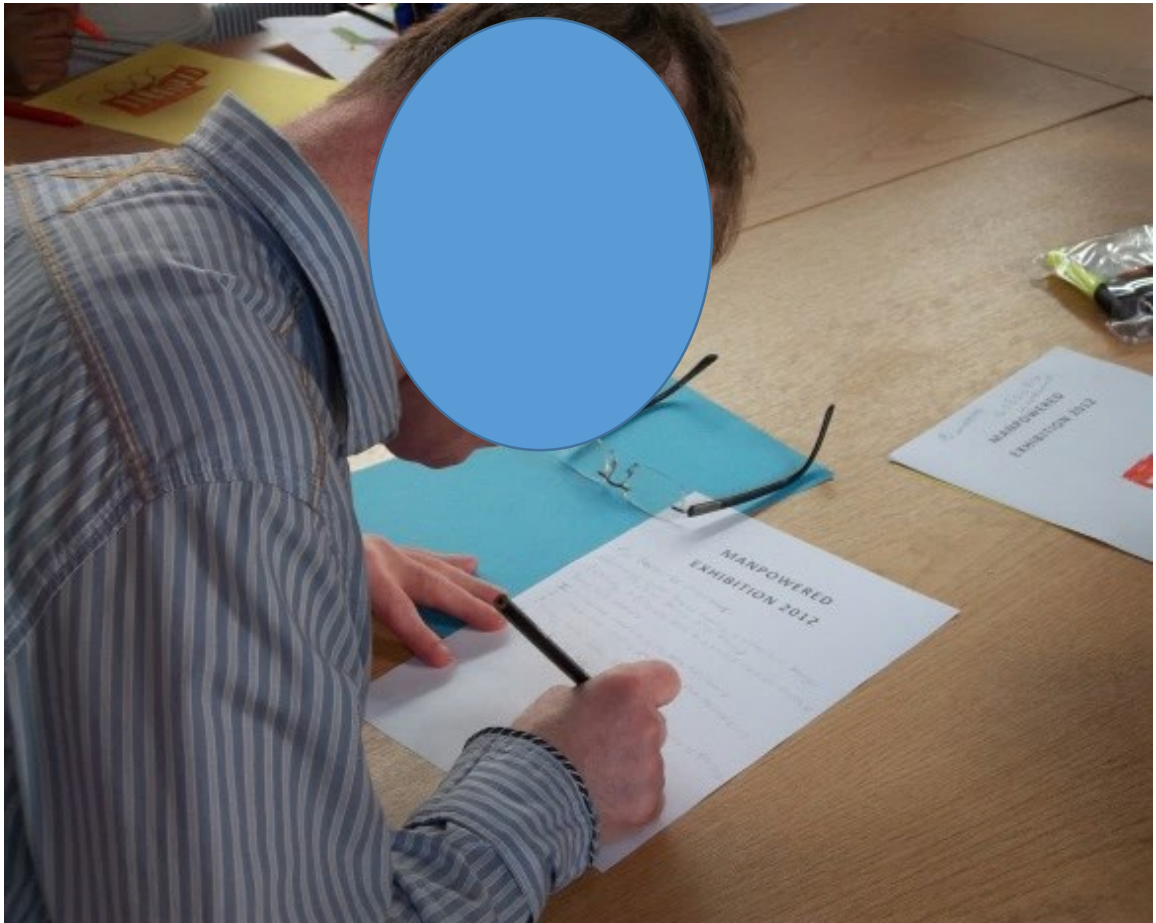
### **7.8 Knowledge and sexuality**

Stephen shared his perspectives and experiences of being gay with the men in the project. Initially a shy and reluctant person to get involved unless asked, he soon (within a few weeks) started to express himself and talk about himself in an intimate and personal way. Stephen was not pressurised into doing anything and instead at his own pace would make the decisions himself. For example, one of

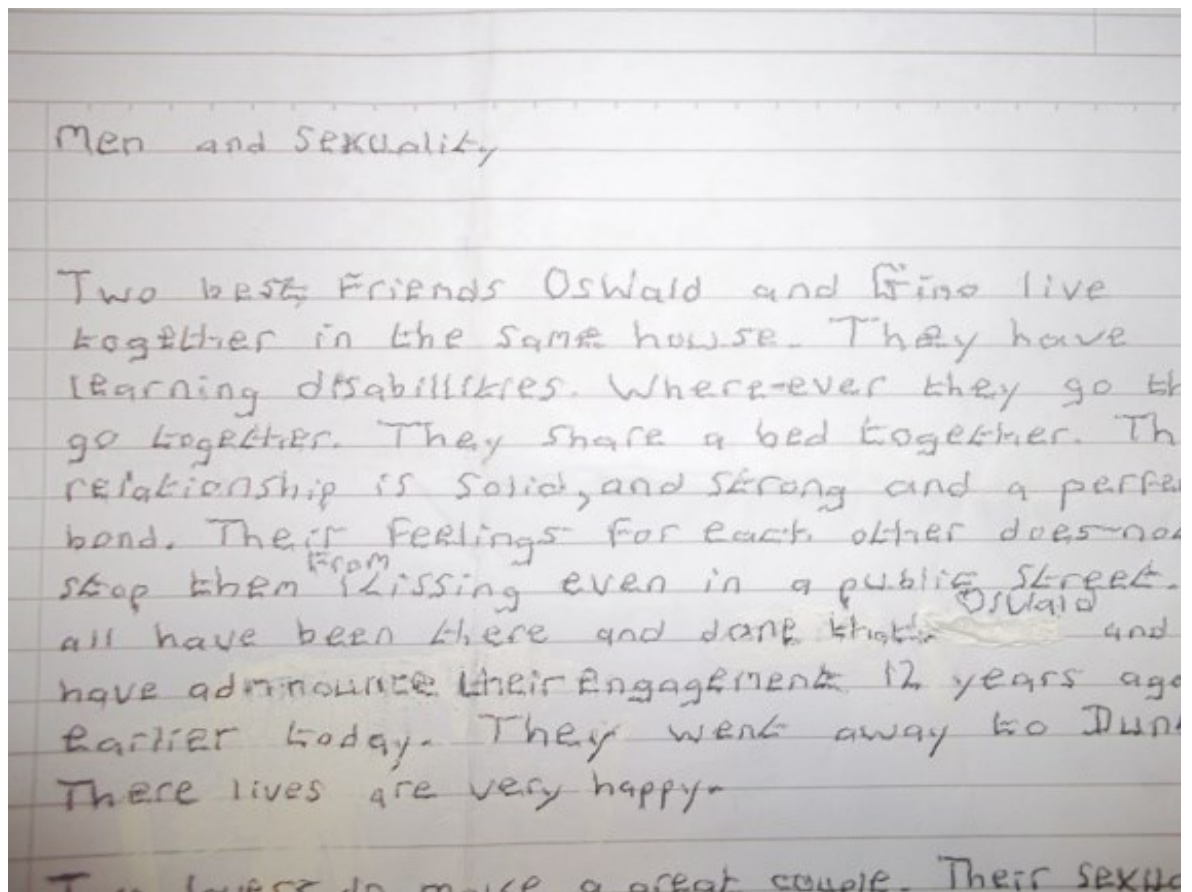
the first workshops the group did was to talk about and write poetry (photograph 20, on the next page, Stephen seen writing his poetry). This was facilitated by James (member of the group), who had asked to do this and the group agreed to participate with James and to write or speak poetry. The week after James facilitated this poetry workshop, Stephen came back and asked if he could read some poetry he had written (photograph 21, on page 182, is an example of his poetry). Stephen's reading of this poem was used as an opportunity by Stephen to share with the group that he was gay. When Stephen ended his poem this way, there were chuckles of laughter and shock throughout the group because they did not expect Stephen to be so emotional in expressing his feelings. However, Stephen received a round of applause and he appeared very happy with what he had done. On one occasion, he shook my hand and thanked me for 'allowing' him to read his work out. Although I reminded him that this was his project and this was the place for him to express himself, in his own way. He had chosen to write the poetry and to read it aloud.

Nevertheless, Stephen's confidence in sharing his experiences and knowledge about his sexuality and about sexuality in general was soon quashed. Not long after 'coming out' to the group, George (film-maker and development worker at Springfields) asked Stephen, in a one to one discussion with him, to stop writing poetry about sexuality because Stephen was making people feel uncomfortable. George's actions was a response to one of Stephen's poems that was written expressing his love for one of the volunteers, Matthew, which Stephen had read out to the group in front of Matthew. However, Matthew was fine with this and took it in his stride, whereas George, who would noticeably sweat and blush when Stephen spoke about his sexuality, decided to respond by asking Stephen to stop writing this type of poetry. Hence, George was devaluing the importance of Stephen's knowledge about sexuality and legitimising his own knowledge above Stephen's in relation to sexuality. In addition, on another occasion, two carers were invited to sit with the group, to listen to Stephen read out another poem about love and sexuality. Halfway through the reading, both carers ran out of the room laughing out loud. Stephen was interrupted but continued to read whilst the rest of the group listened. I invited the carers back in once they had calmed down and challenged them in front of the group about what they thought about Stephen's poetry. The carers said they did not really have an opinion, but referred to Stephen as a 'service user', so did not even say his name even though they knew it.

Overall, Stephen had to face some difficult times in sharing his knowledge and experiences about sexuality, with George and the carers making it more difficult for him by legitimising their actions and behaviour as more important than Stephen. George and the carers were directly ignorant and disrespectful towards Stephen. However, Stephen kept on writing and sharing his knowledge with the group, with my support and the support from the men.



**Photograph 20 - Stephen writing poetry.**



**Photograph 21 – An example of Stephen’s poetry.**

Stephen spoke explicitly about his sexual fantasies through poetry, which he would write in secret at the home he shared with his brother and family, which he then revealed to the group. Thus his identity and knowledge he felt were ignored at home, to the extent, that he had to write in secret, in fear of being found out about writing his poetry and for being gay. Below is an extract from one of Stephen’s poems (seen in photograph 21), which reflects upon Stephen’s perspective on how gay sexuality should be viewed. Stephen described his own fantasy about how he would like to live life with a man:

Two best friends, Oswald and Gino live together in the same house. They have learning difficulties. Wherever they go they go together. They share a bed together. Their relationship is solid and strong and a perfect bond. Their feelings for each other does not stop them from kissing even in a public street. We all have all been there and done that. Oswald and Gino have announced their engagement ... they went away to Dubai. Their lives are very happy (Stephen, 16.06.11).



**Photograph 22 – June 2012 – ‘Let people be who they want to be, different and free’.**

The knowledge Stephen shared about being gay and his fantasies was portrayed in the ‘thought for the month’ exhibit. In photograph 24, Stephen and Jeffrey wanted to portray ‘difference’, which the rest of the group agreed to as well, so the knowledge Stephen shared about sexuality was considered to be important to the men too. Jeffrey and Stephen portrayed themselves as two gay men, married in their own home. The scene was inspired by Stephen’s poetry and the group felt that because the men were viewed as different, and had been treated differently often negatively in their lives, the group wanted to send out a message that celebrated diversity. This is portrayed in the caption the men decided upon that connects to the photograph, *‘let people be who they want to be, different and free’*.

## **7.9 Summary**

In summary, the men within this project were able to share knowledge about specific subject areas such as ‘cancer’ or human ‘rights’, and share knowledge about their lives through different methods whether the person could express

themselves with or without using speech. The men discussed and debated the importance to them about having rights and how these rights have been stifled or dismissed by society. The men expressed their frustrations and hopes through creating a sculpture, which was the centre piece of the community exhibition. In addition, the men shared knowledge about 'being clean' and that being clean was important for their daily health and well-being, but also if they wanted to have relationships with people. Moreover, the men shared their technical and experiential knowledge about cancer. For example, Gareth and Joseph's revelations about having cancer and health checks were shared with the group, but some of the men shared knowledge about other cancers too. From the beginning of the project, the men felt comfortable to share their knowledge and feelings about life and different subject areas (such as family life, work and school), which were often negative experiences. This was reflected in the community exhibition in which the men shared their knowledge through different methods with the general public. The final part of this chapter considered Stephen talking about his sexuality and the positive effects it had on him.

Nevertheless, the knowledge and experiences of the men were devalued at almost every opportunity, wherein, a hierarchy of knowledge was established over the men. For example, the men knew what 'being clean' meant and its implications, yet much work was done on 'teaching' the men (by myself and George) about this despite them already having the knowledge. In other words, the men's knowledge was not only devalued, but also the knowledge of myself, volunteers, carers and workers was legitimised over the men's expertise, because the men were labelled with 'learning difficulties'. A good example of this was when Alfie visited and attempted to share biological and academic knowledge to a group of men who already had much experience as well as knowledge of cancer. Again, the knowledge of the men relating to cancer and health was devalued. The knowledge and experiences of Stephen's sexuality that were shared with the group, was an emotional experience for everyone, not just Stephen but the reactions of George and the care workers in response to Stephen's brave acts completely devalued Stephen, and the significance of his knowledge and experience.

Overall, the project contained clear examples of the men sharing knowledge and acquiring knowledge with each other and with the facilitators within the



project, but these examples were almost always devalued at some point. In the next chapter, I will consider the final theme to the thematic analysis, 'participation'.

## Chapter 8 - Act three: participation

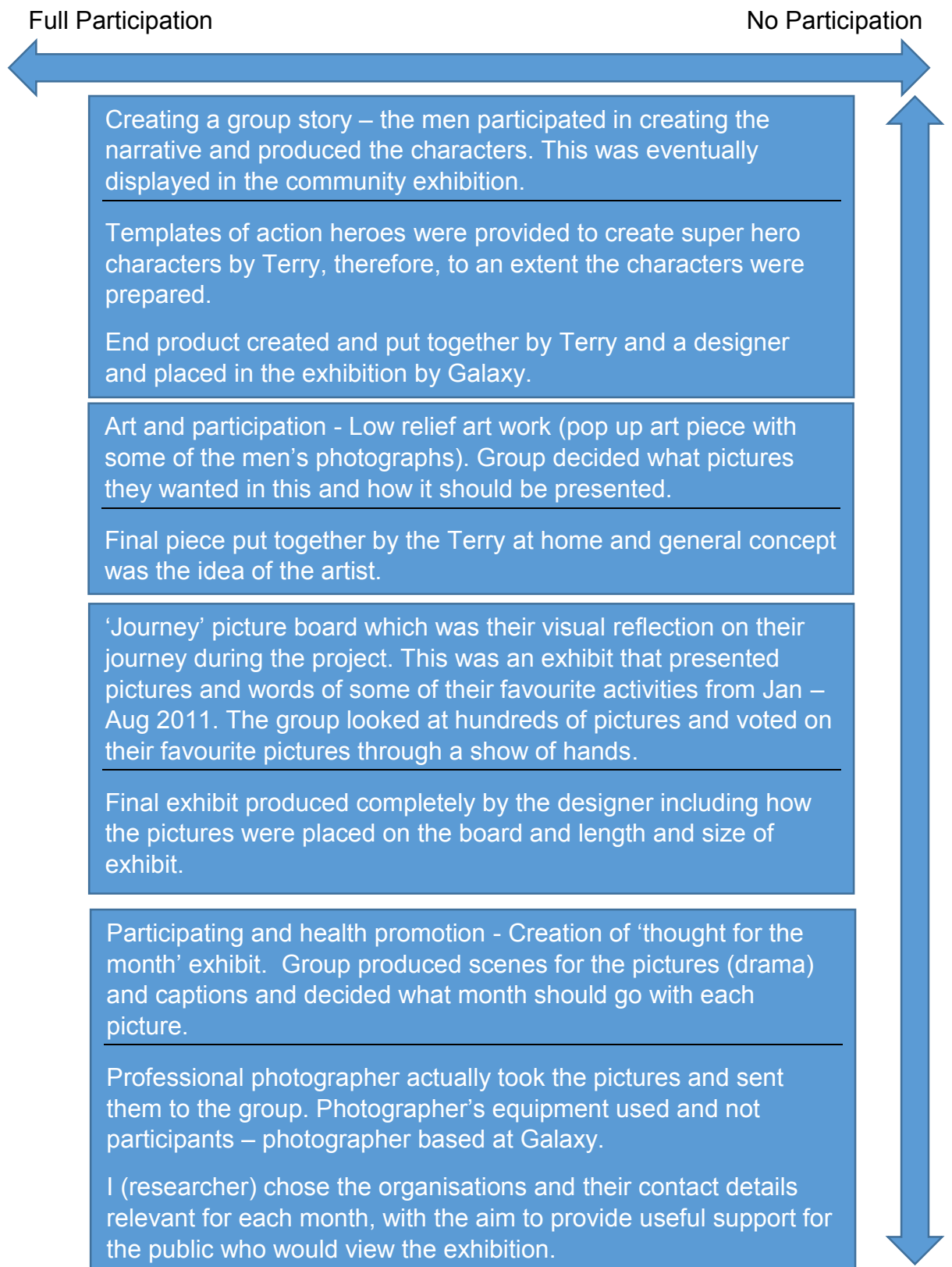
*'I have my books  
And my poetry to protect me;  
I am shielded in my armour,  
Hiding in my room, safe within my womb.  
I touch no one and no one touches me.  
I am a rock,  
I am an island'.*

*(Paul Simon, 1965, I am a rock, Sound of Silence).*

*'I am not disabled. I just need some help' (Martin, 2011, one of the men in this project).*

### 8.1 Introduction

In chapter seven, I used Boyatzis's (1998) ideas on how to code and develop themes, to conceptualise the theme 'sharing knowledges'. In this chapter, I will analyse the next main theme that emerged from the thematic analysis, 'participation' (see chapter five, page 122 for how this theme was conceptualised). This theme can be defined as the activities the men were involved with inside the project, in which the men engaged at different levels of participation (See Lave and Wenger, 1991; Wenger, 2002; Lawthom, 2011) including full and non-participation at different stages. Hence why the diagram on the next page places the examples of participation in between a continuum, because, participation would usually be at different levels at different times, so participation was usually neither completely full or non-participative. I will now analyse each of the examples of 'participation' and analyse the moments when there was participation and no participation.



**Figure 10 - A diagram of a continuum that places different examples of participation in the middle, indicating that participation occurred at different times and levels.**

However, before I consider this theme in more detail, I will now reflect on some of my own experiences in participating, reflecting on times when participating has been both easy and difficult, and will reflect on aspects of my identity and character.

## **8.2 Developing my character and participation**

Within this project, there were men who would engage and participate with activities at different levels. For example, Stephen would get involved with almost all activities whether there was art, drama or poetry involved, whereas Scott, would rarely get involved unless he was encouraged or supported to do so, it was almost like he needed permission to take part. Thinking of Scott and Martin's quote 'I am not disabled. I just need some help' reminded me of my own reluctance sometimes to get involved and participate, and where I have found sanctuary in my 'fortress', thinking of Simon and Garfunkel's song at the beginning of this chapter. What became a 'fortress' for me was my little box room at home, in which I have spent years reading, writing and planning for the future. Whether completing degrees, writing books or relaxing, this place was a kind of sanctuary of peace for me. In this sense, it became like a 'womb', a place of reflection, where 'no one touches me'. I view it as my own version of Dylan Thomas's shed or, Roald Dahl's hut in the garden, a place to think and write.

Although this might seem like a place in which I appear emotionally detached from the world around me, it is nice to just be able to think and read in peace. Yet my family often think that I have just sat in for there for years watching TV, not fully aware of the effort and time needed to be a student or academic and that it involves a lot of time being isolated, to get work successfully done. These experiences remind me of when people that have said I am 'anti-social' and yet I am happy in my own company, just as I am happy to work with people in the community and work with many students. However, this critique of me being anti-social or being socially detached does make me reflect on my character within the different contexts in which I have found myself. For example, when I first became a postgraduate (2008), with hindsight, I think it was quite overwhelming because although it was the position I had worked hard to get myself in (for so many years), suddenly from being quite an isolated person, I was now consistently the centre of attention in a way that, maybe I had not been since I was at school. When I

became a postgraduate, people wanted to listen to what I had to say and people were coming to me for answers, whether they were students or colleagues and at times marginalised people I worked with in the community. I was used to just needing to find answers and be successful for myself without needing anyone else. During this time, I think I started to become quite shy, quietly spoken and blushy in a way that I had not been since I was a child, which might have exposed my anxieties and unfamiliarity with being with people all the time. Although I did start my critical community psychology life facilitating work on sexual health, which I imagine many people would feel uncomfortable about doing (because it is quite a sensitive subject area). However, by developing sexual health programmes (reviewed in chapter one, pages 15 - 33) and facilitating many different types of activities and events, it led to me becoming more participative than I have ever been before and enjoy it very much.

Overall, I actually love socialising and being with people, but equally enjoy my own company. I think you need this kind of balance to be a successful academic and community worker, as both can involve being a lone worker whether you are marking piles of work or writing a paper or being participative when facilitating a group of students or marginalised groups in the community. I still feel I am adjusting and further building my confidence, but developing this PhD as extensively as I did in 2010-2011 and writing this thesis strengthens that resilience all the time.

My reflections on my own 'participation' and thinking about the different levels of participation within this research highlights that participation is not an 'either or approach', but one that is a continuum. With this in mind, I will next consider the participative ways the men worked together and one of the striking ways the men participated together was through the creation of a group story, which I will analyse first.

### **8.3 Creating a group story**

The men participated in many ways during the course of the project. On the next page is a scene that is a good example of how the men participated with one another, during one of the most popular workshop that was done, a workshop that involved working with animals. Here the men worked with Adrian, whose occupation was to take animals into schools (such as spiders and scorpions), to

help people get over their fears and anxieties with these animals. I thought it would be a good idea to bring these animals in and do a fun, interactive activity, not necessarily focusing on phobias or anxieties, but more for entertainment and having fun:

*There was a lot of excitement and anticipation at today's workshop. Adrian's job during the day was to take animals, the kind of animals that people did not like such as snakes, spiders, rats and lizards, to schools and community groups to get people to engage with these animals. The group were thrilled and the attendance at this workshop was double the usual number (about 20 people including carers and volunteers). Some of the men including Martin and Gareth were a little anxious when they were informed about the kind of animals that were going to be at the workshop. Martin did not like snakes and Gareth did not like rats. However, they were encouraged to get involved and see how they felt once the animals had arrived.*

*The much larger group than normal sat around the tables that had been put together to make a big space to place the animals. The animals came in a series of dirty plastic boxes, like small, contained jungles for the animals to live in and eat. Adrian informed the group that the animals were not dangerous, to help the group feel more comfortable, although I thought that was a bit odd considering the size of Vincent the python. Adrian started to take the smaller animals out of the boxes first such as the lizards and frogs and shared them around the group, so everyone could have a go of holding each animal. There was tension in the air and a silence when the animal first came out of the box. But then once everyone was comfortable with the animal, there was laughter and joking and a really good positive atmosphere. When it came to Gareth and Martin getting over their fears for the rats and snakes, initially they were very nervous, but the men in the group who had already held the animals would go and stand with Martin and Gareth and reassure them that everything was going to be ok. There was a sense of participation and collaboration between the men through reassuring one another and helping each other feel comfortable with the animals. For example, James put his arm around Martin and encouraged him to hold the snake whilst he was there to help him. James would say 'don't worry now, it doesn't bite'. Martin seemed reassured by this through nervously smiling.*

*Initially, the men just watched as Adrian lifted and held the animals, but when he*

*started to pass the animals around the group, the men would come to person holding and surround him to take pictures or just in pure eagerness to be the next person to hold onto the animal. Some of the men got really excitable like Joseph and Martin, by laughing a lot if the animals suddenly moved, whereas, the quieter men would just sit and wait their turn, but would sit smiling in anticipation in getting ready to hold the animal.*

**Scene 3 – An example of the men participating in an activity.**

Scene three is a good example of how quickly the men saw the group as a project in which they felt comfortable to participate in, albeit that some were quicker to participate than others, particularly the quieter ones (who were more reluctant initially), but soon got involved with the animals. Therefore, men participated at different levels at different times. The next couple of examples in this theme will demonstrate how at different levels of participation, particularly through the arts (art and craft and drama), the men were able to have the confidence to express their feelings visually and confidently.

Participatory approaches were applied throughout the creation of this project (discussed in the methodology), particularly in activities about health issues, which helped the group to come together, grow and make collective decisions. For example, on the next page is a comic strip that captured the development/process of a large comic strip the men created for the exhibition. From the beginning, the group created storyboards and discussed ideas about a fun story that represented the group and could be adapted into a large comic strip:

# TELLING A STORY



Comic Strip 6 – The process of group development of super heroes and their comic strip.



The group decided that they wanted to create a story about being super heroes, wanting to save a woman who had been kidnapped by an evil sorcerer. The story ends with the evil sorcerer renouncing his evil ways and unites with the super heroes. The super heroes were created individually by the men over a couple of weeks, using the materials provided. For example, below is an extract of the story that the group collectively put together based on different ideas and thoughts they had about what the story should be:

A group of men came together looking for support to be able to express their super powers to the world. A lady who looked after them by providing tea and coffee and biscuits, was suddenly kidnapped by an evil sorcerer who wants to get rid of the super heroes and any good that they do. The super heroes speak to the 'Ekim' the wise one (me) who advises them to save the lady (being Janet from Galaxy, who the men held in high esteem) and to defeat the evil sorcerer. The men turn into their alter egos – strong man, Barbados man, ice skater man and fire man and seek to find the lady. They find her in a burning building at Galaxy and the evil sorcerer is laughing at them, thinking the heroes cannot save her. However, the super heroes defeat the evil sorcerer and save the lady. The evil sorcerer decides to give up his evil ways and decides to unite with the super heroes, believing life will be better (Reflexive diary – 22.09.11 – this extract is my own interpretation of the story they created and based on their characters).

The story the men created was a combination of individual ideas and group conformity. There was no real dissent or disagreement. When people had different views, I would facilitate a discussion with the group and we would have a vote on any decision to be made, but ultimately their choice in agreeing that this story was what they wanted displayed in their community exhibition. Thus the men participated together to create a striking, colourful comic strip. The men participated together through discussion and the men who did not verbally communicate would signal with their hands or write or draw what they wanted in the comic strip (as analysed in chapter seven). On the other hand, despite my analysis suggesting that the men were fully participating, this was not always the case. For example, the action heroes were templates provided by Terry (volunteer and artist), therefore, to an extent the characters were pre-prepared. In addition,

the actual end product (the giant comic strip) was edited and finally put together by Terry and a designer from Galaxy and it was Galaxy who alone placed the giant comic strip within the exhibition room, so at this stage there was no participation from the men.

The men did not just participate together at different levels to do this comic strip and story, but also participated in other pieces of art, which is analysed in the next section.

#### **8.4 Art and participation**

In a similar way to how the men participated in creating the comic strip, the men created a 'low relief', which contained pop up pictures on a background board like the one produced by the men in photograph 23 (on the next page). The photographs were produced by Jack and Terence, who were the main photographers within the group, but were selected from many pictures by the group overall. Moreover, the group decided how the photographs should be placed and presented on the low relief. This participative process involved the men shouting out opinions or using hand gestures if they were happy with decisions or not, so again another example of using the voting system.



**Photograph 23 – The ‘low relief’ – a pop up art piece capturing the essence of Galaxy and the men’s pictures.**

The low relief contained pictures of the men doing different activities at Galaxy. For example, working with the animals, dancing and taking pictures or filming. Specifically, the low relief captured the essence of Galaxy itself, which is something the group wanted to do. For example, *‘I like coming to Galaxy’* (Gareth) and *‘I want to keep coming’* (Joseph).

Bricks dominated the background to the low relief, which is a major characteristic of the buildings at Galaxy and other similar structures around Bromhead. Although there is no specific reference to any significance to the bricks, it does however suggest that the men considered their physical surroundings to be important to them and for them to be at this location (Galaxy) in participating in activities. However, similar to the giant comic strip, the final piece was put together by Terry and the designer from Galaxy and the actual idea of a doing a low relief came from Terry, therefore, again the men participated to a

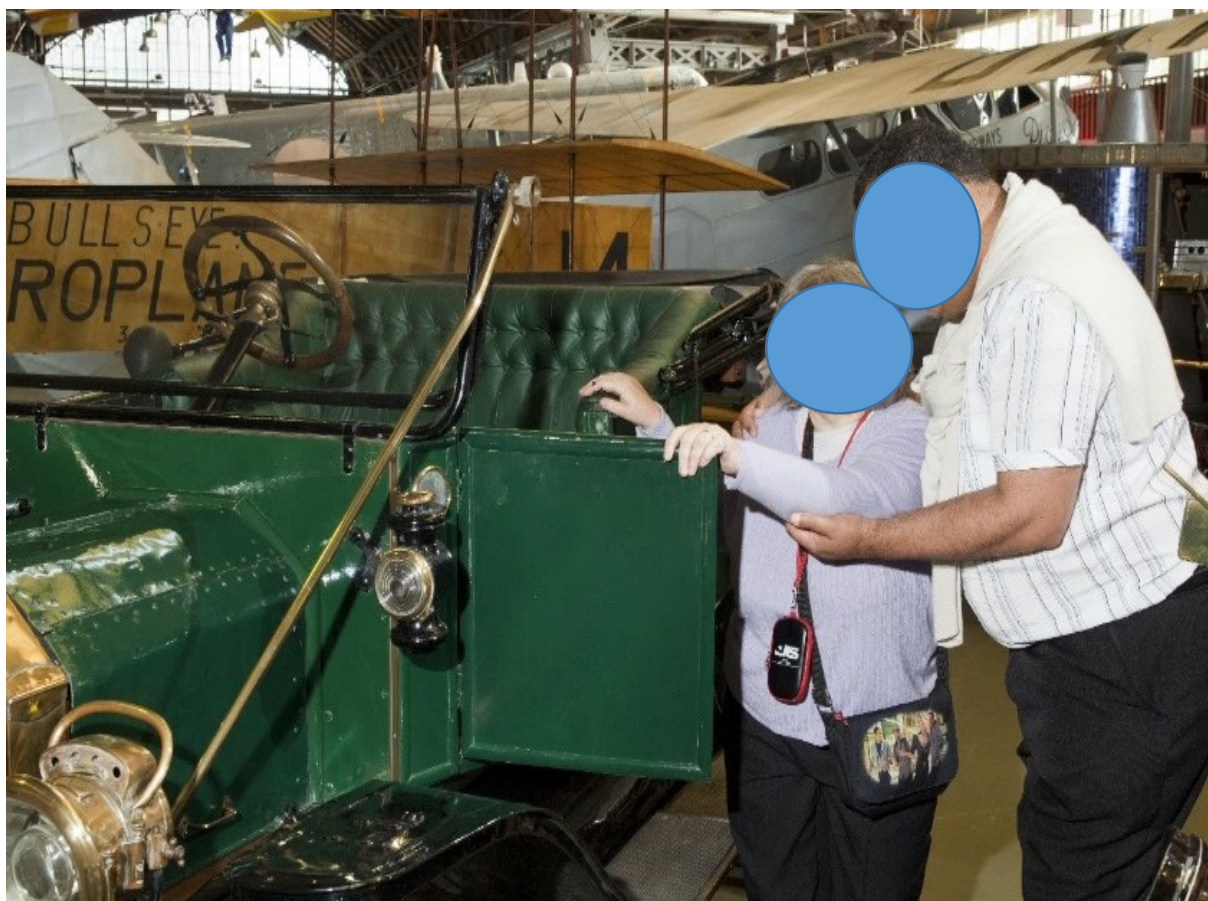
certain extent. Next, I want to consider how the men participated together on issues relating to health promotion and participation.

## **8.5 Participation and health promotion**

The 'thought for the month' exhibit (which I also considered in chapter six) captured an example of participation within the project. I had thought of the concept myself, through my experiences of working with young people in creating a calendar used in previous research (discussed in chapter one, pages 15 - 33). However, the production, creation of ideas and final choices came entirely from the men who worked together to produce this exhibit. The concept was simple enough in that the men chose twelve themes relating to their health experiences. The group produced a picture for each month of the year and provide a caption with information about relevant organisations, which the public could contact if they wanted more information. Below is an extract that captured the feelings of how the first scene was produced and how the group participated in a new activity:

The photographer allowed the men to help him with the equipment. The only disappointing part was I had to choose men for particular scenes, otherwise it wouldn't work because some of the ideas the men had on creating these scenes only needed one or a couple of men to do each scene. However, I suggested that they had to show patience like a real film scene, which involves involved a lot of 'hanging about' for a scene. James and his wife were chosen for this scene portraying 'men's image' (James's wife had joined the group later in the project by agreement of the group). It was a tricky scene because his wife struggled to get back down from the car because it was quite high up for the pose of James helping his wife onto the 'T-Model' car. Doing these scenes were a challenge because we had a limited amount of time to do the scenes and it involved trying to facilitate a large group of men and keeping them all interested while they waited. It was also going a bit slow, so we had the pressure of 'one take only'. I could see some of the men were disappointed not to be able to use the car, but they perked up when they were able to get involved when they participated in other scenes soon after (Reflexive diary, 13.10.11).

Photograph 24 is a picture of the first scene where the group participated in and produced, which reflected the men's frustration at men's image being seen in negative way. For example, some of the men felt men in general were seen in a bad way, for example, 'some men do cry, I do when I think of my mum (who is dead) (Gareth) and 'I think being a gentleman is important ... like opening doors for people' (Stephen). Hence, the men wanted to capture this in some way, as a way to promote men's image in a positive way. Here James and his wife Pauline demonstrated that men do have good manners and are respectful:



**Photograph 24 – Caption – ‘Celebrating the truth about men’.**

The idea of 'men's image' (my words) was regularly debated within the project. For example, James always tried to fit in with the norm in relation to his fashion. For example, James stated that he liked to 'wear suits because I like to be smart like a man should be' (James, 08.09.11). In addition, Joseph stated that:

(It is) difficult to be a man because you can't cry, but you need too sometimes, but not all the time (Joseph, 08.09.11).

Thus, the men agreed that they wanted a scene they could produce and participate in that challenged the negative views of 'men'. On the other hand, it was a professional photographer who took these pictures, employed by Galaxy, therefore, although the men were creating the scenes, the men did not direct how the image would look like. Furthermore, the 'thought for the month' was an opportunity for the men to demonstrate their enthusiasm to participate. For example, January's photograph (photograph 25, on the next page) sees the men huddled together. To get the best picture they wanted, there was a lot of manoeuvring, but the group had fun in doing so. The men can be seen huddling together, which demonstrated how strong the relationship between them to participate together. Although in this instance I was directing and wanted to capture this kind of scene because I felt it reflected what 'Manpower' was all about and the theme of this scene, the men still decided collectively through a voting system which version of this picture they preferred and wanted in the community exhibition. However, again it demonstrated that the men were participating at different times and levels, although usually by my direction. Additionally, the caption was agreed upon by the group, although the caption are my own words, which came from Galaxy asking me for a quick response, this being for their website for which they needed a description of the project. Consequently, I too chose the organisations and contact details relating to each photograph's theme, with the aim to provide useful support information for the public who would view the exhibition, so again, the men did not participate at this point.



**Photograph 25 – Caption - ‘A men’s group challenging disability’.**

The men enjoyed participating in this project, particularly because it was fun. This is depicted in photograph 26 (on the next page), where the men participated together to demonstrate that having fun was a great thing to feel. The caption ‘have fun, fun, fun’ and the repeated use of the word ‘fun’ suggested that the men placed great emphasis in enjoying their time at the project and wanted to share that with the public in the community exhibition. Again, I was directing at this point, but what the photograph does not convey is that when the pictures were not being taken, we all discussed how we wanted the scene to be. Other scenes where there were fewer men in the picture, those men were in fact helping me to direct the scenes or watch, so participation levels were different for everybody at different times. In the next section, I will consider how the men worked together to explore and reflect upon their time throughout the project.



**Photograph 26 – Caption – ‘Have fun fun fun’.**

### **8.6 Capturing the men’s journey – working together**

The project lasted for forty-five workshops, thus there were many activities and much data was collected using different methods as discussed in the methodology chapters. What made the process of choosing items such as photographs, art or poetry easy was the process of participating in the selection to choose the men’s favourite works to go into the community exhibition. This was time consuming as there was so much to vote for, but the process worked with everyone being involved verbally or non-verbally. Photographs 27 and 28 (on the next two pages), are the final selection of pictures (which amounted to 31) the men chose. The men are conveying that participating in this project helped them to feel good and they enjoyed coming each week and engaging in different activities. Here the men decided that the various activities they had participated in (during their time at the project), made them feel ‘good’ (Joseph). In addition, for the men, the pictures they chose (pictures were a mixture of my own, Jack and Terence’s) made them feel that the group ‘developed’ and ‘came together as a group’ and being ‘together’ involved being participative.





**Photograph 27 – ‘Our journey’ picture board.**



**Photograph 28 – Close up of ‘our journey’.**

Above I considered some of the examples in which the men participated with one another, but now I want to analyse how they participated together. On the next page is a photograph (photograph 29) of the men working together to record a scene in which some of the men talked about their hobbies. The men spent much time working together to create ‘scenes’ that involved talking about their views and opinions on different topic areas, ranging from football to royalty. A scene would develop from conversations on these topics. In this scene, the men would decide who wanted to be involved and the ones who did not, would sit down and observe or help to direct or handle the camera/camcorder. The men who did not speak, would mime if they were participating in a scene.



**Photograph 29 - Developing a scene together.**

Typically, the scene would last about 5 – 10 minutes and the men would end the scene by finishing what they wanted to say. As a group, we would then discuss the issues, usually I would begin this discussion that arose through the scene. From this we then discussed more scenes we wanted to do (see photographs 30 and 31 on the next page), therefore, participating at different times and different levels. On the other hand, scenes that were recorded by film and presented in the community exhibition were edited by the film-maker and the location of the films or photographs of the scenes, that were produced, were decided on by the designer from Galaxy, so the men's participation often only went to a certain extent.



**Photograph 30 – Discussing issues that arose from a scene.**



**Photograph 31 – Men waiting for directions.**

Photograph 32 is another example of the men doing a scene which they created. We went around the Galaxy building one afternoon, looking for a location to film, but it started to rain heavily and Joseph started singing and dancing to the song 'singing in the rain' and each man gradually started to do the same. It was a fun way to film and everyone enjoyed doing it and that it was good to have fun together.



**Photograph 32 - Men 'singing in the rain' and dancing.**

## **8.7 Summary**

In summary, the men within this project participated with each other and with facilitators and volunteers involving activities such as comic strips, art and photography, whilst participating together to make decisions about how these exhibits should be presented. Both the men who could and could not verbally speak were able to participate in the activities analysed. The men developed the storyline and the characters that were portrayed in their giant comic strip and the characters were the men's creation of what their super hero would be and how their powers could save the lady (Janet) and defeat the sorcerer (Terry). In addition, the men worked together to present the 'low relief' in a way they wanted it

be seen by the public. The men participated by voting and making gestures with their hands or by talking, which was the same process used for the 'our journey' exhibit and the choosing of the pictures and captions for the 'thought for the month' exhibit.

However, participating in this project came at different levels and times for the men, so there was never any full participation in terms of producing work completely to then go into the community exhibition. For example, the action heroes were templates created by Terry and the low relief, and giant comic strip were both ideas originating from Terry. This influenced, to an extent, how these exhibits were designed and where they were placed in the community exhibition by both Terry and the designer employed by Galaxy. Moreover, the thought for the month' exhibit was an idea that originated from my previous experiences of work within the community and the actual photographs themselves were taken by a professional photographer employed by Galaxy, therefore, despite the scenes being created by the men, the men's participation went to a limited extent. Overall, the project contained clear examples of the men participating with each other albeit at different levels and times to complete exhibits. The extent to which the men participated was often dictated by me, Terry, George and people employed by Galaxy.

Despite chapters six, seven and eight showcasing different examples of 'making choices, 'sharing knowledges' and 'participation' as well as the complexity and problematic issues that emerged with these themes, I have only analysed some of these problems, to an extent. In the next chapter, I will continue the analysis of this research, using aspects of narrative analysis (discussed in chapter five, pages 88 - 128) by presenting a series of soliloquies that present the positive and negative aspects of this research in more detail.

## Chapter 9 – Soliloquies

*Is this a dagger which I see before me,  
The handle toward my hand? Come, let me clutch thee.  
I have thee not, and yet I see thee still.  
Art thou not, fatal vision, sensible  
To feeling as to sight? or art thou but  
A dagger of the mind, a false creation,  
Proceeding from the heat-oppressed brain?  
I see thee yet, in form as palpable  
As this which now I draw.  
Thou marshal'st me the way that I was going;  
And such an instrument I was to use.*

*(Macbeth, Act 2, Scene 1, in the Tragedy of Macbeth, William Shakespeare).*

### 9.1 Introduction

In the previous three chapters (chapter six, chapter seven and chapter eight), I analysed the data that emerged from the thematic analysis. I continued to write autoethnographically about myself and the experiences I felt at different points through the past thirty years including my own difficulties in being able to make choices, share knowledge or what 'intelligence' means and challenges I have faced in participating. The main themes that emerged from the thematic analysis included 'making choices', 'sharing knowledges' and 'participation'. I analysed different examples of the men making choices for themselves, sharing their experiences and knowledge of their lives and interpretations of the world and the different levels of participation within the group that took place. However, I also analysed the limitations and complexities that come with making choices, sharing knowledge and participating and consider why making choices, sharing knowledge and participating is not straightforward for men labelled with learning difficulties.

In this chapter, I will analyse further the complexities that came with making choices, sharing knowledge and participating. I will consider the different viewpoints of some of the characters by developing a series of soliloquies. In other words, thematic analysis (Braun and Clarke, 2006) helped to break down the large amount of data into manageable chunks, whereas the form of narrative analysis

(Sykes and Gale, 2006) I will use in this chapter will help me to focus the lens in on some of the other activities and situations that took place in finer detail.

In chapter five (pages 88 - 128), I explained that I would apply narrative analysis to help explain more interpretatively the perspectives of some of the main stakeholders in this research in my view, specifically through the use of soliloquies. A 'soliloquy' is a dramatic device that comes in different forms in which it represents a character expressing his thoughts and feelings about a situation (Hirsch, 2003). In this chapter, I will present a series of soliloquies that will present my perceptions on how I felt the main stakeholders felt about the project, cutting through the beginning, middle and end of the project. I will write and interpret the soliloquies, the soliloquies being my thoughts about the situation presented at the time. I will consider specifically how I believe three stakeholders viewed some of the situations in this project including George, (the main link to Springfields and film-maker); Janet (the main contact at Galaxy) and Stephen (one of the men) who attended almost all the workshops and worked with me before and after the project ended. Hence Stephen had a key role in almost everything that was analysed or discussed in this thesis. The soliloquies are created entirely by myself and are based on my reflexive diaries. In this respect, before I consider my autoethnographic thinking in this chapter and present the soliloquies, I want to explain further why I have used soliloquies (also see chapter five, pages 123 - 126).

## **9.2 Using soliloquies to focus the lens further on the data**

In chapter four (pages 70 - 87), I explained how I structured this thesis and discussed why I adapted a Freytagian pyramidal to provide understanding to the structure of this thesis. Whilst Freytag (1863) used his five-part structure to make sense and provide some coherence to a Shakespeare play, and I used it to add more meaning to the structure of this thesis, what Freytag's pyramid does not present is some of the dramatic techniques Shakespeare used to develop characterisation. One of the most common dramatic devices Shakespeare used in his plays was the 'soliloquy'.

My personal interest in soliloquies came from my interest in the development of characterisation in plays and in novels such as ones written by Frederick Forsyth, often having extensive descriptions of a character. Soliloquies frequently capture a



specific point in time like in Macbeth's situation when he is reflecting on whether he should kill King Duncan. In fact there are different kinds of soliloquies including audience-addressed speeches and interior monologues (Hirsch, 2003). However, in this chapter the soliloquies I will use will contain the following characteristics based on one type of soliloquy '*self-addressed speech*' (Hirsch, 2003): (1) it is spoken by a single 'actor' (that being me) and (2) the character does not intend the words to be heard by any other character in the story (based on Hirsch, 2003:13). A self-addressed speech may involve a character in the midst of a struggle or dilemma that he/she wants to reflect upon to himself/herself, whilst the audience listens in on what the character is saying. This type of soliloquy can show a character giving voice to a range of emotions or an idea that he/she would not share with any other person, therefore, this type of soliloquy can show a character in the process of talking himself/herself into action or develop a particular frame of mind (Hirsch, 2003). Hence soliloquies are stories told from one character's point of view. In this case the soliloquies are from my point of view. On the other hand, Shakespeare's soliloquies were written for an audience in a theatre, to entertain, driven by the political issues of that time and soliloquies were written for the character. In this thesis, I write my soliloquies as a device to imagine people's positions in their dilemmas and perspectives, based on the data collected, recorded in my reflexive diaries, wary of:

The gap between textual meaning and social meaning can never be completely filled for meaning is constructed every time the text is reproduced in the changing ideological dynamic between text and audience (McKluskie, 1985:93).

The use of self-addressed soliloquies connects with what I discussed in the methodology (chapter five, pages 123 - 126) that narrative analysis can encourage connection and empathy (Sparkes, 2002). As a result, narrating imagined soliloquies can be considered an interactive process of constructing and interpreting experience about others (Cortazzi, 1993, 2001; Squire et al, 2008). In addition, exploring narrative in this way is potentially useful for the insights it can give into how the protagonists in this research identify themselves within the research context i.e. Galaxy (Smith and Sparkes, 2006). In this respect, self-addressed soliloquies, I feel, to some extent, will unravel the multiple guises and

identities of some of the stakeholders in this thesis and provide deeper meaning and a richer backdrop to the findings in this research. This approach is coherent with the autoethnographical approach I have applied throughout this thesis. However, before I consider the soliloquies, I want to look back to some of the times where I found myself thinking to and with myself.

### **9.3 Thinking to and with myself**

I remember speaking to Gareth about his trips to Lourdes (see chapter six, page 147, for his painting of Lourdes) and he was very proud to go and 'drink plenty of beer' with the priests. Gareth also spoke about his upbringing and how he used to hate school because the nuns would beat him. Gareth's reflections took me right back to my childhood and my experiences with my (biological) grandmother.

I always remember dreading every Tuesday throughout my childhood because that was when my grandmother would visit us, usually when she got her pension, so she could spend it on alcohol with her daughter (my biological mother). She was a foul-mouthed old woman, who would lecture you on how bad you were and would always bring in religion (Roman Catholicism) to support her arguments. When I got a little older, this Roman Catholic vitriol was followed up further when she provided me with a catechism<sup>8</sup> of Roman Catholic doctrine on how to be a 'good human'. Funnily enough Gareth remembered having a catechism, but could not read or write. Her voice was always so loud and she never seemed to take a breath between sentences. Seeing her was even worse when my brother and I went around to stay there or visit her because she would just go on about how we should be better to our mother, knowing perfectly well that she was a drunk like herself. We were always accused of being liars, which was always frustrating when you knew you were telling the truth. She would cry to manipulate and we were not allowed to laugh without being told off because she always thought we were laughing at her, a kind of a weirder version of Mrs Havisham from '*Great Expectations*' by Charles Dickens. I remember the droning sound of her voice when she lectured, and I would just sit there nodding, whilst I was thinking to myself about what me and my friends were going to do on a Friday night, or what

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<sup>8</sup> A catechism is a summary of principles, often in question and answer format, containing an assemblage of key Roman Catholic teachings and doctrine. Essentially, the catechism is an instruction book of how to live life according to Roman Catholic teachings.

a great goal Ryan Giggs had scored last Saturday in the FA cup. Interestingly, speaking to Gareth, it felt we had a shared past because his experiences were similar, despite there being almost forty years between us both.

One lecture she always came up with was her experience as a pensioner being a university student at the University of Manchester in the 1990s, where she did an art diploma. She would go on about how disgusting students were for drinking and taking drugs and considered them not to be very intelligent. I remember thinking to myself, and smiling at the thought, that actually university life sounded exciting. I also remember thinking to myself that it was wrong of her to describe black people as 'niggers' because she would always claim that she came from a time when you were allowed to say that, so she actually knew it was wrong but continued to do it anyway. Even as a child I knew that this was not right, even if I did not fully understand the implications of this racist word, but I did not dare to challenge her in case I was punished. Eventually when I became a teenager, I found a way to escape from this headache, by going in the damp, cold cellar whenever she knocked on the door and visited. Although she soon came to realise, so actually raised her voice even more so I could hear it through the floorboards. Unsurprisingly, I just covered my ears whilst I read a book or played on my small snooker table, a little victory because she continued to shout without knowing I could not hear her. This came to mind when Gareth use to say that he would cover his ears and duck down as he was being struck with a ruler by the nuns.

There were some better memories including trips to Liverpool to see a regatta of tall ships to celebrate five hundred years since Columbus discovered America and I remember taking some pictures of the King and Queen of Spain, who came with the ships to Liverpool. I remember the cheese scones and sweets she made, so she was a good cook. But even on these better occasions, I feel they were only done to emphasis the negative points from the lectures that would soon follow, a way to make you feel bad and inadequate because she did something good for you in the first place. I always remember thinking to myself, about the ways that I could escape this pointlessness and how frustrating it was that I had to put up with this nonsense. However, my mini victories of covering my ears and singing to myself or making plans on what I wanted to do in the future helped me to think rationally and positively and be optimistic that the tyranny of home life would eventually go.

Thinking to and with myself, sometimes like self-addressed soliloquies, just without the audience, and speaking to Gareth about his own troubled childhood, fits in with how the self-addressed soliloquies will now be presented in the next sections. I begin by considering how we all felt before and after the project first began.

#### **9.4 The making of a project: how did we all feel at the beginning?**

When I approached Springfields and met some of the men and Galaxy, the development of what was to be called the 'Manpower' project, picked up momentum quickly. Below is a soliloquy about my perspective on this experience:

##### **November 2010 – at Galaxy**

*I'm really getting excited about starting this new project at Galaxy. The more meetings that take place with Galaxy, the more I feel confident that the start of my PhD is going to be great, in a great setting with plenty of resources at my disposal. At the meeting the other day, Galaxy asked me and George to deliver some training, which I was happy to accept and do, but I emphasised to Janet that I want to do this in collaboration with some of the men I had been talking with at Springfields like Gareth and Joseph. I am really looking forward to working with these men because they are humorous and creative and really want this new group to work.*

*Galaxy have also asked us to do some risk assessments and again I emphasised that the men should be a part of this process and not be the process and both Galaxy and Springfields seemed happy to accept this, which was a relief, otherwise it would be an awkward start to this new project. I'm determined to set a tone from the beginning that the men who are going to make this new project happen would be a part of the project in every way.*

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##### **December 2010 – at Galaxy**

*I felt good today going to Galaxy and presenting with the men to the staff at Galaxy. I spoke about the kind of project we were looking to develop and discussed with the men how they want to be treated and related some of this to the issues they had faced in life like being controlled and told what to do by carers and family. I feel Galaxy had a sense of what was to come in developing this new*

*project because some of the audience came up after the event (although I did not who they were and what their roles were) and said they were really looking forward to supporting the group. This is an exciting time for me and I'm looking forward to starting another community psychology project.*

**Soliloquy 1 – My perspective on building up towards the making of the project.**

My first soliloquy was positive about the build up to the making of this project. The more myself, the men, Springfields and Galaxy met up and discussed how the project should work, the more I felt relieved and excited about laying down the foundations to completing a successful PhD, as well as a successful project for a marginalised group of men labelled with learning difficulties. In addition, meeting the staff at Galaxy with the men and doing the training felt like we had the power to challenge and change attitudes about the label of learning difficulties because we got the staff to come and sit and listen to us. Similarly, George, who was the development worker at Springfields, seemed to have had positive feelings about creating this new project, which I consider below (see chapter five, pages 97 - 101, for more information about stakeholders in this research):

**November 2010 – at Galaxy**

*I felt that George and the people who ran Springfields were glad that I approached them. Springfields were keen on working with their members on issues relating to health promotion, so my experience in the local area and working in the community, seemed to fit in with their agenda.*

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*I remember the positive meeting we had prior to contacting Galaxy. Although George looked a bit frustrated because we were not getting anywhere with making a decision about where to do a new project, George did take control and made a suggestion that we could contact Galaxy, a place George had previously done some group work. George contacted them and spoke to Janet, the community worker at Galaxy, who had the job to work with community groups, and set up a meeting with her. George appeared to be enthusiastic about this meeting like everyone else in the room.*

\*\*\*\*\*

**December 2010 – at Galaxy**

*George appeared pleased with the training we did today. He was smiling a lot and fully engaging with the audience. We spoke about the kind of things we like to do like how we work with men and support them to play football in other projects we manage. However, I got the impression that George did not understand the 'community psychology' perspective. I suspected that George was not too sure about what I meant when I used the term 'labelled'. Yet George seemed eager to work with the group and to teaching the group how to film and use a camera, almost like he was doing something good for the men.*

**Soliloquy 2 - George's (development worker at Springfields) perspective on the initial making of the project.**

My soliloquy about George reflected upon the enthusiasm he and Springfields had on starting a new project with myself and Galaxy. George appeared excited about the thought of a new group that would end with a community exhibition. Springfields contributed towards the training, so an opportunity for Springfields to talk about themselves and how a project should/might be organised to support the opportunities in a project for men labelled with learning difficulties. On the hand, George appeared to have had a different understanding to some of the terminology I used in reference to 'labels', but did not communicate this to me. However, Janet from Galaxy was positive about the new project starting:

**November 2010 – at Galaxy**

*When I met Janet, I got the impression that she was enthusiastic about the new group being proposed and that she was happy to work with me and Springfields. She supported our ideas because it fitted in with their criteria, to work with groups in the community, to get them to engage with the museum.*

*Janet also offered myself and Springfields the possibility of doing a community exhibition, an opportunity they offer some of the groups from the community they work with to showcase their museum and their work. Janet felt this could be a good way to sustain the new project proposed and be beneficial to the members of the group, allowing Galaxy to fulfil their aims of working with community groups to engage with the museum.*

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**December 2010 – at Galaxy**

*Janet met with myself and George on a couple of occasions to discuss how we could all work together. Janet felt the training that was delivered and risk assessments that were done was a good thing. About twenty of Galaxy's staff attended and the staff apparently relayed to Janet that the project seemed like a good thing to do. On the other hand, I did get the impression that Janet was looking for more detail about the implications of working with 'disabled people' (how the group were referred to). She seemed unsure about what the research proposal was about and how it would be delivered. However, Janet did say that she got a sense of what the project was to be about and who we would be dealing with.*

**Soliloquy 3 – Janet's (community worker from Galaxy) perspective on the initial making of the project.**

The soliloquy above highlighted that Janet was enthusiastic about working with myself and Springfields because we said yes to accepting that we would use their premises and resources to do the group, whilst creating a community exhibition for display at Galaxy. This did not just suit their agenda to promote their museum through working with community groups, but it also suited the ambitions of myself and Springfields because doing an exhibition sounded exciting as well as a great opportunity to promote our work. Janet stated that she was happy to work with us to develop this project. Nevertheless, Janet was critical of the style of training that was delivered and suggested that she wanted, maybe more training to understand the project being proposed and about whom she would be working with. However, what was Stephen's perspective about starting a new project? Below is a soliloquy about how I felt Stephen viewed the proposal of the new project:

**July 2010 – at home**

*When I spoke to Stephen about the possibility of starting a new project, Stephen looked eager. Stephen enjoyed getting away from home, to get involved with projects and generally met the same people he knew in one project, also participating in other projects.*

*The first time Stephen actually heard about the new project was from Springfields. He was invited to a forum to talk about his views, which he was told after his sister in law opened his post for me. Stephen had been invited to these kind of things before, but he felt he was not usually asked to talk about his views.*

*Stephen would usually just sit and listen. Stephen was sent a survey to complete, which he thinks his social worker filled in for him.*

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### **August 2010 – at a local university building**

*Within the member's forum, Stephen recognised most of the faces there. He had seen some of the men before in other events. He recognised some of the staff, constantly asking if he was ok, which irritated him. He did a quiz, which he found easy, so did not find the activity exciting. But he did let us know that he wanted to get out more and do different activities.*

\*\*\*\*\*

### **September 2010 – at home**

*Stephen was asked to take part in some training and to do some risk assessments. He had done some presentation work before, but he had never been asked to do a risk assessment. He was usually seen as the risk and the one to be assessed. He looked pleased to be asked and seemed empowered that he was in charge for a change, at least for a while.*

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### **December 2010 – at Galaxy**

*He did not understand some of the words at the presentation of the training, but everyone in the audience seemed to be happy to have met Stephen and gave him a round of applause. He gave a story about some of the project work he had done before, but they loved him for that. However, he was looking forward to this new project, in a different location, doing the kind of things he liked to do like poetry and acting.*

### **Soliloquy 4 – Stephen's (one of the men) perspective on the build up to the start of the project.**

My reflections above discuss Stephen's experiences of the events before the project began. Stephen is eager to start the new project, but even before the project begins he is frustrated about his sister-in-law opening his post for him. Therefore, before he even takes part in the project, he is being controlled. However, Stephen decided to take part in the forum and at first felt that he had done this kind of group many times before and was not particularly excited, but was pleased at being able to express his views about what he wanted to do. Stephen was pleased that he was asked to take part in delivering the training.



Overall, George, Janet, Stephen and I were positive about starting this new project, in my opinion, and the momentum in starting the project built up quickly. Some of the men were involved in the initial making of the project alongside the organisations involved, which was a good basis to making this project a participatory project in which the men could do what they wanted to do, which also fitted in with the research aim and Springfields and Galaxy's aim of completing a community exhibition. On the other hand, early on, tensions relating to how the workshops were facilitated and the 'structure' of the workshops such as a Galaxy's preference for a planned programme of events and activities, started to emerge about how the workshops were facilitated and there was confusion about what the research aims concerned. However, before I consider some of these tensions that emerged, in the progression of the project, I want to consider the experiences everyone felt when the project actually began on the first day, and feelings about the workshops beyond day one.

### **9.5 The first experiences: day one and beyond**

In my experience, there is always some anxiety when you start something new and meet new people, so how did I feel about the first day and how the workshops would develop?

#### **January 2011 – at Galaxy**

*I'm excited and a little anxious today, being the first day of this new project. It doesn't matter how well you think about these workshops, you still never quite know how it is going to go in my experience. Seven men have turned up, which is pleasing, a good start, and some carers have come along with some of the men. Gareth and Joseph have just arrived, I can see them walking down from a distance and it is good to see these two who have worked hard with me to get the project started. I'm offering them tea and biscuits as they come in, so they can feel relaxed and welcomed.*

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*I've just got them all together, a bit of a delay because there was so much chatter, which I did not want to break up or disturb, but think it is now time to begin. I had a think last night about what I wanted to say, so I think I'll start by introducing myself and then give an overview of what the research is about and the kind of things we might want to do. I decided I wanted to emphasise that this*

*project is for them and that their ideas and decisions will play an integral part in all that we do. I've just said all that to the group in an air of silence. This doesn't surprise me because we still do not know one another, so hopefully this icebreaker I have prepared will get them engaged more.*

*This icebreaker is something I have used before in other groups, so know it gets people to get involved. It involves sending a tin around and each person has to open up a scroll of paper and answer questions i.e. what's your favourite film and why? Although as we go around the group, I sense there are differences in how people feel they would have done this activity, maybe it's just my imagination, but George looks uneasy, almost as if he is cringing, whilst each man takes his turn to speak. Yes, some of the men could not read, but the carers and people who could read helped and by doing so got involved without standing on the side-lines looking into the group, which feels intimidating to me. The men seem happy enough to answer the questions and are enthusiastic about going on the tour of Galaxy. What I'll do is have a word with George and some of the others who look like they are pulling their faces about how this is being done and wait to see if they want to express their views.*

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*I got to speak to George about him looking unhappy about how things were going. I asked him if he thought the activity went well and whether he thought we had a good start. Despite appearing to look unhappy, his response was very positive and he said he really enjoyed coming and was looking forward to coming again, so all seems well.*

#### **Soliloquy 5 – My perspective on how the beginning of the project worked.**

Although I was anxious about starting this project on the first day, I was glad to meet the men as a group for the first time and was glad to see the project begin. However, I also felt that the semi-structured timetable of activities did not work in my view because although the plan was to attend Galaxy every other week, the men actually wanted to attend each week and Galaxy themselves were happy for them to do so. In addition, if we were to have stuck rigidly to the timetable, adapting the workshops to suit how the men wanted the workshops to be would have been very difficult. For example, if we decided initially to do a filming activity followed by an art and craft activity, sometimes the men wanted to continue to film rather than do some art work. Therefore, after about two or three workshops, I

changed the direction of the forty-five workshops, to work on a 'on the go' basis for each week. In other words, with the men I would discuss what they wanted to do each week, in collaboration with the volunteers and carers. I felt this made it easier for activities to be based on what the men wanted and fitted in with the participatory nature of this research, although I did make this decision alone, believing that people would automatically agree.

Looking back, I am glad I made that decision because I feel it contributed to the reasons why the same men wanted to come back each week to participate in the workshops rather than being in different locations. From the start I emphasised to the men that it was a project for them to make decisions based on what they wanted to do. The men liked to do a mixture of activities, so the workshops would involve a mixture of activities. For example, a workshop might involve taking pictures and talking about them in the first hour or so, and then the second half might involve art or filming or doing some sculpture, which helped the men to participate because there was always something on offer that each man liked to do.

The first workshop was a positive session because people were relaxed and talkative and maybe I did not expect this because of my own anxiousness of starting a new project that I wanted to see work out well. However, the way I facilitated created some immediate tension, which I interpreted as coming down to differences in how a workshop was facilitated by myself. For example, the icebreaker involved reading bits of paper which contained a question such as 'what is your favourite film?' or 'what is your favourite soap opera?', to get the men talking and thinking about themselves with a group of men they were going to get to know overtime at this project. Some of the men could not read, or verbally say anything, and I feel that George was not comfortable with this. On the other hand, he did not say anything. George was a filmmaker who is used to participants in his work doing drama scenes, who have scripts and this activity is possibly considered to be more fun and active, whereas my approach was relaxed, sitting down with a cup of tea and about building relationships in a way that would not make people feel uncomfortable. Moreover, the men who could not read had support from carers and workers to read out what the question was and the men who could not speak provided hand signals, which were interpreted by their carers, who had come to understand what those hand signals meant.

Overall, my approach was to support people where they might need it, whereas I felt with George and some of the carers that a more 'let me do it for you' approach was the way they would have preferred the workshops to be, which I felt would stifle participation, when I felt the men had a greater role to play. Thus, making choices and sharing knowledge and the level of participation for the men was complex and limited. Below I reflect on how I felt George thought about the first workshop:

#### **January 2011 – at Galaxy**

*I felt that George really picked up the buzz between the men and I at the first workshop. There was a good atmosphere, and George, who was a bit late, seemed happy to be there. However, speaking to him briefly and seeing his facial expressions gave me the impression that if he was the facilitator, he would have done things differently. He always seemed to be a little nervous and shy, which rubbed off on me at times I felt, so there grew a little awkwardness between us.*

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#### **February 2011 – at Galaxy**

*George was not able to attend every week because he had other commitments, but he felt he was getting to know everyone well. George seemed to enjoy coming down to film with them and editing some of the footage for them to view. George would witness how I facilitated the project and always seemed a little bit on edge, almost like he was not always happy with the way I did things. Yet George never raised any issues regarding the way I did things. The workshops varied from filming to photography to art to drama. When George was not filming, he would help do the cups of tea or finish/leave the group early. On average, he came to about half of the workshops and seemed happy for me to be with the group with the carers, support workers and volunteers to support me. I always kept George up to date with any developments or issues that arose like with the transport for the men not arriving on time.*

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*George always placed importance about the fact that Springfields was self-funded and self-governing and placed importance on the promotion of the charity. Therefore, saw Springfields presence at Galaxy as important. George would often say how wanted to come away from church buildings and day centres and instead see members in the community doing group work, so people in the community can*

*see that they are people like everybody else.*

**Soliloquy 6 – George’s perspective on tensions within the project concerning facilitation.**

In my view, George’s and Springfields were really supportive in my aims to work with the men. However, it is clear that although they supported me to do this research and facilitate the group, there was to some degree, a lack of confidence in my experience of facilitating. On the other hand, George would often acknowledge that he was not always there. In fact, any attendance from any member of staff from Springfields was sporadic, considering there was an expectation from Galaxy and myself that they would provide training for volunteers and support the running of the workshops. Yet Springfields were eager to see the exhibition done, which they felt would boost the credentials and outlook for Springfields. Next I want to consider my perspective on how Janet felt about how the workshops developed.

**February 2011 – at Galaxy**

*What was clear to me (researcher) was that there was tension between myself and Galaxy. The initial timetable that was presented about the activities and events I expected us to do was not happening and did not happen. Janet asked me and George for explanations on this issue because it broke the agreement we had between us. I explained that the men should have more choices in what they do here at Galaxy, so needed to adapt and not keep to the timetable. George did not really respond and let me do the talking. I felt that Janet was not too happy about this. However, Galaxy still seemed happy for the group to attend each week at Galaxy, but Janet never seemed to sure about the approach that was being taken. Galaxy seemed to be use to a fairly formal, structured approach to learning, which fitted in with how children are taught in schools.*

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**February 2011 – at Galaxy**

*I got the impression that Janet thought this project was disorganised because it was not sticking to a formal procedure you might expect in a school. Despite Janet happy enough to provide refreshments each week, she gave me the impression that the content of the workshop did not always seem to connect with the aims of the group being about health promotion. For instance, the connection between the*

*men portraying football or TV soap characters during drama and relating it to health or poetry about the sexual lives of the men. I felt that Janet wanted the workshops to have more coherence and structure, with aims and objectives for the project to be coherent and worthwhile. Janet seemed to misunderstand that a participatory approach needed flexibility and could not be entrenched in specific, ordered ways, all of the time.*

**Soliloquy 7 – Janet’s perspective on tensions within the project concerning facilitation.**

Compared to the views of myself and how I felt George viewed the project, I believe that Janet was irritated and confused about how and why workshops were facilitated in the way they were. On reflection, I feel that Janet did not make the connection between health promotion and the activities that the men engaged in which was through her frustration of not understanding the research aim. Although this may have been because I did not communicate or explain my research aims very well. Janet felt that a more formal approach would enhance the learning in the group, similar to what Janet was used to adopting in working with other community groups and schools. Janet was complimentary on what Galaxy had to offer, to add value to the group, in terms of the resources and setting that the men/the project used. Additionally, soon after the project started, Janet relayed back her frustration when the timetable she was provided with by myself started to change. Janet seemed confused because Galaxy was used to structured learning plans and activities and not a more fluid, adaptable way of working, so the communication between Janet/Galaxy and Springfields/me was not clear. Below is a soliloquy reflecting on how I felt Stephen reacted:

**January 2011 – at Galaxy**

*Stephen seemed excited on the first day of this project because he was able to get away and be somewhere different, but with familiar faces like Gareth and Joseph. I always noticed that Stephen seemed ‘on edge’ when the table the men were sitting around was surrounded by the carers. Stephen did notice that I tried to bring them into the group, to participate, but this rarely happened. Stephen and some of the men were critical of the fact that despite it being a ‘men’s group’, female carers were in attendance. I believe Stephen appreciated being asked what he wanted to do rather than being told what to do, but he was happy to do*

*what was on offer anyway.*

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*Stephen seemed to enjoy the tour and icebreaker because he got to know the place. However, I felt that the way I spoke to him at times made him feel patronised. I did not intend to come across in that way and it may have something to do with the fact that he is much older and experienced than me in doing these projects.*

### **Soliloquy 8 – Stephen’s perspective on the beginning of this project.**

Stephen’s experiences on his first day, I believe, were positive in that he was glad that he felt listened to, but was wary of the peripheral involvement of the carers/support workers who were there, but not really involved. In addition, Stephen felt that he was being patronised and yet he was still happy to be involved and be there at Galaxy. Below is my perspective on how Stephen felt about the workshops further down the line:

#### **April 2011 – at Galaxy**

*Stephen had got to know more people and helped to create a friendly, engaging atmosphere, doing different activities and being in a place in which he could freely express himself.*

*Each week he came and had a cup of tea and biscuits and would have a good chat with whoever came and spoke to him. Stephen was never ignored or alone. He really seemed to enjoy the room we were based in, because it was comfortable and had everything you would need to do your work. It did feel like a fishbowl because whilst Stephen worked, members of the public walked on by and stared in or entered the room thinking there were exhibits to look at. Sometimes he would just wave at them and they sometimes would wave back.*

*Stephen took part in all sorts of different activities including filming, drama and art. He always seemed aware that some of the men took pictures and recorded films, but he didn’t mind this. At break time, Stephen would help make some tea or coffee and sometimes there were squabbles over how many biscuits some of the men could have or not. This soon stopped and we would talk more about the activity or themes or about life in general. The carers separated themselves to the other half of the room rather than join in. In the second half, Stephen would usually take part in a different activity such as drama or go for a walk around Galaxy. We*

*ended by talking about what we might do next week. He always said how much he is looking forward to coming again next week. Although sometimes his sister-in-law said that he had to attend the day centre, which is on at the same time and day as going to Galaxy, but he preferred to come to Galaxy.*

### **Soliloquy 9 – Stephen’s perspective on how workshops worked.**

Here Stephen appeared positive about his experiences of being at this project. Stephen felt comfortable in this context, although he seemed uncomfortable at times about being in a room with ceiling to floor windows in which the public would wave at them as they passed by, which made him feel uneasy. In addition, Stephen was conscious of the carers/support workers segregating themselves away from the group of men and he seemed to be aware of pictures being taken of him too, but was comfortable with that. Furthermore, Stephen was particularly keen on talking to the men and being involved with the activities on offer and the variety of activities that took place. However, Stephen did not discuss other factors with me in relation to stakeholder meetings because he was not involved and was not privy to what was being discussed, unlike what has been explained in my soliloquies in relation to decision-making with George and Janet.

Overall, from the start of the project, there were signs of tension between the collaborators on issues relating to the facilitation of the workshops, understanding what the label of learning difficulties means, as well as choice and control, and it was these different understandings that subsequently caused the tensions. This demonstrated that making choices was difficult for both the men and myself and that participation could only occur at different levels and different times, usually limiting the extent to which the men could participate.

George, Janet and I had different perspectives on how a project should be organised and facilitated. Stephen and the men were not as interested in these tensions. They appeared to have not been aware of these early tensions, but were happy enough because they got to do what they wanted to do what was on offer at the project. Although this highlights that the men’s experiences were devalued because they were not involved with the discussions in which Galaxy raised concerns. Additionally, George and Janet had different understandings of how they considered the label of learning difficulties compared to me. They saw the men as people who needed help and support, whereas I saw the men as people I could work with and get to know and learn more about. George and Janet wanted



to control the running of the group, whereas I wanted to do this in collaboration with the men. Although Stephen, the men and myself were happy with what we were doing in the workshops, Galaxy and Springfields were not as happy. However, despite their differences in opinion, they did not really express their views to everyone else at this point. Moreover, Galaxy were not happy that the workshops were not done in a structured, formal way, but Springfields and I were happy with how we worked with the men. More importantly, Stephen/the men were satisfied with the approach. Nevertheless, these tensions highlight that making choices, sharing knowledge and participation are complex, limiting and not straightforward to implement. Next, I want to consider further tensions that emerged within the project relating to a situation when one of the men, Winston, was banned for life from Galaxy.

### **9.6 Tensions – Winston being banned for life from Galaxy**

In the previous section, my interpretation of the soliloquies suggested that tensions started to emerge early on, but were not really discussed between us. Looking back, I do feel that we were good at sitting down to talk about any issues, but nobody ever really was prepared to compromise and adapt their approaches and perspectives to suit one another. This could be related to the power dynamics between the collaborators and the men. For instance, Janet/Galaxy might have felt that they should have the project done how they wanted because it took place on their premises and we used their money to get resources to do activities, despite the work the men produced was to be in a community exhibition, exhibited at Galaxy, to promote Galaxy. That could be the reason why George never really expressed his concerns because George/Springfields did not want to lose an opportunity to promote their organisation through the community exhibition. On the other hand, both Galaxy and Springfields, on reflection, might have seen me as a volunteer/student who did not have money or an artistic area of expertise to the project, so felt that my opinions were not as valuable as their own, in making decisions about the project.

The issue of power emerged again, a few months into the project. For example, in one situation it led to one of the men, Winston, being banned for life from Galaxy, which I now reflect on below:

## **May 2011 – at Galaxy**

*What a situation I have found myself in, completely unexpected. Winston had become agitated (having been to the dentist earlier in the day) and his carer thought it was best that he was taken away from the group, back to the studio at Galaxy where we're based. The carer who made this decision decided it was best to get Winston away from the group to calm down. However, I have just been informed that Winston had assaulted a child, leaving a mark on his chest on his way back to the studio. I'm not just surprised, but I'm wondering how the men feel and how Winston is. I can't help but also feel worried about whether the project will continue now. But I am frustrated that the carer had taken the decision to bring Winston even that he clearly was not happy to be there in the first place. Galaxy are now suggesting that a barrier should be placed outside the studio and a note to say that groups/the public could not access the men's group space. I am not too happy with this because it feels like we are re-alienating the men, when the aim of this project was meant to be the opposite and it feels like we have little choice but to go along with this.*

*Winston has now been banned from the group permanently by Janet after consulting her manager at Galaxy, which is a real shame. Why can't we work this all out together? Some of the men in the group including Stephen and Gareth however have just said that it was right that he was banned, maybe they feel uncomfortable with Winston, but I think it is harsh on Winston – what a terrible day he has had. Winston has not been consulted himself and there has been no acknowledgment from the carer that he made the wrong choices leading to this incident. From my view, the carer had made him participate after Winston had communicated his distress by grinding his teeth and making growling noises.*

*What it means now for Winston is that he isn't now going to benefit from the experiences of doing this project. I know carers are pressurised and poorly paid, but Winston's agitated behaviour occurred before he came to the workshop and the obvious decision to me was to protect Winston and keep him away from that workshop that week. There was an assumption that he 'would be ok', but he clearly needed support.*

*The other problem I have now is with the project still being fairly new, I'm concerned that the group might be asked to leave. I'm now guessing that there will be tensions between myself, Springfields and Galaxy because there is now an uncertainty whether the project would continue.*

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*Just spoken to Janet and she has asked that from now on all carers must remain with the men at all times. I thought this was an unusual decision considering that the incident occurred with a carer anyway. But relief that the group can still continue to work at Galaxy. Although my feeling is that there would always be an expectation each time we came that something bad was going to happen.*

**Soliloquy 10 – My perspective on the tensions surrounding Winston being banned from Galaxy.**

My interpretation of the situation Winston found himself in is that it was dealt with in a clinical and unsympathetic way. Yes, it is wrong for him to hit anyone, but it could also be said that it also was wrong to bring Winston that day, as he was uncomfortable and distressed in the first place. Should the carer have been banned from attending if he was the one responsible for the care of Winston? Maybe so, but instead Winston's attack on a child was individualised and the blame was put entirely on him. I felt disempowered because I did not have the power to change things because I was at the mercy of Galaxy, as a result of this incident, because it set a precedent that rules and procedures are to be applied at every opportunity regardless of whether the men, myself or Springfields agreed or not. Again, the processes in decision making needed to be questioned. For example, who should have made the decision to ban Winston? Who was in charge? To what extent was this process empowering or disempowering for the men? But how did George react when Winston was banned from Galaxy? I now reflect on this below:

**May 2011 – at Galaxy**

*George was shocked to hear that Winston had been involved in an assault on a child. But George was also concerned that this could mean the end of our time at Galaxy and he thought this would be a real shame for the other men who attended, who enjoyed coming. I also felt that he could potentially see a lost opportunity in not being able to have a community exhibition to exhibit the work of the men and promote Springfields.*

*I got the impression that despite acknowledging that this was an unfortunate incident for all parties, Winston being banned was for the best because it meant*

*the group surviving and the exhibition still going ahead. George agreed that a barrier should be placed outside the studio and a note to say that groups/the public could not access the men's group space.*

*George did not actively encourage carers to leave the men at the group until they had finished, but was eager to now keep them within the group, in response to Galaxy's request that they wanted all carers to remain with the men at all times. George did raise concerns that he did not understand why I insisted, as far as possible, that this should remain a men's group, so female carers ideally need to leave the men with the 'men's group'. I don't think George ever really got his head around this i.e. being a men's group, so for men only. He did ask me for an explanation and I stated that in my experience mixing groups up meant that men would not express their feelings and opinions about health as much as they would in a single sex group. George seemed to acknowledge this and did not ask again, but seemed confused by it. I got the impression that he thought I was simply being sexist.*

#### **Soliloquy 11 – George's perspective on the tensions surrounding Winston being banned from Galaxy.**

George agreed that Winston should be banned, especially if it meant that the group remained at Galaxy and that the exhibition would eventually still go ahead. Furthermore, George was happy for the group to be separated from the public in that it was made clear to the public that the room, which we were based in, was for private use only. George also revealed his confusion and questioned why the carers were not in the room with the men during the workshops, but also why I asked, where possible, that carers and support workers should be all male, being a men's group. George hints that it is sexist to not have mixed groups, but he did not try to change anything about it. However, in comparison to George, Janet's perspective on Winston and what should be done in this situation was more serious, which I reflect upon below:

#### **May 2011 – at Galaxy**

*In my view, for Janet, attacking a child in anyway is unforgivable. Therefore, Winston's assault made her anxious because she was responsible for letting the project use Galaxy's facilities and to do the project. At one point I thought that she might phone the police and stop the project from continuing, but this would have*

*made her and Galaxy look terrible, after all it was one man who did it and not all of them. The parents of the child decided not to take any further action and so Janet decided that the group could carry on within the building, but that Winston was to be banned for life from Galaxy. Janet decided that a barrier would be placed outside the room and a note would be placed there to say that groups/the public could not access the men's group space. Janet asked that in future the men must be accompanied at all times by their carers and workers and should not be left alone.*

**Soliloquy 12 – Janet's perspective on the tensions surrounding Winston being banned from Galaxy.**

Janet's reaction did not show concern for either the group, Winston or the child, but more directed towards protecting the reputation of Galaxy and maybe her own reputation in being able to do the job. Consequently, Winston was banned, despite myself highlighting that the carer was responsible and that carer would continue to attend the project with other men. Again, there seemed to be less focus on the men/the group and more on protecting Galaxy. However, George, Janet and I had views on these tensions, but what does Stephen think about these tensions?

**May 2011 – at Galaxy**

*Stephen's reaction to Winston's assault was similar to Janet in that he was outraged that Winston could assault a child and he felt that Winston should be banned. On the other hand, Stephen would not have known about it if he had not been informed by myself, because Stephen and the men were not asked about their opinions on the subject or were involved with the decision-making. Stephen did notice the sign and barrier outside in response to Winston's assault, and I got the impression that he felt awkward about it and was not really sure why a barrier had been placed outside.*

*Stephen noticed that since the incident happened, the carers/workers seemed to stay in the group more often, but was not that happy to see them back because he felt that he could not express himself properly.*

**Soliloquy 13 – Stephen's perspective on the tensions surrounding Winston being banned from Galaxy.**

Despite being there on the day that Winston assaulted a child, Stephen was not fully aware of what had happened (the incident took place away from the group within Galaxy). Nevertheless, when Stephen found out, he was outraged that Winston assaulted a child and agreed that Winston should be banned. Stephen was adamant that Winston should be banned, although without knowing the context to the incident i.e. carer's involvement. Moreover, Stephen raised concerns that the carers/support workers in attendance made him feel uncomfortable and as a result was more reluctant to express himself. Therefore, Galaxy's insistence that carers should remain with the men disrupted the participative engagement within the group between the men.

Overall, Winston's assault on a child revealed more clearly the power dynamics within this project. Galaxy was quick to ban Winston for life, through fear of the organisation's reputation being made negative in the public domain, but I am also sure Galaxy did this because they were concerned for the safety of the public, staff and group members in the project. However, Galaxy ignored the significance of the role the carer had in bringing Winston to the project that day, and 'caring' for him. Galaxy's decision to ban Winston highlighted that despite Springfields role in supporting the project and my role in facilitating the project, which are significant roles, both Springfields and I had no choice but to accept Galaxy's decision because of fear the project would end for ourselves and the men. Galaxy did not consider once how the other men were feeling or how Winston was feeling in this situation. In this respect, making choices was non-existent for Winston and he did not have an opportunity to share his knowledge of the experience. In addition to this, Springfields and I were not able to make choices, despite the knowledge we had to share concerning the carer. Next, I want to consider more tensions that emerged in the coming months, particularly relating to the location of the community exhibition.

### **9.7 Further tensions – location of the community exhibition and other issues**

In the previous section, I considered the perspectives of the stakeholders (in my view) in relation to Winston being banded from Galaxy. I highlighted that the power dynamics surrounding the project were made clear, with Galaxy able to ban Winston without any exploration into the context surrounding the incident. This situation highlighted the limited amount of power Springfields and I had, as well as

the men, in making choices and decisions. Now I want to consider further tensions, which highlight further the power dynamics within the project. Below is my soliloquy on how I felt as tensions started to develop further:

### **August 2011 – at Galaxy**

*When I think back, one of my lasting memories of my work with young people was the tensions that arose, whether it be about differing perspectives, good practice or how to facilitate groups or work with individuals. Although I do think that tensions can be really healthy because it keeps you on your toes and helps you reflect and make changes. Tensions also make me feel anxious and nervous and the tensions of this week make me feel like that now.*

*The other day Galaxy called for a meeting between myself and Springfields, which made me feel intense and uncomfortable as I walked to the meeting, based on the emails sent around, which sounded very formal. But as I walked into the room, despite the feeling of tension in the air, everyone was being nice with one another. Janet started by saying how well Galaxy felt the project was going and were glad to have us based at their museum. This put an extra edge to this for me because my instinct said that in my experience when you feel tense and the other people start by saying how good things are, you know the 'bad' bit will come soon.*

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*It turned out that Janet was concerned with an issue the volunteers had raised that they feel they are being pressurised to create activities and facilitate workshops. It seems that the volunteers do not have faith in how I facilitate and have a lack of direction from me. What on earth are they talking about? I asked them every week how they were feeling and happy to apply any ideas they have, if the men are happy with it. Apparently, this stems from a situation that occurred last week after the workshop had ended. Joseph was 'escorted' to the bus stop by a volunteer, like he even needs to be escorted because he knew where to get the bus and how to get around Bromhead (it was not until the next day I heard about this) by a volunteer from Galaxy. I found out that Joseph was a couple of hours late (independent traveller anyway because he had a free bus pass and is use to travelling alone on public transport) and ended up at the airport. Galaxy were not happy that a volunteer had walked with him to the bus stop without 'training'.*

*The other thing she brought up was about Terry contributing to the group. I told her that that Terry (the main, regular volunteer) had put pressure on himself to*

*create activities and facilitate art activities because without my knowledge, he would go home and create activities and turn up expecting to do them. I'm happy for him to do this, if he wants to do this and if the group are happy to do it. But I think that he feels that his thirty years of experience with SEN schools means his ideas were better, so hence why he tries to enforce his ideas on me and the group. I'm frustrated that Terry could moan about this when he is offered support continuously and I think he is using his experience here to try and control the facilitation of the workshops, which is rather irritating. His teaching background in schools would have been teacher-led in the classroom, limiting choices the students could make. The settings Terry is used to would have been formal and structured and this is what I feel he was trying to apply to the way I was facilitating, so I think he is trying to 'teach' me how to 'teach'. But he is not aware that it is that formal, structured way of 'teaching' that I am trying to turn my back on and instead I want to facilitate a project in which all group members can make decision on what they want to do.*

*Then Janet brings up the whole timetable business and she is placing emphasis on needing a 'structure' or a timetable so everyone knows in advance what is going to happen each week. I try to explain that applying structure would limit choice and disempower the men from making decisions. I feel that both Galaxy and Springfields representatives are not getting this and only respond by repeating their concerns about Terry feeling pressured, pressure he puts on himself, to create activities and to come in and teach these activities to the men. At this point I remind them that I am a volunteer too, whose role is to facilitate the workshops. Transport, and what happens before or after a workshop with the men cannot be my responsibility because I am not there to be involved. In my view, this was Springfields and Galaxy's responsibility because they supervise the volunteers. I do understand and agree that more explanation is needed about how to move things forward and that a briefing/debriefing element could be applied at each workshop for the volunteers, that would involve me speaking with the carers and volunteers before each workshop to discuss any concerns and to consider some of the activities the men want to do.*

*At least the meeting as ended cordially and with us mostly being in agreement with one another that the men enjoyed being a part of the project and continued to attend each week. But I'm starting to feel that I am up against people, particularly George and Terry, who are not used to challenging their own views and instead*



*are set in their ways of how to facilitate or teach a group. Terry, for instance, clearly favours a formal, structured approaches to group work, the kind you might find in a school and had set ways of doing things, in the way Terry was use to before he retired from teaching in schools. Of course this approach by Terry fits in with the way Galaxy like to deliver activities to school children who regularly visit Galaxy. Therefore, I do feel alone sometimes in challenging this formalisation of this project to change into something that is not dominate and overpowering, but one that is relaxed, creative and participative at the men's own pace and therefore not dictated by the agenda of Galaxy and their volunteers (Terry).*

**Soliloquy 14 – My perspective on tensions within the project concerning facilitation.**

This soliloquy highlighted my frustrations with some of the decision-making and perspectives from Galaxy concerning the expectations of volunteers. I did understand that if they are informed by one of their volunteers of a problem, then it is good practice to communicate to the relevant people and to be transparent. Nonetheless, Galaxy's concerns in my view, needed to be directed at Springfields, in relation to the training of volunteers because they had the training resources and staff to train these people. However, Springfields were quiet on this and I felt Springfields needed to take responsibility and be clear on what the type of training was needed for volunteers and more importantly, the views of Joseph, and the men, would have been useful here, but were not referred to. I raised the issues of the significance of speaking to the men about this, but both Springfields and Galaxy agreed that the men would be bored at meetings and that meetings should take place before a workshop. If meetings took place after the workshop, it was argued that this could have caused problems with arranging transport and for some workers, particularly the carers, who wanted to end their shift on time. It seemed that there was a lack of understanding all round about which role everybody played. However, these problems were never really resolved, as I reflect upon in the next soliloquy:

**September 2011 – at Galaxy**

*So another meeting is called and still even that we are halfway through the project, I feel anxious, but also kind of used to all these meetings now. Galaxy wants to discuss an issue concerning the location of where the community*

exhibition will be. Janet suggested that the community exhibition room will be changed to a smaller room, which raises concerns for me that the project is not considered that important. Again, I feel at this meeting, with Springfields and the volunteers in attendance, that I am fighting the corner of the men, who are never invited to these meetings and I have never been given any decent explanation for this either. I believe that the exhibition is going to be placed somewhere less accessible for the public to see it, but Janet has informed us that in fact they have money to re-structure the proposed exhibition space, so it is considered a good enough reason to move where the community was going to be presented. I do feel relieved that there are alternative, but the alternative rooms they have proposed are either dark, dirty or inaccessible or further away from where the public are more likely to go. I cannot help but feel that the exhibition is now considered not to be important and maybe does not fit in with the ideas Galaxy had because it does not relate directly with science or engineering, the kind of areas the museum are most interested in. I feel that it is insensitive to put the exhibition below the ground, hidden away and seems symbolic to me that there is a lack of understanding on what 'disability' means and the importance to share what the men, labelled with learning difficulties, have created, with the public.

For me, there are two main problems with this meeting at this stage. Firstly, meetings are usually called between the collaborators – Galaxy, Springfields and me and in this instance volunteers were invited. However, the men who participate in the development, decision-making and production of the project in the first place as well as the men who had participated in the twenty odd workshops at this point, are never invited despite my protestations that the men should be involved. I find this frustrating because I do not feel the collaborators really understood why I place significance on working in unison with the men at every point.

Secondly, the proposal of this new exhibition room is something both Springfields and I feel could reduce the importance of the project. The options available compared to the spacious, well lit and well-structured room where previous community exhibitions had taken place were not of the same standard. Despite the reasoning that the room where the previous exhibitions had taken place was to be reconstructed, it still feels that the project had lost a good opportunity to present the work the men did in the best possible way by not being in that room.

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*I feel like I am being interrogated in the second half of this meeting. Janet is concerned that the previous meeting's action points where Springfields was meant to produce more risk assessments and provide a training manual for volunteers had not been done and I feel it is being directed at me. For each workshop Galaxy wanted a risk assessment to be done, a similar risk assessment that was done prior to project beginning. For example, ensuring that doorways were accessible, making sure that the room was clear and easy to walk around and that the toilet functioned and was accessible. I thought this was a waste of time because the men knew not to walk into things or knew that if a toilet was not working that they should use another one. Again, a misunderstanding of what the label of learning difficulties means because here this label implies that the men are not capable of understanding their immediate contexts or able to make conscientious decisions.*

*I joked that I felt like I was on trial, which released some of the tension in the air. What surprises me is that Galaxy wants more risk assessments to be done, particularly in relation to the men's background i.e. medical circumstances for first aid purposes (so they had the information to use). I cannot help but speak up about this and argue that information being accessed by inappropriate people (Galaxy staff) and where storage of information should be (men's personal information i.e. medical records) is for the men to make this decision. They are trying to balance this out by suggesting that Galaxy first aider's needing to know data such as the type of antipsychotic medication the men were on. A long debate is occurring now about what would happen in the event if one of the men was injured, distressed or needed some kind of medical intervention. Galaxy are insistent that they want access to the men's medical records (neither me nor Springfields would have access to that information anyway), to be stored away at Galaxy and only they could access this information if one of the men needed first aid. I am strongly objecting to this because the men needed to give consent and I am trying to tell them that a first aider's expertise at a basic level does not justify access to personal information. It seems to me that they do not understand the importance of consent and confidentiality. Now there is a drawn out discussion about volunteer expectations, but as I say, and Galaxy are agreeing, we are still learning to develop as a collaboration. Springfields and I have agreed to use Galaxy procedure in term of writing a risk assessment every week and following protocol for first aid – seeking a Galaxy member of staff and they made me the official 'project leader. But there is no agreement and rightfully so with regards to*

*accessing medical records.*

**Soliloquy 15 – My perspective on further tensions concerning how the project should work.**

This soliloquy described more tensions that started to develop during the making of this project. Here I expressed my continued frustration at not involving the men in meetings, particularly, when talking about their personal issues and personal business i.e. medical records. For me, this completely rejected the experiences, skills and rights of the men, the same values and skills that would be central, to the making of the community exhibition, for example, the sculpture that was enshrined with their frustrations about life and hopes for the future. On the other hand, despite this soliloquy depicting the frustration I felt, I also felt that Galaxy were not intentionally trying to marginalise the men, in the respect that they saw people labelled with learning difficulties in a derogatory way. I felt that Galaxy simply did not understand the issues and concerns on the subject of 'disability' and instead, analysed situations clinically and through being formal because that is how the organisation dealt with matters responding to wider societal discourses and expectations on people labelled with learning difficulties. I felt that the silence of Springfields is obvious here, and this is where they should have stood up and spoken up in the way I did for its members. Springfields silence made me feel that I was a lone voice in challenging people's perspective on learning difficulties. Hence, the sharing of my knowledge and experience was mostly ignored. Next, I will consider George's views about the tensions:

**August 2011 – at Galaxy**

*George was frustrated in my view about being told how to run projects because he had so on many other occasions before. He did not like the formality of the emails that had been sent by Galaxy, but mixed in with his frustration was a genuine worry that the project could be closed down, especially when the men appeared to enjoy it.*

*He was relieved to hear that Janet felt that the project was being well attended and enjoyed by the men, but did not really react to Janet's concerns about a lack of direction from myself and that there was no 'structure' or timetable in place so everyone knew what they were doing in advance. George was irritated that Galaxy appeared to put responsibility on him regarding Joseph ending up at the airport*

*because he was not responsible for Joseph in a 'caring' capacity. George did agree that volunteers needed to be trained and agreed to arrange some training.*

*Although George did show some empathy, I felt, regarding Joseph and his journey to the airport, he did not think it was such a big issue because Joseph was an independent traveller anyway and Joseph is simply forgetful at times. George felt the volunteer who escorted him made his own choice to act as Joseph's 'carer'.*

*George was fully aware about Galaxy's request to apply a more structured timetable, but I felt that he knew, like myself, through experience, that projects need to be flexible and adaptive, to suit the members of the group.*

### **Soliloquy 16 – George's perspective on further tensions within the project.**

George was frustrated with Galaxy on how they thought about how to work with men labelled with learning difficulties. George was frustrated with the questioning of how Joseph ended up at the airport after the conclusion of a workshop. George was much more relaxed about it than Galaxy because he knew Joseph well and was confident that despite his forgetfulness (at times), Joseph knew his way home. In addition, George felt that it could not be his or Springfields responsibility to ensure the men got home, if not there to supervise.

When Galaxy brought up the subject of how the workshops were structured, he did not say much, but in my conversations with him, he admitted that when working with groups, you need to be able to adapt to suit the people in a group. Next, I consider more tensions and how I feel George felt about this:

#### **September 2011 – at Galaxy**

*George seemed relieved that we had got through the first six-months, especially getting through some of the tensions. However, when more issues arose, he seemed to become more accepting to Galaxy in granting their wishes because he did not say a lot, even when I felt he disagreed with Galaxy.*

*George was frustrated that the room for the exhibition was to be changed to a smaller room, which raised concerns for Springfields because the promotion of their organisation and the men's work did not now seem as important. He was relieved to hear though that the room change was not about demoting the project but because Galaxy were re-structuring the place. However, he did not think the new room was as good, but as long as the exhibition took place, then George was*

*happy.*

*When Galaxy demanded that a training manual and risk assessments should be produced, George promised to do this, like he had done in the past, but I felt a hesitancy because being in a small organisation, with limited staff, meant he did not have the time to realistically produce new documents.*

*When I brought up the issues relating to confidentiality and personal information, George was quiet and did not back me up directly. I think he agreed with what I was saying, but that there was still an overriding sense of that the project must work and the exhibition must go up, to promote Springfields, so happy to go along with what Galaxy demands.*

**Soliloquy 17 – George’s perspective on where the community exhibition should be placed.**

George raised similar concerns that I raised, in that the exhibition room change caused problems in accessibility to the wider public and seemed to reduce the importance of the exhibition to Springfields and I by being placed in a smaller room. However, George suggested that as long as the exhibition actually went up on display, he did not mind where it was. In addition, George seemed relaxed again about producing more risk assessments and training for volunteers. Although he revealed that with Springfields being a small organisation, with few staff, that they were not able to do everything, because it becomes too much to do and more than what they already do. However, he appeased Galaxy by promising that he would train volunteers and produce a manual for volunteers about working with people labelled with learning difficulties, presumably a guide on ‘how to work’ with people labelled with learning difficulties. Next, I consider Janet’s viewpoint (in my opinion), on the tensions in the project, which are somewhat different:

**August 2011 – at Galaxy**

*Janet let us know that her bosses last week informed her that money had been made available to redecorate the community exhibition room, which meant that the usual space for the community exhibition was not going to be available for this project. I sensed Janet was a bit worried about the reaction she might get from me and George. Janet invited two of her senior managers to the meeting because, I think, she wanted to reassure us that although the exhibition room has become unavailable, there were still other alternatives.*

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*When we had been informed about the room change, Janet looked relieved. Janet explained the choices and one particular (where the exhibition was to be in the end), had a large footfall of members of the public/schools who could come and view the exhibition. Therefore, Janet considered the potential numbers who could visit to be advantageous for all involved. However, Janet used this meeting as an opportunity to cover other issues she had with the project.*

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*Janet was concerned that risk assessments were not being completed and a training manual has not been produced for the volunteers. I insisted that I did risk assessments every week, but Janet wanted to see this down in writing and sent to Galaxy. The tone in Janet's voice suggested that she was annoyed and maybe felt Springfields apparent reluctance to produce a training manual for volunteers as being unprofessional because there was an expectation that organisations have systems in place to ensure that the right protocols/information are in place. Janet did request this three to four months previously.*

*Janet also used this meeting as an opportunity to express more concerns. Janet was concerned that in the event of something bad happening i.e. a member of the group falling ill, we would not know what to do or a first aider would not know what to do. Janet felt we needed to know the medical details of the men to ensure that they got the best care in the event of an emergency. However, I was the only person in the room who challenged this and the implications of this declaration. But Janet insisted that this was appropriate.*

*Janet was pleased that I had become the official 'project leader', so ensuring that if any problems/issues arise, I would be the first point of call. I think Janet was reassured with this decision because it ensured some kind of accountability.*

### **Soliloquy 18 – Janet's perspective on further tensions in this project.**

Janet's perspective on changing the exhibition room was positive, although she was anxious about telling Springfields and I that essentially the better room that is normally used for the community exhibition was to be replaced with something smaller and less adequate. On the other hand, this anxiety soon left when Janet explained to Springfields and myself her concerns about different aspects of the project. For example, Janet wanted Galaxy to have access to the personal medical records of the men, so that in the event of something medically bad happening,

Galaxy were then able to help support the men. However, Janet did not see the pitfalls to this and did not understand why this was challenged by myself. In reality, neither myself or Springfields or even the men had direct access to the men's personal information, so their demand for it seemed inappropriate. On the other hand, Janet was promised that risk assessments would be done each week and felt more comfortable that I had been made 'project leader', so that any concerns that were raised meant I was accountable to that. As a result, Galaxy were moving responsibility onto myself and Springfields if anything wrong was to happen. But did Stephen have a perspective on this?

### **September 2011 – at Home**

*Stephen was never asked to attend the meetings that took place with the people involved in making this project. In fact, Stephen may not have been aware any meetings took place. I suspect that because Stephen became increasingly involve and developed his confidence, he would have liked to have attended the meetings in which he could make joint decisions. I believe Stephen felt that any decisions that were made about him or on his behalf should have been done in consultation with him including the use of personal information about his health. Stephen liked the room we planned to have the exhibition in, however in truth he was happy for it to be anywhere but it was out of his hands anyway.*

### **Soliloquy 19 – Stephen's perspective on the tensions within the project.**

In this soliloquy, Stephen emphasised that he was never asked to participate in meetings between Galaxy, Springfields and myself, but also stated that he did not have an awareness that meetings took place anyway concerning the men in the group. Stephen is clear about his feelings in being involved with the decision-making about the project, particularly when it involved his personal information. He believed that his consent and participation was crucial and important. On the other hand, he admitted that the room change for the exhibition was out of his hands.

Overall, from the start of the project, there were obvious signs of tension between the collaborators on issues relating to the training of volunteers, the change of exhibition room, the facilitation of the workshops and the non-involvement of the men in decision-making. These experiences clearly demonstrate that the men were not involved with the major decision-making in this project relating to issues directly involving the men. Thus ignoring the knowledge



the men had to share, which they had shared consistently throughout the forty-five workshops (evidence of this can be found in chapter six, seven and eight and, in this chapter). Notably, there was a push from Galaxy to gain access to the men's personal information without their consent, this reinforcing the exclusion of the men, in an attempt to limit the making of choices by the men. In addition, Springfields were notably quiet and reserved in arguing against Galaxy's determination in some of their decisions such as the permanent banning of Winston, ensuring that the levels of participation were ultimately decided by Galaxy and not the men or facilitators of the workshops. Instead Springfields focused their frustrations more on their lack of understanding for the aim of this research, which suggested that what was being communicated from myself was not very clear or accessible. However, next I want to consider to what extent the project was advantageous for all involved.

### **9.8 What did we all gain from this experience?**

Despite the tensions over the course of the project, I feel that there were many positive outcomes, particularly for myself as an individual. Below is a reflection of my feelings when we opened the exhibition:

#### **February 2012 – at Galaxy**

*I'm excited to be a part of the opening ceremony to this community exhibition. I've just made a speech and made a point of getting all the men off their feet to stand with me as I said a few words about each man and how much I loved working with them. It's been a great day, although I'm tired because everyone is asking me questions as so many people have turned up, the press and radio wanted to talk to me, although noticeably, the men were not asked to contribute to the press or radio.*

#### **Soliloquy 20 – My perspective on what I have gained from participating in this project.**

So I have been successful by working on this project. The data I collected was used to be able to write this PhD. The skills and confidence I have developed through this research process has led to other successes such as in teaching employment, receiving a student research award as well as other successful community projects. Even the soliloquy above puts me at the centre of the stage at

the opening ceremony. In addition, I have worked on other projects, which have involved some of the men from this research to produce radio shows, a hate crime event and also citizen advocacy work (these activities/events will be discussed in chapter eleven).

I have disseminated information from this research through lectures, conferences, seminars and publications. Students I have taught have been inspired to work with Springfields through the work this project has produced. Ultimately, the community exhibition was completed and presented for a six-month period, with great feedback from the people who viewed it. Overall, I have gained enormously from participating in this project in many different ways in terms of career development as well as identity development as a person and researcher. But what did George and Springfields gain?

#### **February 2012 – at Galaxy**

*George was pleased that the community exhibition was opened. It gave George the chance to get involved with the press and do some filming. But after all the tensions and problems I think he was relieved that we finally got to this point.*

*With the exhibition up, Springfields felt proud that the men did a great job in producing this work. Springfields had the publicity and coverage for Springfields has been really positive, in a time when small organisations are struggling to find funds to keep projects running.*

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*George was pleased that I returned to the organisation in helping to develop other projects, working with members including some of the men from this project.*

#### **Soliloquy 21 – George’s perspective on what Springfields gained from participating in this project.**

George’s perspective on what Springfields gained is clear in that for them it was important that the men involved achieved something in creating and producing the exhibition, but it is clear that George is happy that the organisation itself had received publicity and coverage that put their organisation in the public domain. George was also happy for me to return to the organisation, therefore, despite his reservations on how I facilitated workshops, he was happy enough to keep working with me. However, did Janet share the same view about the completion of the exhibition?

### **February 2012 – at Galaxy**

*Like George, I believe that Janet was relieved to see the project come to an end because of the tensions and dramas that occurred. Janet enjoyed the end of project opening ceremony and seemed to have a good time. Janet got in the press team and local newspapers to promote the exhibition, to generate as much support as possible in getting people to visit Galaxy.*

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### **March 2012 – at Galaxy**

*Soon after the project finished, Janet commissioned an associate to write a report about the project, which backed up her frustrations with the project i.e. risk assessments not being done, no support for volunteers etc. The exhibition lasted for six-months and the exhibition was then given to me to keep, with the only stipulation that in the event of it being exhibited that Galaxy is referenced.*

*Janet did have a meeting with the collaborators and I and discussed the possibility of developing a new women's group or an extension to the current project, but this was never to prevail. Janet's expectations for a new group to develop would mean that there would be more structure to the workshops, fully trained volunteers and support for all members involved.*

### **Soliloquy 22 – Janet's perspective on what Galaxy gained from participating in this project.**

From Janet's perspective, Galaxy had gained what they set out to, and that was publicity. This was achieved by working with a local group in the community (Springfields), which forms part of their business agenda, through the completion of a community exhibition with a local group and resulting in the likelihood of more members of the public visiting Galaxy. However, Janet also expressed her relief that the project ended because of the tensions and problems that had arisen. On the other hand, following the report Janet had commissioned, Janet/Galaxy were happy to consider the continuation of a formatted version of Manpower or a new women's group, but this was not to occur, mainly because of differences of opinion. Once the exhibition was complete, I was given the exhibition to display in other areas so long as Galaxy were referenced, hence continuing Galaxy's promotion long after the exhibition ended. But did Stephen and the men gain anything by completing the project and exhibition?

### **March 2012 – at Home**

*Stephen always says to me that he had a great time coming to the project and came to most of the workshops on offer. Stephen was listened to and he developed his confidence by getting involved with different activities, new and old. He was proud that he was able to help create an exhibition and for everyone to see it. He was able to see his work on display and to share his views with the public. Although he only saw it once.*

### **Soliloquy 23 – Stephen’s perspective on what he/the men gained from participating in this project.**

Stephen recalled having a great time being involved with the project and contributing to the development of the exhibition. He felt proud to have engaged with new and old activities, but despite his contribution to this exhibition, he only saw it once and other than personal pride being involved with the creation of the exhibition, Stephen did not gain much else in my view.

Overall, Springfields, Galaxy and I all gained what we set out to do and more because the project lasted much longer than what was planned. We completed the exhibition successfully and gained much from promoting the project and exhibition. As an individual, I have gained the most. However, I feel that Stephen’s sentiments suggested that the men have gained the least because, most of them only saw the exhibition once and although the men loved coming to Galaxy, their time and efforts were restricted when making choices, sharing knowledge at crucial times and participation occurred at different levels, so full participation was rare.

### **9.9 Summary**

In this chapter, I continued to analyse the data I collected during the making of this project and have captured this data in the form of self-addressed soliloquies. I provided a series of soliloquies from my own perspective, considering my perspective and what I feel were the perspectives of some of the main stakeholders including George at Springfields, Janet at Galaxy and Stephen, one of the men, on issues relating to how the project began, the workshops themselves, the tensions that emerged and what was gained by each collaborator.

A number of issues arose from the soliloquies, but one thing that was positive and the same for all, was that everyone including Stephen, was enthusiastic and excited about starting this project and ending it with an exhibition showcasing the activities and work produced subsequently throughout 2011. Therefore, everyone involved from the beginning saw the potential to gain from the project including my own PhD through data collection; Springfields need for publicity and to provide a project for their members; Galaxy's commitment to local groups and to produce a community exhibition as well as Stephen being able to express himself and get involved with activities he enjoyed doing.

However, from the start of the project, there were obvious signs of tension between the collaborators on issues relating to the training of volunteers, the changing of exhibition room, the facilitation of the workshops and the non-involvement of the men in decision-making. From these tensions it is clear that the men were not involved with the major decision making of this project, relating to issues directly involving the men limiting choices and highlighting the complexity that comes with making choices. Notably, there was a push from Galaxy to gain access to the men's personal information without their consent, reinforcing the exclusion of the men. In addition, Springfields were notably quiet in arguing against Galaxy's determination in some of their decisions such as the permanent banning of Winston. Instead, Springfields (specifically George) focused their frustrations more on their lack of understanding for the aim of this research, which suggested that what was being communicated from me was not clear or accessible. Yet I also felt that for both Galaxy and Springfields, there was a fear that if this project was not controlled and managed in formal ways they adopted in running projects, then both Galaxy and Springfields would gain bad publicity or they feared that bad publicity would affect their personal reputations.

Additionally, Winston's assault on a child revealed the complex power dynamics within this project. Galaxy was quick to ban Winston for life, through fear of the organisation's reputation being made negative in the public domain, but I am sure also, because they were concerned for the safety of the public, staff and group members in the project. However, they ignored the significance of the role the carer had in bringing Winston to the project that day and 'caring' for him. Galaxy's decision to ban Winston highlighted that despite Springfields role in supporting the project, and my role in facilitating, that both myself and Springfields had no choice but to accept Galaxy's decision. We feared the project would end for ourselves

and the men, so this limited the choices we had, despite the knowledge and experience we brought the project. Galaxy did not appear to consider once how the other men were feeling or how Winston was feeling in this situation. This could be related to the power dynamics between the collaborators and the men, but also the irrelevance that Galaxy placed on the knowledge and experience the men had to share. For instance, Janet/Galaxy might have felt that the project should have been facilitated how she/they wanted, because it took place on their premises, using their money to get resources to do activities, yet despite the work produced was to be in a community exhibition exhibited at Galaxy, to promote Galaxy. Similarly, that could be the reason why that despite the opinions George had about how things should be facilitated, he never really expressed his concerns because he/Springfields did not want to lose an opportunity to promote their organisation through the community exhibition. On the other hand, both Galaxy and Springfields, on reflection, might have seen me as a volunteer/student who did not have money or an artistic area of expertise to the project, so felt that my opinions were not as valuable as their own in making decisions about the project.

Nevertheless, despite the tensions, I feel that both Springfields and Galaxy were not consciously looking to exclude the men. With hindsight, I feel that it was down to the poor communication between all collaborators, which led to confusion and a lack of understanding. I think we needed to have built up the relationships more before commencing the project, which was rushed at the beginning, but driven by genuine enthusiasm to do the project. Yet the men were generally happy to be there and be involved and a community exhibition was successfully completed. But I do feel that the tensions never fully resolved hence why the exhibition became the end of the project, although I was to later work with some of the men again on other projects following on from my experiences with the Manpower project (which will be discussed in chapter eleven). As an individual, I have gained the most. However, I feel that Stephen's sentiments suggested that the men have gained the least because most of them only have seen the exhibition once and although the men loved coming, their time and efforts were restricted when making choices, sharing knowledge at crucial times and participation occurred at different levels, so full participation was rare.

In the next chapter, I will discuss the analysis from chapters six, seven, eight and nine in line with relevant academic research and literature, which will present

my contribution to knowledge and theory, specifically in relation to the aim and objectives to this thesis.

## Chapter 10 – Dénouement

***‘A rhizome may be broken, shattered at any given spot, but it will start up again on one of its old lines or on new lines ... Perhaps one of the most important characteristics of the rhizome is that it always has multiple entryways’ (Deleuze and Guattari in ‘Capitalism and Schizophrenia’, 1977:9).***

***‘Critical community psychology learns from its practice, its successes and failures and from those with whom it makes alliances. It refuses complacency, being restless in its search for learning from multiple sources’ (Kagan et al, 2011a:63).***

### 10.1 Introduction

In chapter nine (pages 207 - 247), I followed up the analysis of my data using thematic analysis (chapters six, chapter seven and chapter eight) by focusing on the perspectives of the key stakeholders and I used self-addressed soliloquies as a form of narrative analysis to convey some of the problems and struggles as well as the positives during the making of this project. This part of the thesis will now focus on reflecting on what these findings mean, particularly in the context of theory, research and literature, which provides a basis to my contribution to knowledge. I have titled this chapter ‘dénouement’, which in French means to ‘untie’. In other words, following on from my interests in theatre, stories and plays, I have taken the word, ‘dénouement’ is the unravelling and sense making of the complexities of a ‘plot’, the plot in this instance being the findings from the making of this study. Hence why I think of Deleuze and Guattari’s (1977) words above, because although I will try to make sense of the findings with relevant literature, it is not easy because there are *‘multiple entryways’* to consider. However, Kagan et al’s (2011a) words are reassuring because this chapter will help me to reflect on the meaning of this thesis, by considering the successes and failures with whom I made alliances (Galaxy, Springfields and the men) and by searching for learning from *‘multiple sources’*. Therefore, this chapter will bring together the findings from the thematic and narrative analysis and will be applied to the literature and will be interpreted in relation to the research aim and objectives.



Here it is useful to re-state what my aims and objectives were in this thesis to provide some direction into this dénouement (also stated in the prologue pages 9 - 14 and chapter one pages 15 - 33). The aim of this research was to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. Three research objectives were set out to meet this aim:

- 1. To explore the experiences of the men labelled with learning difficulties, participating in a group centred around creative activities formed to promote health awareness.*
- 2. To collaborate with a group of men labelled as having learning difficulties in understanding how labels are constructed and understood.*
- 3. To develop a new understanding of the ways in which a critical community psychology and disability studies perspective can be utilised for men labelled with learning difficulties.*

In this chapter, the main findings from the analysis are considered relating to; health promotion, the label of learning difficulties and the relationship between disability studies and critical disability studies, which were reviewed in the first three chapters. There are overlaps between the sections of this chapter, but this is to be expected given the inter-relatedness of the concepts I considered in the literature review and methodology chapters. In addition, there were other discussion points that were considered but will not be discussed here relating to 'male identity' and 'men, disability and sexuality'. Although these themes will tentatively emerge in some parts, I felt that I had to focus on discussion points that would provide the most richness and depth to provide a fully justified dénouement to this research, and what I felt were the most important issues recognising that not all can be covered. The main discussion points have titles that connect with the findings, but also, by keeping with the story/play metaphor and Freytagian influenced model, the titles will be connected to some of Shakespeare's plays and famous words. However, before I consider my findings, I want to consider the autoethnographies I have written and make sense of them through my own identity, my very own dénouement.

## 10.2 Making sense of things

I was facilitating a discussion group with Stephen from Manpower in April 2013, at a local art gallery, and through my mobile phone, I found out that Margaret Thatcher had died. I have always disliked what she represented politically, and also morally as well as how she divided a nation with her policies such as regressive taxes. However, it still made me sad because hearing about a death is still a finality, an ending, and this made me think back to my earliest memories, of seeing Thatcher on television and wondering who this woman was. Again, like my previous mini autoethnographies, there have been many moments during the making and subsequent write up to this thesis, in which I reminisce, making me think about my identity.

In previous autoethnographies I considered my Welsh identity and the background of my dad and how this filters through my everyday thinking and interaction with people. I explored the difficult moments of growing up at home and in school, whereby through adversity I have been able to develop a career in the making in academia. I think from the adversity I have experienced personally, it has helped me come to an understanding about injustice and hardship, which complements my work with marginalised groups such as those who are labelled with learning difficulties. I know what it is like to be marginalised, but I have still managed to be successful by my terms, which many marginalised people do not manage to be. Some may say I have been lucky, but I think that this response is too easy and does not reflect upon the hard work and dedication I have shown. Yet I am fully aware how it easy it could have been for me to also have been marginalised in such a way that I could not be successful like many people that I have worked with in the community. In chapter eight (thematic analysis chapter, 'Participation'), I touched upon my struggle at times at being overwhelmed once I became a postgraduate. When I became a postgraduate, I was working in the community, the combination of which have made me a leader, a facilitator, a man with 'knowledge', and so essentially became the centre of attention, which I have learned to become better at (See chapter eight for my autoethnography that reflects on this, page 188). Mix this in with my determination to fulfil my ambitions and desire to do my best to make a difference in the community (sometimes against much opposition and anger), means that being me, being a critical community psychologist, student, academic, and community activist can be an

emotional rollercoaster. However, despite these reflections on my character, at this moment and in this time, I do in a sense feel that this 'dénouement' is not heading towards an end (end of being a student/end of PhD), but in fact it feels like an epiphany of new learning and experience, emerging through the journey I have taken through doing this research. In this respect, I feel that reflecting deeply as I have done on my background and identity (and on the making of this research which is not easy), has not just made me understand myself more, but made me a better researcher, a better psychologist and one that works with people labelled as having disabilities.

Similarly, in this discussion, I hope to make sense of the data I have analysed by connecting the literature with the data in connection to the research aim to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. Next I begin to discuss the main findings and want to consider the knowledge the men shared about health, and its implications for health promotion and awareness for people labelled with learning difficulties.

### **10.3 To have knowledge or not to have knowledge – that is the question**

My engagement with the men in this project and the collaborators (Springfields and Galaxy) identified that men's health awareness was considered important and formed part of the activities that were undertaken at Galaxy in 2011, which underpinned the aims and objectives of this research. On the other hand, despite my own as well as Springfields eagerness to deliver health promotion type activities (such as on men's cancers, diet and exercise), the findings in this research suggested that the men already knew much more about health promotion than anticipated by myself and Springfields (See chapter seven and sections on 'being clean', page 163 and 'cancer' page 167). Here I want to consider this in more detail in relation to the literature on health promotion and disability.

In chapter one (pages 15 - 33), I considered some of the evidence concerning disability (including labels of impairment and learning difficulties) and health promotion referring to health promotion interventions, such as physical activities, which have been found to be beneficial for people labelled with disabilities (Durstine, 2000; Rimmer, 2004; Allen, 2004; Fragala-Pinkham et al, 2006; Mead et al, 2008). However, I argued that health promotion activities rarely target people

labelled with disabilities and so people labelled with disabilities often experience multiple barriers in participating in health promotion activities (Becker and Stuifbergen, 2004; Equality treatment: closing the gap, 2008; Rimmer et al, 2008). Additionally, I critiqued how people labelled with disabilities can expect to find barriers to health promotion because of health service provider attitudes, knowledge and skills that ensure health practices negatively contrast with the rights of people labelled with disabilities (Alborz et al, 2004; Disability Rights Commission, 2006; World Report on Disability, 2011). These circumstances are barriers to people labelled with disabilities talking about their health and sharing this knowledge.

Nevertheless, in this project, the men shared knowledge about experiences and opinions on their specific knowledge in relation to healthy lives without barriers to participate. For example, in relation to making choices about their health, Stephen indicated that he knew the difference between, what might be deemed as healthy or not, but how having the freedom to make a 'choice' in the first place is even more important, *'it doesn't matter whether it's oranges or biscuits, it's your choice what you want to do'* (Stephen). Thus, Stephen had an awareness of what might make a healthy diet, and an awareness that he should be able to choose whether he wants to eat healthy or not but, the analysis highlighted that choice is often limited and complex. In addition, the men shared knowledge by talking about 'being clean', particularly about their personal experiences and demonstrated their knowledge of why it is important to be clean and the effects on their lives and personal relationships if they were not so. However, the impression I got was that this was a topic area that the men did know much about because the men were able to share a fair amount of specific knowledge and experience relating to this i.e. brushing your teeth if you want to kiss a girl. Although people labelled with disabilities may be reluctant to seek health care because of stigmatisation, ignorance, inaccessibility and discrimination (Learning Disability Coalition Report, 2008; World Report on Disability, 2011:77), here the men were happy with one another to share their knowledge, a knowledge the facilitators (including myself) did not consider they had. Thus, I found that the men's knowledge was devalued and even ignored.

In chapter one (pages 15 - 33), I discussed the recurrent problem people labelled with disabilities face in their experiences of institutionalisation, abuse and neglect (Carlson et al, 2012), these examples being contextual. In addition,

according to Keyes and Brandon (2011), the ways support workers and care workers (and similar roles), who are non-disabled, interact with people labelled with learning difficulties, may be significant (Williams et al, 2009). For example, the levels of interaction may affect how people labelled with learning difficulties experience empowerment that comes with being in control and making choices (Llewellyn, 2009) such as making choices without support or having knowledge and experience being taken seriously by carers. On the other hand, despite the men coming to the project, to a space in which the men felt they could make choices, many people labelled with learning difficulties live in environments where choices are limited and most of the men who participated in this research lived within these settings (Kishi et al, 1988). This was problematic for some of the men in this project who came with carers because they would see these carers on a regular basis at home and in projects such as this, suggesting that making choices is complex and not straightforward (having the carers present restricted (to an extent) the men from making choices). For example, Winston had no choices to make in whether he felt right about attending the project on a day he felt distressed. Therefore, choice is restricted if a person does not have the means or power to make a choice (Kennedy and Haring, 1993; Grove et al, 1999), which subsequently can exclude someone (the men/Winston in this project) who wants to share their knowledge about health and make choices more widely and can reduce any confidence they have to express these feelings.

Connected to this are the more intricate examples of negative experiences in the health system that have resulted in people labelled with learning difficulties being suspicious of health providers (Van Loon et al, 2005; Drainoni, 2006) because of instances of disrespect and ignorance. For example, Robertson et al (2007) noted the lack of training for facilitators, timing issues and lack of resources all may have an impact on the provision of person-centred planning, with choice being an important part of person-centeredness. Thus, this would indicate that if there were fewer of these problems associated with choice and more focus on listening and sharing experience with people labelled with learning difficulties, more learning could take place about health promotion, and the awareness of issues relating to people labelled with disabilities. For example, one set of workshops the group participated in was the creation of 'a thought for the month' in relation to health promotion and health issues the men considered important such as, male cancers, diet and exercise. Here the men listened to one another about

their views on these health issues and shared their experiences and knowledge of it.

For me, witnessing the men (Ellis et al, 2010; Hanauer, 2012) do these 'healthy' activities and making the choice to depict these health themes in drama and art in that way, suggested that making choices that represented their perspectives was important to the men. Although again, my analysis indicated that even this choice was limited due to the fact a professional photographer took the pictures. In addition, the men did not just enjoy the freedom to express themselves, but had fun doing it. In fact, despite cleaning, cooking, the laundry being seen by most as mundane jobs, they can actually be fun to do. For example, *'I enjoy cleaning. It keeps me busy... focused on doing something'* (William), yet this again could be because he has no choice or limited options to do anything else.

Some health care providers may feel uncomfortable about 'treating' people labelled with disabilities (Aulagnier, 2005), which can be influenced by negative attitudes learned from their own personal contexts. For instance, the misconception that people labelled with disabilities are not sexually active often leads to, people labelled with learning difficulties not getting the right advice and care related to reproductive health services (Kroll and Neri, 2003; Nosek and Simmons, 2007). Likewise, health care workers can lack the skills in how to effectively manage the health care needs of people labelled with disabilities (Kroll and Neri, 2003; Morrison and Mosqueda, 2008). Therefore, service providers may find it difficult on how to address health needs related to labels of disability, and may not understand the need for comprehensive care (Scheer et al, 2003). Here, the men wanted to make choices about health for themselves, with knowledge about health without the intervention of 'health promotion' activities.

Thinking about the men sharing their knowledge and experience, and the facilitators insistence that the men needed to be flooded with more knowledge about health promotion suggested, that there was a need to educate and support people, to manage health, as in turn it helps improve the likelihood of healthy outcomes (Wagner et al, 2005; Lorig et al, 2006; Meng, 2007). Although this could result in supporting people labelled with learning difficulties who have more knowledge and who can communicate better, leading to more satisfaction with their care (Leveille, 2009), it appears to completely ignore the knowledge they have, devaluing knowledge and experience. For me this indicates that it is not the individual (s) (the men) that are the problem (Oliver, 1990; Finkelstein and French,

1993; Shakespeare and Watson, 1997; Goodley, 2003), but instead the problems are strongly connected to the men's contexts, which relates back to the social model of disability (Oliver, 1990) and the ecological model (Nelson and Prilleltensky, 2005). Emerson and Baines (2010:3) put it in simple terms concerning the health of people labelled with learning difficulties:

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable.

If poor health is avoidable for people labelled with learning difficulties, then it suggests that the problem lies in the surrounding contexts such as health service providers, care homes, home life, workplaces and in the community. This is important because the wider context to this thesis is the ramifications of austerity and welfare cuts whilst, at the same time, it is estimated that more people will be labelled with learning difficulties in England between now and 2021 (Emerson and Hatton, 2008a). Consequently, the risk of health inequalities will become more widespread, particularly for people labelled with learning difficulties and people with mental health issues, as they are at greater risk of health inequalities. But by working harder to listen to these experiences and knowledge of the men (in this case) had to share about health, a better understanding for health promotion and disability may emerge, because the focus will be on the contexts and experiences of these men, rather than their perceived lack of knowledge and understanding of health awareness.

In summary, the men felt comfortable in this context to share their knowledge, but what was more noteworthy was that this was not knowledge the men had just learned, but knowledge they brought to the group. This is in contrast to my literature review in chapter one (chapter one, pages 15 - 33) on health promotion and the label of disability, because although people labelled with disabilities may be hesitant to use health services, due to stigmatisation, inaccessibility, poor communication and discrimination (Emerson and Hatton, 2008b; World Report on Disability, 2011:77). Here the men were happy with one another to share their knowledge, a knowledge the facilitators (including myself), who did not consider them to have. In this respect, although we knew the men had knowledge about health promotion, we (Springfields, Galaxy and myself) still pursued providing

more health promotion, devaluing and ignoring the experience and knowledge the men had.

In this section, I have considered health promotion and the sharing of knowledge about health. I have also considered the participatory nature of the project such as sharing knowledge, experience, listening to one another and building relationships, which are key stepping stones in creating a '*community of practice*' (Lave and Wenger, 1991; Lawthom, 2011), which I will discuss in the next section.

#### **10.4 The merry men of Galaxy - creating a 'community of practice' together**

In chapter eight, I analysed the data in connection to the theme 'participation', which I defined as the activities the men were involved with inside the project in which they engaged with at different levels of participation. However, as analysed in the soliloquies in chapter nine, participation did not always seem to be at different levels. For example, Stephen felt left out and ignored despite having an opinion in a group, in which he remembered that he was promised, he would be able to participate and make decisions. This could be related to participation being problematic because it is complex, dynamic and flexible in nature during its process (South et al, 2011) and is a '*perpetual allure, persistent challenge*' because of varied interpretations and difficulties in implementing participative work (Morgan, 2001:221). For example, in chapter nine my interpretation of the soliloquies suggested that we all had different perspectives on how to facilitate the workshops, which subsequently influenced the level of participation within the group. This can be related to the way Diamond (2004) drew attention to the ways in which participation consultation that is based on external requirements to involve local people, which will often proceed too quickly, so in fact fail to listen to local people or fail to build in to the consultation process ways in which people can discuss and develop their own awareness and ideas. For example, the soliloquies suggested that the project began quickly, with emphasis on meeting the requirements of completing a community exhibition at stake, not the actual process within the making of each workshop. Therefore, participation and decision-making is complex and likely to be out of the hands of marginalised groups.



Furthermore, Laverack and Wallerstein (2001:182) argued that programmes may have an 'explicit agenda' around social and political change and they caution that many participatory approaches '*do not necessarily seek emancipation or empowerment*'. Thus, what needs to be considered is whether participatory approaches that involve the voluntary participation of community members in service delivery, reflects an instrumental use of citizens, i.e. 'using' the men to create a community exhibition, meeting the agendas of others including Galaxy, Springfields and myself or a genuine attempt at power sharing i.e. making choices about what should go into the community exhibition. In addition, another challenge for 'participation' concerns health inequalities. For example, interventions to address health inequalities at individual and community levels can be accused of 'treating' the symptoms of a problem rather than the causes (Whitehead, 2007). Hence, 'participating' in the workshops was looked upon as a healthy experience by the men, who enjoyed participating and attending each week. Also by other stakeholders including Springfields, carers and myself, without actually focusing beyond the workshops to where the causes of health inequality lie, such as at work, home or in general society.

On the other hand, Campbell and Murray (2004) noted that it is bottom up participation and collective action (that includes bottom up processes) that are likely to have the greatest impact on well-being. For example, a good illustration of the men participating at different levels was when the group decided that they wanted to create a story about being super heroes, wanting to save a woman who had been kidnapped by an evil sorcerer (see chapter eight, pages 178 - 198). This activity depicted the different levels or ways of participation that took place and indicates that the disentangling of empowerment and participating is difficult. For example, some men were not participating and others, depending on the type of activity we were doing, but a different scene led to the men swapping over, so the levels of participation changed. However, the more bottom up the participating and collective action, the greater impact it had on how positive the men felt about participating in this project.

The different levels of participation and sharing of knowledge are consistent with the concept of 'communities of practice' (Lave and Wenger, 1991), which can be defined as:

Groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an ongoing basis (Wenger et al, 2002:4 in Lawthom, 2011:154).

Wenger (2000) suggested that 'communities of practice' grow out of an interchange of experience that involves reciprocal engagement. This can be considered through a collective understanding of what their 'community' is about (the men's), and to contribute to the community. Also through shared engagement where interaction takes place and norms are established, what Wenger (2000:229) calls '*shared repertoires*' of communal resources. Similarly, this connects with the participatory approaches I applied to this research that invites people to participate together, to learn more about each through the co-creation of knowledge (Reason and Heron, 1986); 'breaks down the mystique surrounding research' (Chambers, 1997 in French and Swain, 2004:9) and finds common ground between researchers and research participants (Mercer, 2002).

These attributes of participatory approaches connect well to the autoethnographic and reflexive narratives that provided coherence and meaning throughout this thesis:

Narrative descriptions exhibit human activity as purposeful engagement in the world. Narrative is the type of discourse that draws together diverse events, happenings and actions of human lives (Polkinghorne, 1995:5).

Applying a participatory approach is a purposeful engagement because it has a strong history in disability studies (Nind and Vinha, 2012). There are many examples in which participatory approaches have been used to engage with people labelled with learning difficulties (see Minkes et al, 1995; Williams, 1999; Chappell et al, 2000). According to Chappell et al (2000), useful strategies have emerged by applying participatory approaches including asking what the participants want to do and so by doing this, as Stalker (1998) suggested, participatory research challenges traditional research practices that are often objective and positivist. Lawthom (2011:157) argued that there is a connection between critical community psychology and a community of practice and suggested that there is:

Synergistic potential of both fields (critical community psychology and communities of practice) ... in relation to pedagogy, social transformation and change.

Thus similarly to critical community psychology, a communities of practice approach advocates a social approach, which embraces the sharing of knowledge with others through collaboration and participation, therefore, communities of practice look to '*de-expertise*' knowledge (Wenger, 1991; Kagan, 2011a, Lawthom, 2011). Furthermore, Northway et al (2014) suggested that participatory research recognises that some people's voices have not been heard in the research process, leaving participants feeling powerless. In this project, there were moments when the men's voices took centre stage with high levels of participation, but there were moments when there were low levels of participation or no levels of participation. In addition, Burke (2003), suggested that flexibility in participatory approaches is important because of the critical evaluation that might emerge during the research process, which links with my reflexive, autoethnographic stance discussed in the previous sections. This enables participants, who might have different experiences of the research, to be able to share and agree on the topics, approach and methods (Meulenberg-Buskens, 1996).

In practice (although not always), participatory approaches means that research is done with people, rather than on or for people (McTaggart, 1997 in Dadich, 2009; Nind, 2008). For example, creating the exhibits for the exhibition was done together, sharing expertise and skills to create art. Nelson et al (2004) found that participatory action research (one example of a participatory approach), was essential for building trusting relationships and enhancing collaboration between the researcher and participants. This can be viewed within the creation of the 'thought for the month' exhibit, in which, I had a good time in directing, participating and debating how each scene would be created. Without the trusting and mutual relationships between myself (the researcher) and the men (participants), this exhibit/activity would have been much more difficult to execute. The dialogical approach to evaluation (Guba and Lincoln, 1989; Stringer, 2007) and the application of participatory approaches implies a democratic approach to research, which is the ideological basis for participatory research. For example, Dowrick and Keys (2001) suggested community psychological work on disability

issues involving action research, must include people labelled with learning difficulties to ensure they have a voice, so they can speak on their own behalf. Hence, in this project, the refusal of Galaxy to allow the men to participate in meetings, to make decisions, did not give the men a voice and did not make an empowering difference.

Another important part of my aim and objectives in this thesis was 'health promotion' (as reviewed in chapter one, pages 15 - 33). The health benefits of participation in the arts, for instance, has received more attention in recent years (Hamilton et al, 2003). The arts have been used for health promotion and used to tackle forms of social exclusion and to help achieve social capital (Everitt and Hamilton, 2003), promoting social inclusion and promoting public health (NHS Health Development Agency, 2000). For example, the effectiveness of the arts in health promotion has been seen in research on dementia (Spector et al, 2002), raising self-esteem (Matarasso, 1997) and chronic mental health issues (Nicol et al, 2002). Heath (1997) suggested that arts for health should be facilitated by experienced researchers with cross-disciplinary input from other experienced professionals (such as artists, ethnographers and the participants themselves). Consequently, the arts and participating in the arts is an intersectional way to readdressing social and health inequalities (Acheson, 1998). However, I feel this depends on the level of participation within a project and to what extent the knowledge of those participants is mutually shared and respected. In the previous section I discussed that the men had much knowledge to share, knowledge that they were not expected to have, but when they participated in the activities they felt comfortable to share this. On the other hand, when the men were not allowed to participate i.e. in meetings, they did not share knowledge and their experience, therefore, the community of practice that was established within the group was limited, limiting the extent the community of practice was participative and inclusive (Walmsley, 1997, 2004).

In summary, there were different levels of participation, with some parts of the research fully participative and other parts of the research not participative at all, with and between the men. As a result, participation and decision making is complex and is likely to be out of the hands of marginalised groups and depicts that the disentangling of empowerment and participating is difficult. However, a 'community of practice' (Lave and Wenger, 1991) was developed which involved the sharing of knowledge and expertise between the men. By linking participatory

approaches with a community of practice it suggests that there is a link between critical community psychology and disability studies and potentially the more bottom up, the participating and collective action, the greater impact it could have on how positive the men felt about participating in this project. I feel this depends on the level of participation within a project and to what extent the knowledge of those participants is mutually shared and respected.

In this section, I have considered the levels of participation and the creation of a critical community of practice, which provided a context for the men to participate at different levels. However, what remained with the group at all times and affected the levels of participation was the complex (mis)understandings of what the label of 'learning difficulties' meant, which I will consider in the next section.

### **10.5 How do we come to understand the label of learning difficulties? – A medical comedy of errors!**

From the outset in this thesis, I have used the term 'label of learning difficulties', due to the contested nature of what is, or is not, a 'learning difficulty', therefore, from the outset I considered it to be a social construction that is context specific (Higgins et al, 2002; Burr, 2003; Boxall et al, 2004; Goodley, 2011 – also see the prologue, pages 9 – 14 and chapter two, pages 34 - 51). Above, I again pose the question 'how do we come to understand the label of learning difficulties' and here I want to discuss what the men considered to be a 'learning difficulty' and discuss how we can come to a more convincing understanding of what this label can mean and its implications.

In chapter two, I considered the importance of the social model of disability in the UK (Finkelstein, 1981; Oliver, 1990), but argued that, to fully understand the complex meaning of the label of learning difficulties, the social model of disability in the UK needs to adapt to suit other perspectives such as ones proposed by critical disability studies (Meekosha and Shuttleworth, 2009) on issues relating to carnal, intimacy and sex (Paterson and Hughes, 2006; Liddiard, 2014) and discursive approaches (Rapley, 2003; Inglis and French, 2012). However, in 2013, the 'Diagnostic and Statistical Manual of Mental Disorders' (DSM-V) was published and in reference to 'learning difficulties' the DSM no longer refers to this label as 'mental retardation' (DSM-IV), instead it is now known as 'intellectual disability'. The DSM-V defines 'intellectual disability' as:

Intellectual disability involves impairments of general mental abilities that impact adaptive functioning (American Psychiatric Association, 2013, DSM-V, Intellectual Disability factsheet: 1).

Accordingly, this definition can be understood in terms of three domains, which *'determine how well an individual copes with everyday tasks'* (taken from American Psychiatric Association, 2013, DSM-V, Intellectual Disability factsheet: 1):

1. The conceptual domain includes skills in language, reading, writing, maths, reasoning, knowledge, and memory.
2. The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships and similar capacities.
3. The practical domain centres on self-management in areas such as personal care, job responsibilities, money management, recreation and organising school and work tasks.

This 'new' interpretation of what a 'learning difficulty' can be considered to be is still medical orientated, with no reference to the social, cultural and political contexts of the people they would consider to be with an 'intellectual disability', despite some reference to the immediate contexts of people such as school and work. Thus the DSM-V ignores any meaning associated with the social model of disability in the UK (Oliver, 1990) and the ecological metaphor used by critical community psychologists (Nelson and Prilleltensky, 2005; Kagan et al, 2011a). These domains also suggest, that specific 'knowledges' such as 'reasoning', 'maths' and 'language' are examples of intelligence, and consequently ignores other 'knowledges' and dismisses other types of 'intelligence' such as creativity, non-verbal ability or skills in other ways of life such as debate or in the arts such as drama used in the project. Therefore, the creativity the men have shown in this research such as the development of the giant comic strip, or 'thought of the month' exhibit, applying sophisticated and creative skills in producing pieces of work, would essentially be ignored by this 'new' label and its meaning. Furthermore, the DSM-V (2013:1) in relation to 'intellectual disability' goes on to say:

While intellectual disability does not have a specific age requirement, an individual's symptoms must begin during the developmental period and are diagnosed based on the severity of deficits in adaptive functioning. The disorder is considered chronic and often co-occur with other mental conditions like depression, attention-deficit/hyperactivity disorder, and autism spectrum disorder.

The end of this statement refers to specific labels of 'learning difficulties' including autism spectrum disorder and attention deficit disorder, however no reference is made to people who cannot read or write, and yet people who cannot read or write are often considered as 'learning disabled'. In reference to, autism spectrum disorders, the DSM-V (2013, Autism Spectrum Disorder factsheet: 1) stated:

The revised diagnosis (of autism spectrum disorders) represents a new, more accurate, and medically and scientifically useful way of diagnosing individuals with autism-related disorders.

In this respect, it is clear to see that despite the development of the social model of disability in the UK (in the 1990's), the medical model of disability and the psychologising and individualising of people (Oliver, 1990; Goodley and Lawthom, 2005a) perceived to have learning difficulties continue to prevail and evolve into the twenty first century. The 'new' interpretation of 'intellectual disabilities' according to the DSM-V appears to be reinforcing the medicalised interpretation of what 'learning difficulties' means, which may lead to stigma and during times of austerity, a heightened marginalisation through the creation of new 'folk devils' (Briant et al, 2013). This new interpretation also ignores the intersubjective spaces (Watermeyer and Swartz, 2008; Watermeyer, 2012) people labelled with learning difficulties live within, such as in shared spaces like care home and day centres to interpret everyday life, culture and society. Consequently, this ignores the contextual problems surrounding the label of disability and ignores the significance of society, culture and politics, which play a part in the development of human life.

In chapter seven (pages 154 - 185), I analysed data that suggested that the men generally did not consider themselves to have learning difficulties, despite being labelled as such, by family, carers and organisations in society. In the sculpture, which was displayed in the community exhibition (See chapter seven,

page 161), the men reflected on the 'bad' of being labelled with learning difficulties. Thus the men shared their knowledge about the injustices they had experienced in life and considered these problems to have been attributed to them. In other words, the men were experts in knowing about their own marginalisation. Therefore, the meaning the men applied to this sculpture on the issues relating to being labelled with learning difficulties is in contrast to the DSM-V's interpretation of what learning difficulties means to the men who have to live with that label.

For me the contrast between the DSM-V's interpretation of the label of learning difficulties and the men's interpretation of learning difficulties opens up a discussion about what it means to be a human labelled with learning difficulties in the twenty first century. One way to consider this label is from a 'posthuman' perspective. A 'posthuman' or 'posthumanism' is a concept that stems from a variety of disciplines including philosophy (Braidotti, 2006; 2013, Deleuze and Guattari, 1987), contemporary art (Wilson, 2006; O'Donnell, 2011) and science fiction (Dixon, 1990; Herbrechter, 2013; Gomel, 2014), which according to Ferrando (2013) helps to redefine the notion of the 'human' stemming from the onto-epistemological, scientific and biotechnological developments of the twenty, and twenty first centuries. For example, a premise of posthumanism according to Wilson and Haslam (2009) is that a posthuman future is affected by the development of the biosciences (Fukuyama, 2002; Fernández-Armesto, 2004; Bostrom, 2005; Seiler, 2007). Examples of this include genetic manipulation and artificial intelligence, therefore, posthumanism proposes that these biotechnologies may lead to the development of posthumans, who exceed the capabilities of how we understand humankind/humans to be now, meaning that what we understand to be 'human' will no longer exist in its present form (Bostrom, 2003; Hughes, 2004).

However, according to Wolfe (2010), posthumanism produces a multitude of '*different and even irreconcilable definitions*' (2010: XI), which means that posthumanism has not yet fully reached 'maturity' as a paradigm of thinking, but enough has been written to grasp its primary themes (Harfield, 2013). With this in mind, and in relation to posthumanism and the label of learning difficulties, I propose that a posthuman perspective would consider the label of learning difficulties, in all its complexities and meanings, to be somewhat out of date, particularly considering how the DSM-V has established clear and specific



categories of what learning difficulties may mean because the 'posthuman' is different to being a 'human'. Thus exploring the label of learning difficulties in relation to posthumanism is useful in explaining the complex meanings of this label because the label does not 'fit' into a perspective, but instead the label can mean anything. For example, despite being able to trace the roots of posthumanism in postmodernism (Ferrando, 2013) and the posthuman 'turn' being enacted by feminist theorists in the 1990's and cultural studies (Halberstam and Livingston, 1995; Badmington, 2004), according to Braidotti (2013:188) the 'posthuman' is neither postmodern or poststructuralist because it does not rely on anti-foundationalism and deconstruction:

Not being framed by the ineluctable powers of signification, it is consequently not condemned to seek adequate representation of its existence within a system that is constitutionally incapable of granting due recognition.

For example, Braidotti (2006, 2013) argued that the traditional distinction between what we understand to be 'human' and, the 'posthuman', explores the extent to which posthuman thinking displaces the traditional humanistic unity of the subject. Instead, posthumanism helps to make sense of flexible and multiple identities (Braidotti, 2013). For example, when the group discussed what 'disability' meant to the men, there were different views or different knowledges about what disability might mean. These perspectives demonstrated multiple perspectives and identities, but also similar identities because they came to the project with some form of label of learning difficulties. Thus, the creaming off of who is, or is not, a person with learning difficulties in the way DSM-V proposes, is not a reflection on how the men viewed themselves or each other. In this respect, the men challenged the label of learning difficulties and its meaning to them in a way that can be considered 'posthuman'.

In Ferrando's (2014) review of Braidotti's work ('The Posthuman', 2013), she indicated that Braidotti's perspective of posthumanism recognised humans in all of their diversities; the human is not being one but the human being many things. However, in this research, when tensions emerged such as the situation with Winston and when he assaulted a child, Winston was essentially found 'guilty' immediately, and banned for life, even though the parents of the child did not want to take any action and even that the carer responsible for making decisions, made

the wrong decisions, but was still able to attend himself each week with some of the other men. This is not a reflection of a posthumanist perspective in appreciating humans with multiple identities and meanings. If Winston had not been considered as someone who was just 'learning disabled' or a 'criminal', Winston may well have still remained with the project and benefitted from the creative, and diverse processes the men engaged with to express their views and skills. Consequently, from Braidotti's (2013) posthuman perspective, the 'posthuman' aims to deconstruct the rigidity and immovability of the notion of what being 'human' means. Arguably meaning that the human can no longer be defined as a binary with being non-human. From Braidotti's posthuman perspective, Winston would not be considered just a person with a label of learning difficulties or a 'criminal' for hitting a child, but someone who has a personality, a character, a voice, all of which were not considered when Winston was expelled from Galaxy.

In contrast to 'humanism', posthumanism places humans among and not above other humans, and implies that posthumanism takes a critical approach to humanistic 'tiered values' (Braidotti, 2013; Goodley, 2014). Hence, posthumanism is concerned with '*multiple belongings*' (see Deleuze and Guattari, 1987; Goodley, 2007b) in which a subject (the subject in this case being the men labelled with learning difficulties) is relational and works across differences. Posthuman subjectivity expresses an embodied and rooted and, to an extent, accountability, based on a strong sense of relationality and community building – this view rejecting individualism (Braidotti, 2013:49). For example, the group collectively participated in creating drama scenes about issues or situations that they wanted to explore. From this we then discussed more scenes we wanted to do, therefore, participating at different times and different levels, but collectively and relationally, respecting the multiple perspectives and identities of the men. This is in contrast to humanism's inflexible stance, which Braidotti rejects (Braidotti, 2013; Goodley, 2014) because humanism theorises an inherent value for human life, a universal capacity among people for rational thought and a commitment to seeking truth through human means in support of human interests (Rock et al, 2013). Yet from a posthumanist perspective, humanist arguments are no longer so central to events and trends. This decentralisation of the humanist worldview has been attributed to the increasing 'imbrication in technical, medical, informatics, and economic networks' (Wolfe 2010, xv). As Wolfe explained, following Foucault, posthumanism follows a continuation of its obligation to a 'permanent critique of ourselves'

(Foucault 1984: 52; Wolfe 2010: XVI; Harfield, 2013), which fits in with the autoethnographic and reflexive nature of this thesis.

A good example within this project of being 'posthuman' was Stephen's perspectives and experiences of being gay. A humanistic perspective may have pitied him and empathised with him about being gay as well as being labelled with learning difficulties, but instead his poetry led to debate and discussion about sex and sexuality, which in fact caused tensions with George and some carers and opened up discussion and debate about these issues. Stephen's actions unpacked a taboo subject in sex, sexuality and learning difficulties (Cambridge, 1999; Cambridge and Mellon, 2000; Grieve et al, 2006; Abbott and Burns, 2007), which some group members did not embrace and others did. This makes me think of Goodley and Runswick-Cole's (2014:5) assertion, that being labelled with disabilities/learning difficulties and being human is too often oppositional and instead could be better viewed as 'frictional: rubbing up against one another in interesting ... desirable ways' (also see Puar, 2012:50). For example, Stephen spoke explicitly about his sexual fantasies through poetry, poetry he would write in secret at the home he shared with his brother and family, which he then revealed to the group.

Relating Stephen's experiences to posthumanism provides a way to think in relational and multi-layered ways i.e. building relationships with the people around him and using poetry as a way to debate and explore issues of disability, sexuality and identity. In addition, a posthuman perspective on the label of learning difficulties can enhance the perspective of critical disability studies scholars because critical disability studies attempts to move away from the dualistic understandings of social vs. medical, disability vs. impairment, depicted by the social model of disability (Meekosha and Shuttleworth, 2009; Goodley, 2011). In relation to the social model of disability in the UK, for some scholars, such as Shakespeare (2006), the social model of disability in the UK has become an epistemology against which all disability research is expected to judge itself. Yet with the influx of so many perspectives, such as from humanities and cultural studies, it means that the study of disability is not just about social, economic and political perspectives, but also areas such as intimacy and sex (Paterson and Hughes, 2006; Liddiard, 2014) and discursive approaches (Rapley, 2003; Inglis and French, 2012). Meekosha and Shuttleworth (2009) suggested that critical disability studies is important in taking disability studies forward because it:

1. Builds on the work of disability studies through multiple interdisciplinaritys.
2. Continues to employ relevant aspects of the social model.
3. Listens to work emerging from the global South.

Consequently, a posthuman viewpoint of the label of learning difficulties integrated with critical disability perspectives, can build on the multiple interdisciplinaritys and employ aspects of the social model of disability, which help come to a better understanding of the label of learning difficulties/disabilities, from the multiple perspectives of those who are labelled in this way:

Disability is, in many senses, the quintessential posthuman position that necessarily demands interdependent connections with other humans, technologies, non-human entities, communication streams and people and non-peopled networks (Goodley, 2014:844, in review of Braidotti's, 2013 book, 'The posthuman').

In summary, from the outset in this thesis, I have used the term 'label of learning difficulties', due to the contested nature of what is or is not a 'learning difficulty', therefore, from the outset I considered it to be a social construction that is context specific (Higgins et al, 2002; Boxall et al, 2004; Goodley, 2011). However, the 'new' interpretation of what a 'learning difficulty' can be considered to be in the guise of 'intellectual disability' and is still medical orientated, with no reference to the social, cultural and political contexts of the people they consider as having an 'intellectual disability'.

As a result, the DSM-V ignores any meaning associated with the social model of disability in the UK (Oliver, 1990) and the ecological metaphor used by critical community psychologists (Nelson and Prilleltensky, 2005; Kagan et al, 2011a). Moreover, this new interpretation ignores anyone labelled as such others ways that might define skill and knowledge, such as the creativity the men have shown in this research through the development of the giant comic strip or 'thought of the month' exhibit, applying sophisticated and creative skills in producing these exhibits. 'Intellectual disability' also ignores the intersubjective spaces (Watermeyer and Swartz, 2008; Watermeyer, 2012) people labelled with learning difficulties live within such as in shared spaces like care home and day centres to interpret everyday life, culture and society. Consequently, this ignores the

contextual problems that surround the label of disability and ignores the significance that society, culture and politics play in the development of human life. On the other hand, a posthuman perspective on understanding the label of learning difficulties turns away from the fixity and permanence of DSM-V's interpretation of what 'intellectual disability' means.

Posthumanism takes into account multiple and flexible identities as well as multiple meanings in understanding the self and the contexts around us. Consequently, a posthuman viewpoint of the label of learning difficulties integrated with critical disability perspectives, can build on the multiple interdisciplinarity and employ aspects of the social model of disability in the UK. This may help come to a better understanding of what the label of learning difficulties might mean, from the multiple perspectives of those who are labelled in this way and that creative/visual methods allows posthuman engagement and emergence.

In this section, I have considered the label of learning difficulties from the perspective of the DSM-V and posthumanism. However, another key objective to this research, was to consider the relationship of disability studies and critical community psychology, which I will discuss next.

### **10.6 Disability studies and critical community psychology's dénouement - measure for measure?**

In chapter three (pages 52 - 69), I argued that the consequences of a relationship between critical community psychology and disability studies could be 'ground-breaking' (Goodley and Lawthom, 2005a). Hence, I feel that critical community psychology and disability studies are a 'good fit' in working together to promote change and diversity. In other words, promoting a research agenda that allows one to construct or express identity that is both the researcher and the participants in the research, allowing for reflection concerning the ways ourselves are alienated and fragmented in society (Kagan et al, 2011a). For example, Jack's experiences (analysed in chapter six), was a good example of someone who had been marginalised because of his perceived 'disability' by his surrounding contexts. His anxieties stemmed from people such as his family and support workers not being able to understand how he spoke, and his negative experiences of being sectioned, for example, *'I didn't like it (being sectioned), I didn't feel like myself'* (Jack). In other words, Jack's experiences of being labelled in society, as

being disabled, as well as being controlled in a medical environment, made Jack feel like he had lost his identity. This has similar implications to how psychology has arguably caused the exclusion of people labelled with disabilities through pathologising and individualising (Oliver, 1990; Finkelstein and French, 1993; Shakespeare and Watson, 1997; Goodley and Lawthom, 2005a). In addition, Goodley (2003) alluded to the normalising actions of psychology that have maintained the status quo by enhancing institutional power (Foucault, 1975) when people labelled with disabilities know more than most, about the (ab)uses of psychology – what Rose (1985, 1999) called the ‘psy-complex’ (in Goodley, 2003). Additionally, Goodley and Lawthom (2008:191) suggested that psychology continues to adopt a form of positivism that ‘privileges a view of disability as impairment’. Therefore, a psychological view of disability that emphasises only the individual experiences, of people labelled with learning difficulties, fails to contend with the troubles of a wider disabling society. As Goodley and Lawthom (2005a:136) stated:

A discussion of community psychology in the disability studies world brings with it difficulties, not least in the use of the term ‘psychology’.

On the other hand, can there be a ‘dénouement’ between critical community psychology and disability studies despite psychology traditionally ignoring the social contexts of people? (Kagan et al, 2011a). In this research, the social contexts of the men were not ignored.

Instead the men’s contexts were explored through the use of visual methods including sculpture and photography on themes relating to their lives and mutual relationship building as reflected earlier in my discussion concerning the development of a community of practice. Visual methods have become more popular in the social sciences because of the growing emphasis on culture in making sense of human experience, particularly through digital technology and the Internet (Prosser, 2006; Pink, 2007; Reavey, 2012), which fits in with how the men made sense of their human experience in being labelled with learning difficulties.

Using photography, for instance, can encourage people to use technology to represent their identity, emotions and feelings, which suggests that the application of visual methods is a useful link between critical community psychology and disability studies. For example, Jack brought his own film and camera equipment

and Jack became the 'official' photographer and filmmaker in the group. Using this equipment empowered him, because he felt there was 'something to do', which he could feel he could be in control of, and, be able to make choices.

This relates to Booth and Booth's (2003) description of Photovoice as a way of taking pictures to make sense of the world. In other words, Photovoice puts the 'camera person' in control of how they represent themselves, which is important for working with marginalised groups. For example, Rose (2007) suggested that the 'visual' can act as a trigger for memories, which is a powerful way to reflect upon life. With the men sharing their reflections in this way, as described earlier in this chapter, a 'community of practice' was established, with men sharing knowledge about their experiences on a mutual and relational basis. This links in with Freire's (1972) work on critical consciousness raising (Carlson et al, 2006) and with the values set out by critical community psychologists on social justice (Kagan et al, 2011b). In a similar fashion, using camcorders, art and craft, can be used to represent how identity is represented in society and to share stories about life. Thus, the link between disability studies and critical community psychology is strengthened through the use of visual methods and creativity.

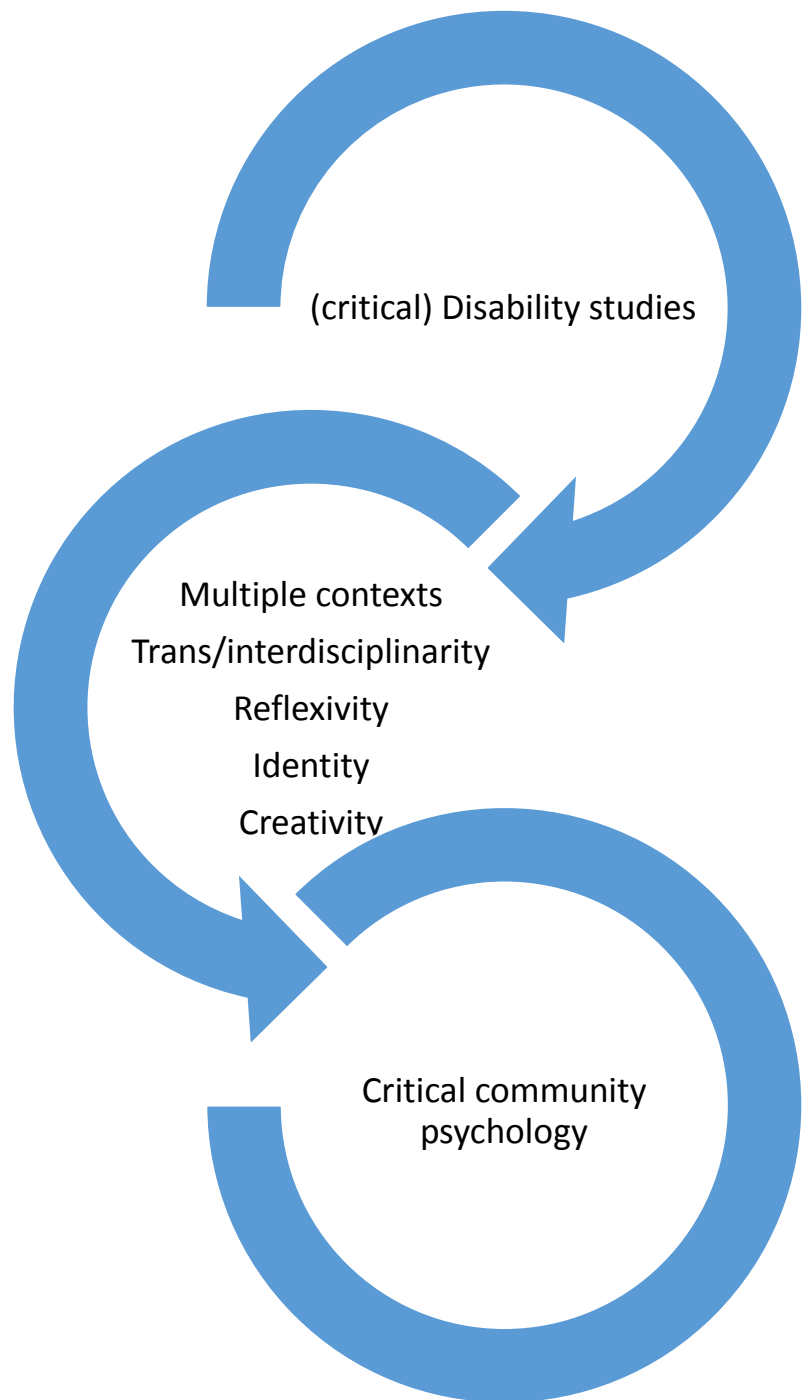
In addition, both disciplines embrace the philosophy behind the social model of disability in the UK (Finkelstein, 1981; Oliver, 1990; Barnes, 1991; Shakespeare and Watson, 2002; Winter, 2003), which considers the label of disability as a social construct created by cultural, historical, social and economic factors that contribute to prejudice and stigma (Oliver, 1990; Finkelstein, 1993). And the ecological metaphor (Bronfenbrenner, 1979; Prilleltensky et al, 2001; Kagan et al, 2011a) of critical community psychology because it places problems and issues people face in their contexts, at multi-levels (micro and macro), not on the individual (Rappaport, 1977; Nelson and Prilleltensky, 2005). For example, in the previous section I discussed how the men placed the problems with the label of learning difficulties in their contexts which they expressed through sculpture.

Despite one claim that critical community psychology is counterproductive and outdated (Forshaw, 2007), in my view, this research provided evidence that a critical community psychology approach can be productive and relevant to the lives of people with disabilities. For example, this project unpacked the intersubjective spaces (Watermeyer, 2012) of the men's lives such as their experiences at home, work, day centres, other projects and relationships with each other. These helping to understand the '*micro-mechanisms of subordination*'

(Watermeyer, 2012:168), which was unpacked through debate, discussion, arts, and drama. Consequently, I feel that by unpacking the intersubjective spaces (Watermeyer, 2012), people labelled with learning difficulties (the men in this project) experience such as in shared spaces (like care home and day centres), to interpret everyday life, culture and society, that we begin to understand the contextual problems with disability and by acknowledging that society, culture and politics play a part in the development of human life. This can be considered within the context of a link between critical community psychology and disability studies because of the interdisciplinary nature of both disciplines (Goodley and Lawthom, 2005a; Goodley and Lawthom, 2005b). Thus a radical critical community psychology praxis seeks to intersect with multiple disciplines about how oppression and marginalisation is caused and use this understanding as a way to take action, to make a difference. As a result, critical community psychologists use 'a multi-level analysis ... to identify the most important power relations and to decide where to intervene' (Burton and Kagan, 1996:206).

Similarly, a critical disability studies (Meekosha and Shuttleworth, 2009) viewpoint as 'open(ed) up spaces for rethinking self and other' (Goodley, 2011:160) and further opened up different theoretical developments. Therefore, disability studies is a transdisciplinary space which breaks boundaries between disciplines (Thomas, 2007) such as psychology (Olkin and Pledger, 2003; Goodley, 2011) and intersects with post-conventionalist (Shildrick, 2009), postmodernist (Corker and Shakespeare, 2002) as well as post-structuralist (Tremain, 2005) thinking. These developments have placed more emphasis on discursive and cultural understandings for being labelled with learning difficulties (For example, see Tremain, 2005; Shildrick, 2007; Roets and Goodley, 2008; Campbell, 2008). Accordingly a strong link between disability studies and critical community psychology can provide an interdisciplinary understanding of the causes of oppression, which can be a way of interrogating the problem space (Goodley and Lawthom, 2005a). On the next page is a diagram that captures how critical community psychology and disability studies connects together in the context of this research:





**Figure 11 – A diagram that connects disability studies and critical community psychology.**

In summary, I have considered and discussed the relationship between disability studies and critical community psychology. There is no doubt that disability and psychology have a negative history through psychology's individualising and pathologising of people labelled with disabilities (Finkelstein, 1989; Oliver, 1990). However, as discussed, the major epistemological connection between disability studies and critical community psychology (and epistemological break from psychology) is that 'disability' is not viewed as an individualised problem, but instead is a problem that is placed within the social constructs created by cultural, historical, social and economic factors that lead to prejudice and stigma (Oliver, 1990; Finkelstein, 1993). This reflects too the meaning of the ecological metaphor used by critical community psychologists (Bronfenbrenner, 1979; Prilleltensky et al, 2001; Kagan et al, 2011a). The men themselves pinpointed the problems they faced in their lives, relating to the label of learning difficulties in their personal contexts and the experiences they have faced in society. Here the men used a variety of visual methods to represent their identity, emotions and feelings, which suggests that the application of visual methods is a useful link between critical community psychology and disability studies. Thus a strong link between disability studies and critical community psychology can provide an interdisciplinary and practical understanding of the causes of oppression, which can be a guide to take action or as a way of interrogating the problem space (Goodley and Lawthom, 2005a).

Now that I have discussed the major findings in relation to the relevant literature and contributed my findings to knowledge, I want to provide an overview which considers whether the aim and objectives were achieved.

### **10.7 Were the aims and objectives achieved in this study?**

The aim of this research (which is immersed into the research objectives), was to explore the experiences of a group of men labelled with learning difficulties in participating in a health promotion project. Three research objectives were set out to meet this aim and I will now take each objective and provide a summary of my findings for each.

*1. To explore the experiences of the men labelled with learning difficulties, participating in a group centred around creative activities formed to promote health awareness.*

I achieved this objective by exploring the experiences of the men who participated in forty-five workshops in 2011, that centred on activities such as drama, art, photography, poetry and film to consider health promotion. The group considered many different themes on the subject of 'health' including diet, healthy eating and 'being clean'. I found that the men felt comfortable in this context to share their knowledge, but more importantly was that this was not just knowledge they had learnt in the project, but knowledge they had brought to the group. This is in contrast to my literature review in chapter one on health promotion and disability, because although people labelled with disabilities may be reluctant to seek health care, due to the negative experiences associated with stigmatisation (Learning Disability Coalition Report, 2008; World Report on Disability, 2011:77), here the men were happy with one another to share their knowledge, a knowledge the facilitators (including myself) did not consider them to have had. In this respect, although we knew the men had knowledge about health promotion, we still pursued in providing more health promotion information and activities. The evidence in this research would indicate that if there were fewer problems associated with choice and more focus on listening and sharing experience with people labelled with learning difficulties, more learning could take place about health promotion and awareness, on issues relating to people labelled with difficulties. In this research, the men wanted to make choices about health for themselves, with knowledge about health, without the intervention of 'health promotion' activities.

In addition, there were different levels of participation. Some parts of the workshops were not participative and other parts involved full engagement, and participation with and between the men. This could be related to participation being problematic because it is complex, dynamic and flexible in nature during its process and varied interpretation (Morgan, 2001:221; South et al, 2011). Therefore, participation and decision making was complex and is likely to be out of the hands of marginalised groups and depicts that the disentangling of empowerment and participating is difficult. However, a 'community of practice' was developed which involved the sharing of knowledge and expertise between the

men. By linking participatory approaches with a community of practice, it also ensures a link between critical community psychology and disability studies and the more bottom up the participating and collective action (Campbell and Murray, 2004), the greater impact it had on how positive the men felt about participating in this project.

*2. To collaborate with a group of men labelled as having learning difficulties in understanding how labels are constructed and understood.*

I achieved this objective by discovering what meanings the men applied to the label of 'learning difficulties', and how the men considered the label to be constructed explored through their experiences and stories they shared (using different activities). I explained the complexity in how we understand the label of learning difficulties and considered the label to be a social construction that is context specific (Higgins et al, 2002; Burr, 2003; Goodley, 2011). However, the 'new' interpretation of what a 'learning difficulty' can be considered to be in the guise of 'intellectual disability' published by the DSM-V (2013) is still medical orientated, with no reference to the social, cultural and political contexts of the people as having an 'intellectual disability'. Thus the DSM-V ignores any meaning associated with the social model of disability in the UK (Oliver, 1990) and the ecological metaphor used by critical community psychologists (Nelson and Prilleltensky, 2005; Kagan et al, 2011a). In addition, I discussed how this new interpretation ignores what might define skill and knowledge such as the creativity the men have shown in this research, through the development of the giant comic strip, or, in the 'thought of the month' exhibit, applying sophisticated and creative skills in producing these exhibits. I proposed that a posthuman perspective on understanding the label of learning difficulties turns away from the fixity and permanence of DSM-V's interpretation of what 'intellectual disability' means. Instead posthumanism takes into account multiple and flexible identities and multiple meanings in understanding the self and the contexts around us. Consequently a posthuman viewpoint of the label of learning difficulties, integrated with critical disability perspectives, can build on the multiple interdisciplinarity and employ aspects of the social model of disability, which can help come to a better understanding of the label of learning difficulties, from the multiple perspectives of those who are labelled in this way.

*3. To develop a new understanding of the ways in which a critical community psychology and disability studies perspective can be utilised for men labelled with learning difficulties.*

I achieved this objective by developing a new understanding of critical community psychology and disability studies through the integration of the literature and data that emerged from this thesis. I found that there is a strong link between disability studies and critical community psychology, which can provide an interdisciplinary understanding of the causes of oppression and be a guide to take action or as a way of interrogating the problem space. Although there is no doubt that disability and psychology have a negative history through psychology's individualising and pathologising of people labelled with disabilities (Finkelstein, 1989; Oliver, 1990), the major epistemological connection between disability studies and critical community psychology is that 'disability' is not viewed as an individualised problem. Instead 'disability' is a problem that is within the social constructs created by cultural, historical, social and economic factors, which lead to prejudice and stigmatisation of people labelled with learning difficulties (Oliver, 1990; Finkelstein, 1993), reflecting also on the meaning of the ecological metaphor used by critical community psychologists (Bronfenbrenner, 1979; Prilleltensky et al, 2001; Kagan et al, 2011a).

## **10.8 Summary**

In this chapter, I reflected on what the findings in my analysis meant in the context of theory, research and literature, which provided a basis to my contribution to knowledge, which is highlighted in the previous section. Therefore, this chapter brought together the findings from the thematic and narrative analysis and was applied to the literature and can be interpreted in relation to the research aim and objectives. I titled this chapter 'denouement', which means to 'untie'. In other words, I unravelled and made sense of the complexities of the findings from this study. However, once the project ended, the work did not stop in terms of working with men and women labelled with learning difficulties. Hence, in the next chapter I will extend my discussion by considering some of the projects, activities and ideas that emerged post-Manpower, where I worked with some of the men

from this project and relate my experiences to the literature and findings to this research already discussed.

## Chapter 11 – Sequel - what happened next?

*‘John and I had a few meetings about what direction the sequel should take.*

*I made some real insane suggestions.*

*True to what you'd expect, he ignored them all and  
just picked up Halloween II where the original left off*

*(Donald Pleasance concerning the ‘Halloween’ movie franchise).*

*‘I’m having the time of my life’ (Stephen, one of the men in this research).*

### 11.1 Introduction

In chapter ten (pages 248 - 278), I discussed the findings to this research by considering the analysed data and connecting it with the literature to form my contributions to knowledge. In this final chapter, I want to continue the discussion and reflect upon what happened once the last workshop had taken place and the community exhibition was opened to the public. I feel that having this chapter is really useful because I continued to work with some of the men in different capacities, once the project had finished. We (including Stephen, Gareth and Joseph) often talked about what we did at Galaxy and clearly it was something the men were proud to have been part of and the activities and skills that were expressed or developed in the Manpower project, were taken forward into new projects. Above, with reference to how Stephen felt about being at the Manpower project, he said he had the ‘time of my life’, but thinking about it in terms of films, the sequel is notoriously a failure, often trying to live up to the expectations of the original. But thinking about Donald Pleasance’s thoughts above, made me think that actually the positive work we did in the Manpower project, in which the men loved participating in drama, debate and camera/film work, could be repeated, but in a different way that the men and women (post-Manpower, my work was not specifically focused on men) wanted it to be.

In this chapter, I will consider the self-employed, paid role I was given within Springfields, and the work I did in that capacity including some of the events I facilitated after the Manpower project finished and relate these reflections back to the literature that I have used throughout this thesis. In addition, I will consider some of the teaching I did with some of the men and women at university, and the development of a series of radio programmes we broadcasted at a local radio

station. From the outset I will say that most of the work I did post-Manpower was a great experience and more enjoyable than Manpower, mainly because in these newer projects, the men had more choice, their experience and knowledge was taken more seriously and they were participating at all levels and there were less tensions and less pressure on collecting data and doing research. However, before I consider some of this (and continue to use Shakespeare's plays and famous words for the titles for each section), in keeping with the story/play metaphor, I want to consider my own feelings once the project was completed by beginning to reflect back on the last workshop Manpower did.

## **11.2 The story coming to an end at Galaxy**

The last time the men's group came together at Galaxy was for the Christmas party. This was the forty-fifth time we had all come together from the beginning of 2011. One of the things I was really conscious about more and more as I went through my personal journey participating and facilitating this project was what would happen to the men and the relationship that we had built between us for so long? In the weeks leading up to the Christmas party, different ideas were floating around about how the group could be sustained. For example, Terry had the idea that we could set up a literacy and maths group for the men, presumably in the teaching style he was used to when he taught at SEN schools. Personally, I was not keen on keeping this group at Galaxy itself. I felt that the community exhibition was a natural ending and I would rather have kept working with the men in a different context if possible. However, I did suggest that with the limited groups for women labelled with learning difficulties in the local area (Brown, 1996; see Fitzgerald and Withers, 2013 for research on the lack of literature on women and sexuality and reproduction), that I might be interested in starting a women's group at Galaxy. On the other hand, I was sceptical because I felt that it was not for me to run a women's group, in the way women were not running this men's group. However, Galaxy were later explicit, in meetings to discuss the future, that they would want a group to be more formal, with tighter risk assessments. In other words, the demands they set out, expressed in the soliloquies such as the need for a structured timetable, would have to be implemented before any group could be based at Galaxy. For me this reinforced my belief that it was time to move on, knowing we had successfully completed the exhibition and we had all gained from



the process. For me, I wanted to continue to have a group that could make choices and decisions on what a project should be.

At the Christmas party, similar to what I did at the opening of the community exhibition, I gave a speech about the funny and great moments for each of the men, which was fun to do and we all had a laugh and good time about it. I had a trophy for each man, made especially with their names on, a little token from me that I was very glad to meet them, not just because they contributed to the making of this thesis, but because I was privileged to have known them and worked with them. We ended our time together by singing an out of tune version of 'Hey Jude' by the Beatles.

It felt strange going into 2012, not needing to prepare myself for the weekly workshop, but as I stated in the prologue, it was at this time that I found out that I was to become a dad, not to mention it was the beginning of the time to start to write up this thesis, so new challenges in life were only just beginning. However, not long after Manpower finished, I became self-employed with Springfields and began to work with some of the men in different capacities, which was wonderful for me to be able to continue my relationship with some of these men. Next, I will explore some of the work I did following this project, with some of the men.

### **11.3 Creative and participative advocacy - as they like it!**

One of the projects within Springfields was a citizen advocacy project, for men and women labelled with learning difficulties funded by a local council. The main aim of this project was to set up volunteers with members of their organisation, over the aged 18 and who lived in the local area, to build a relationship up so that members could access the community more, take part in activities, meet new people and to have support when needed. My specific role was to train these volunteers and to make the connections between the members and the volunteers. Although Springfields was not governed and controlled by people labelled with learning difficulties, something I often challenged them about in meetings, the People First definition of self-advocacy is useful here because we set out to work on the citizen advocacy project with these values in mind (Aspis, 1997:648, from the People First definition, 1996):

1. Speak for yourself.
2. Stand up for your rights.
3. Make changes, be independent.
4. Take own responsibility – (for example, to lead and facilitate projects).

These were the kind of aims we wanted to apply to our work. In addition, with my colleague, Megan, we decided that for this to work in such a way that the volunteers learn more about what learning difficulties might mean and its contextual influences, we wanted to develop the training in collaboration with the men and women members of Springfields. In other words, we wanted to apply the ideas behind the social model of disability as a 'practical tool, not (just) a theory, an idea or a concept' (Oliver, 2004:30) and for this model to be a tool to translate ideas into practice. Hence, the social model of disability (Oliver, 1990) was considered to be the starting point, without the focus on the 'problematic' individual (Goodley and Lawthom, 2005a). In relation to this, the findings from my research with Manpower indicated that the more choice and focus on listening and sharing experience with people labelled with learning difficulties, more learning could take place about health promotion and awareness on issues relating to people labelled with disabilities. Accordingly, my learning from the experiences of Manpower, particularly my own ignorance that the men already had knowledge to share and yet we still pursued to 'deliver' knowledge about health promotion, really helped because with citizen advocacy, the men and women involved had much more control in making choices.

Megan and I set up a group, which included Stephen, Joseph and Gareth from the Manpower project, to develop drama scenes depicting issues in their lives which they would then deliver at training sessions with volunteers. The drama scenes included issues to do with the control of money, sexuality and sex and relationships. The aim of the scenes that were delivered at the training sessions was to engage volunteers in debates and discussions, to make them aware of how people labelled with learning difficulties are treated and how they wanted to be treated. The drama scenes were preceded by informal interviews conducted by the members of the group and the drama scenes were followed up by some poetry readings from Stephen.

Overall, it was a different kind of training people might be used to in terms of it not being formal, instead it was about building relationships from the start and

learning about the experiences of people labelled with learning difficulties from their own voices. For example, Northway et al (2014) suggested that participatory research recognises that some people's voices have not been heard in the research process leaves participants feeling powerless. Therefore, participatory approaches concerns building relationships between the researcher and the participants to equalise power, which I attempted to do with the men and the volunteers. In addition, Burke (2003) suggested that flexibility in participatory approaches is important because of the critical evaluation that might emerge during the research process. This helped to explore and critically consider the experiences of the men and women labelled with learning difficulties in this group as well as the volunteers attitudes and perspectives using a range of methods such as drama and poetry. These experiences relate to the importance of valuing and sharing knowledge with people labelled with learning difficulties, which was limited in the Manpower project.

This group did not just deliver training to volunteers, but also took part in events locally, such as hate crime events in which they presented drama and poetry on the stigma that comes with being labelled with learning difficulties. The group set up a drop in group at a local art gallery every Monday, which was an extra support network for volunteers and members to be within the community. In this group we often went to restaurants, cafes, the pub and walks, which built up relationships and friendships. Next, I consider another different project created by the group members and me, which emerged from the many discussions and debates around sexuality and sex.

#### **11.4 LGBTQ and the label of learning difficulties - much ado about our identity**

Another group Megan and I set up with a local lesbian, gay, bisexual, transsexual and queer (LGBTQ) organisation, was a group that supported men and women labelled with learning difficulties, which was the first of its kind in the local area. In collaboration with social workers and disability networks we knew, a mixed group developed which included lesbians, transgender, gay and bisexual people labelled with learning difficulties. The group went out for meals, watched DVD's and had discussions about day to day life. The group aimed to provide a 'safe space' to engage members and to feel supported in talking about their sexual

identity. Setting up this group for people labelled with learning difficulties was a positive step and was inspired by Stephen and his poetry on his own sexuality, which is in contrast to the disability literature that generalises to all people labelled with disabilities (Chappell et al, 2000 – see Baxter, 2008; Taleporos and McCabe, 2003; Guldin, 2000 – examples of sexuality and physical impairment). This inversely suggests that people labelled with learning difficulties are not expected to have a sexuality or have sex because they are judged not to have adult maturity (Shakespeare, 1999).

Moreover, the group's aim was in contrast to what some have suggested that people labelled with learning difficulties are viewed as incapable of understanding the affectionate side of sexual understanding and are overly sexual (Cambridge, 1999; Cambridge and Mellon, 2000). Barron (2002; also see Scior, 2003) suggested that people labelled with learning difficulties were not expected to have gender identity and are perceived as being non-sexual and heterosexual (Snyder and Mitchell, 2006). This is in contrast to my discussion on the label of learning difficulties from a posthuman perspective (Braidotti, 2013), which turns away from the fixity and permanence of DSM-V's (2013) interpretation of what 'intellectual disability' means. Posthumanism takes into account multiple and flexible identities and multiple meanings in understanding the self and the contexts around us. The aim of this new LGBTQ group was to provide a space where sexuality and people labelled with learning difficulties could be celebrated.

Alongside these groups, I had the opportunity to teach at university. Next I reflect on those experiences which some of the men and women collaborated with me on.



**Photograph 33 – Stephen and Ken (who joined the groups post-Galaxy) acting out a scene on what sexuality means for a training session for volunteers.**



**Photograph 34 – Joseph having fun at a local art gallery.**

### **11.5 Shall I compare intelligence to a creative way?**

For me it was a real thrill to be able to collaborate and teach with the men and women I had built up a relationship with through my work in the community. I wanted to do this because my belief was that students are more likely to learn better from first-hand experience rather than talking on behalf of the people I work with in the community. I asked the members of the group if they wanted to help me teach and they were glad to do so and after the teaching ended, we would usually go for dinner or to a pub. This relates to my discussion in chapter ten (pages 248 - 278) concerning a 'community of practice' (Wenger, 2000; Lawthom, 2011) which was developed involving the sharing of knowledge and expertise between the men and now sharing with students at university. I discussed that by linking participatory approaches with a community of practice it also ensures a link between critical community psychology and disability studies and the more bottom up the participating and collective action, the greater impact it can have on all who

participate, similarly to when the men in the Manpower project were able to participate and express their perspectives.

The members helped me deliver lectures on critical community psychology specifically talking about the films they produced for the volunteer training and drama scenes they had created to showcase their views on identity and their experiences of life, which were often unpleasant. This inspired some of the students to come and volunteer with us in developing group work and was a way to add value to the learning experience of students. In addition, we delivered a lecture on counselling psychology to Master's students, again the group did some drama and poetry for the students and considered these methods as alternative ways to develop counselling relationships with people they work with. This form of 'teaching' could be considered as advocacy on behalf of, and with, people who cannot speak for themselves, which is both a skill and strategy of community psychology (Kagan, 1997). Moreover, according to Campbell and Murray (2004) bottom up participation and collective action are likely to have the greatest impact on well-being. Although I did not expect these lectures to have an enormous impact, students in lectures learning from people labelled with learning difficulties (in a space where there are limited numbers of people labelled with learning difficulties) at university did ensure that participative consultative processes were taking place.

Hence, engaging in critical reflection about the experiences of the label of learning difficulties with students was a transference of knowledge between the men and the students (not from myself as the educator). As discussed in chapter ten, Dowrick and Keys (2001) suggested community psychological work on disability issues involving action research must include people labelled with learning difficulties so they can have a voice. Also working with people with expertise in helping to assist that voice and creating action to make changes is important because this can be empowering and inclusive for people labelled with learning difficulties. For example, in one lecture, we debated the meaning of 'intelligence' with undergraduate students in psychology. The lecture was designed to look at traditional ways of measuring intelligence in psychology, and to compare and contrast it with other ways to understand what intelligence might mean. So I started by getting the students and the group members to do a standard IQ test. I then asked them to feedback their experiences of this, and asked to what extent did they think this type of test reflected how intelligent they

were and how important 'intelligence' is as a concept. The group members reactions were very negative towards the test because they did not get why they would be asked questions on maths and drawings, and felt they did not have enough time to read (IQ tests are usually limited in time to complete). The students were generally comfortable doing this type of test because they were familiar with testing in psychology (Weinberg and Pearson, 2008), but there were mixed views on how far an IQ test can test how intelligent you might be.

After the break, it was the turn of the members to present some drama scenes, similar to the ones they delivered for the volunteers on the citizen advocacy project (such as drama and poetry). The drama depicted the men's experiences and feelings on times when people have ignored that they have a sexuality and sexual needs. The poetry expressed similar sentiments and lead to some students to shed some tears because of the emotional impact the words of the poem had. I brought this back to the discussion on what intelligence means and we discussed that there are many ways to express experiences and knowledge other than just IQ testing and similar tests that have been employed by psychologists. I ended the lecture by doing a seminar in which the students were asked to write a poem or do some form of creative writing that considered what they think it would be like if they were labelled with learning difficulties. At first there was a groan because they did not want to write poetically, but eventually they got into it and some students did some raps and others more rhythmic style poetry. We had a laugh when they presented their work in the lecture theatre and the poetry conveyed some understanding into the difficulties that come with being labelled with learning difficulties. Overall, between us, we critically reflected on the meaning of intelligence and came to a clearer understanding of what it means and what it might not mean, all of us together sharing knowledge about our experiences. Next, I will consider some of the group work I did with the group and with young people from some local special education needs (SEN) schools in Bromhead, developing radio shows with a local radio station.

### **11.6 'The taming of the shrew' - taking on psychology using the radio**

Through my connections at Springfields, I started to get involved with supporting a group of adults labelled with learning difficulties at a local radio station. The group included some of the members from Manpower and the men and women



involved with the projects described in the previous sections in this chapter. Eventually I started to help to facilitate this group and help them produce shows that discussed a range of topics relating to sexuality, sex, employment, music, food and other day-to-day life topics. The preparation and live recording of these shows were some of my favourite times over the past couple of years because we had such a fun time, laughing and joking, going out and socialising and doing and saying what we wanted to, without the kind of tensions and constrictions experienced doing the Manpower project. For example, I discussed how Galaxy would not allow men into the meetings or how Winston was banned, both situations excluding the men/man from participating in work and on issues relating to their lives and work.

Soon after this experience, I was awarded a grant in collaboration with my supervisor to create a series of shows with men labelled with learning difficulties on different psychologies. This involved interviewing academics, students and the public and then we produced a show on that psychology. I worked with Stephen and other men in producing these shows, which evoked their opinions and feelings and experiences of understanding psychology. In table six, on the next page, is the show schedule, which presents the spectrum of psychologies the shows covered and we ended this project with a show that discussed the 'way forward for psychology' in relation to the label of learning difficulties:

<b>Show Number.</b>	<b>Subject Area.</b>
Show 1	What is psychology?
Show 2	Neuropsychology and parapsychology
Show 3	Clinical and counselling psychology
Show 4	Health and exercise psychology
Show 5	Forensic psychology
Show 6	Developmental psychology
Show 7	Community and critical psychology

Show 8	The way forward for psychology and learning difficulties

**Table 6 – Schedule of radio shows produced by myself, Megan and the men.**

The aim of the project was to work with adults labelled with learning difficulties in promoting and learning about different aspects of psychology through the use of radio, which stemmed from my experiences with the group previously using radio. In addition, the project aimed to engage with the wider community in bringing new ideas and perspectives about psychology such as academics, clinicians, parents and the general public through the radio. This would culminate in learning how far psychology related to people's lives in different ways by collaborating with a diverse group who wanted to be heard on the radio. For example, the group would interview an academic on one of the psychologies, but would then later discuss how it related to their own experiences and would decide whether this should be edited into the show. The show itself would be edited by Megan, but the content was decided by the group. The show would then be broadcast the following week.

In chapter ten, I suggested that a strong link between disability studies and critical community psychology can provide an interdisciplinary and practical understanding of the causes of oppression. This is in contrast to the negative history of disability studies and psychology with psychology's emphasis on individualising and pathologising people labelled with disabilities (Finkelstein, 1989; Oliver, 1990). However, as discussed in chapter ten, the major epistemological connection between disability studies and critical community psychology is that 'disability' is not viewed as an individualised problem, but instead it is a problem that is within social constructions created by a wide range of factors that ensures prejudice and stigma for people labelled with disabilities (Oliver, 1990; Finkelstein, 1993). This reflecting too the meaning of the ecological metaphor used by critical community psychologists (Bronfenbrenner, 1979; Prilleltensky et al, 2001; Kagan et al, 2011a). The men from the Manpower project pinpointed the problems they have faced in their lives, relating to the label of learning difficulties in both their personal contexts and their experiences they have faced in society. Here the men used visual methods to represent their identity and

feelings (Spencer, 2011; Mountain et al, 2012 in Reavey, 2012), which suggests that the application of visual methods is a useful link between critical community psychology and disability studies. Similarly, with specific programmes to do with 'psychology', the men who participated in these radio programmes challenged the stereotypical attitudes of people labelled with learning difficulties by their engagement of interviewing people and producing radio shows. Although the extent to which this happened is difficult to quantify, the fact that shows in which the content was decided by the men and the interviews with academics were decided/agreed upon within the group, is evidence that the men could contribute experience and knowledge to these psychologies and were able to share this with an audience potentially in excess of 50,000 for each show. Thus disability studies and critical community psychology can help/has helped, to an extent, shake off the shackles of an individualised psychology to a psychology that embraces collective action with people labelled with learning difficulties.



**Photograph 35 – Stephen preparing to talk about ‘psychology and learning difficulties’ on the radio.**

## 11.7 Summary

In summary, despite the ideas and suggestions being made by volunteers, staff and myself about the continuation of the Manpower project in its then present form, those ideas were never to prevail. With hindsight, I am glad because I have no doubt (although Galaxy had good intentions), that if the group had continued the men would still not be allowed to make decisions or be in control of the running of the group. Nevertheless, I had the good fortune to be able to get involved with Springfields post-Manpower and was able to engage with some of the men and other men and women in different projects, with the aim to challenge the stereotypes around the label of learning difficulties and have a lot of fun. My role as a volunteer coordinator ensured that I worked with the men and women members of Springfields to train volunteers and challenge the volunteers stereotypes around disability through drama, debate and poetry. In addition, some of the men collaborated with me to deliver lectures and teaching to university students, using similar methods to challenge thinking around disability. Probably the most enjoyable parts of this post-Manpower work was producing radio shows on a range of subjects that interested the men and women I worked with, again to a wider community audience like the community exhibition. We had fun producing the shows and for me they were unforgettable. I was pleased to receive a grant with my supervisor in 2013 to produce radio shows that discussed psychology. This was another project that demonstrated that people labelled with learning difficulties do have the skills, experience and knowledge that can add value to the way people think and feel about the world.

## Epilogue

***Geppetto: Now close your eyes and go to sleep.***

***Pinocchio: Why?***

***Geppetto: Everybody has to sleep – and besides, tomorrow, you've got to go to school.***

***Pinocchio: Why?***

***Geppetto: Oh, to learn things and get smart.***

***Pinocchio: Why?***

***Geppetto: [starts to fall asleep] Because.***

***(Pinocchio, 1940 film, directed by Sharpsteen and Luske).***

Here I am walking in the park with little Robin, as he runs about shouting 'what is it?' all the time and calling everything a 'ball', which makes me laugh as we spin around on a childrens roundabout. Being with Robin is a great feeling, especially when I look at him and his facial expressions as he tries to learn for himself what everything around him means or does not mean. You can see the concentration in his eyes when he looks at something and his eyes are always asking 'why?'

Walking back through a forest in the Brecon Beacons, I think back to how this project began as well as the battles, victories and losses over the past twenty years to get to this point in completing this marathon of thinking, and writing this thesis. An emotional firework of explosions of colours and darkness. I am now thirty years old, which reminds me of how young I actually am, but how far I have come. I am proud that I have been at university for nine years, a time in which I have published work, become an academic, a critical community psychologist, visited different countries, worked on many community projects, most of which I have created or facilitated myself and of course I became a dad. Yet I cannot forget the self-doubt that is still forged into my mind because of the difficult contexts I grew up in, which often leads to a lack of confidence, and whilst reflecting on the making of this project and writing this thesis, you lose confidence when you know you have tried your best in the community and yet you still get the insults, derogatory comments and sometimes complete dismissal of your views and work. This can be hard to take and is likely to continue in a cutthroat academic world. However, I think about the resilience I have shown and determination to be successful in my own right, but I also reflect on the ways that my determination

has helped others particularly in this project and many other projects with marginalised people.

In the prologue, I proposed that I wanted to contribute new knowledge to research concerning the label of learning difficulties and health promotion centred on a group of adult men labelled with learning difficulties. I explained that telling a good story can be evocative and allows for creativity, which is what I aimed to do in this thesis by writing autoethnographically (Spry, 2001) and by working with multidisciplinary perspectives ranging from insights from ethnography (Anderson, 1989), disability studies (Oliver, 1990), critical theory (Parker, 2007) and philosophy (Braidotti, 2013). As explored in chapter two (pages 34 - 51) and three (pages 52 - 69), there is existing literature on what learning difficulties means and what a critical community psychology approach concerns. And there is established research by critical community psychologists or similarly connected researchers in relation to disability (Goodley and Lawthom, 2005b; Kagan et al, 2011a). However, I suggested that there is limited research on the inter-connection between disability studies and critical community psychology and there is limited work on considering men labelled with learning difficulties and health promotion. Nevertheless, I feel this research has added value to established literature in disability studies and critical community psychology, and feel that this research is of current policy relevance working with men labelled with learning difficulties in times of austerity during the current Conservative-led Coalition government (Phillimore et al, 2010). Furthermore, while literature exists on men's health (see Branney, 2012), health promotion (see World Report on Disability, 2011) and learning difficulties (see Chappell, 1993 and Chappell et al, 2000), I feel that that this research provided a rich, detailed discussion of the label of learning difficulties and men's health and health promotion as an entity using a critical community psychology approach. Hence, I feel that this research has added value to the literature and to debate on the issues raised in this thesis.

My research provided a rich and contextualised account of the men's participation in the development of forty-five workshops throughout 2011. Through the qualitative, visual and participatory approaches I adopted and applied in this story, I uncovered the ways in which the men demonstrated their understanding for health promotion using methods, such as art, drama, poetry, sculpture and photography. This is in contrast to other research that have explored these

concepts quantitatively (see Geary et al, 2012; Peng and Fuchs, 2014) or used qualitative methods that are mainly interview based (see Heslop et al, 2013).

Writing this thesis using a story/play metaphor, helped me to be reflexive throughout, but it also helped me to highlight the complexity, the messiness, of working in the community, which surrounds people labelled with learning difficulties. In this research, I do not claim to have resolved the difficulties that people labelled with learning difficulties face, but I have reflected on a messy story from a personal and professional perspective, which I do think brings some understanding of how we understand the label of learning difficulties in diverse contexts. Although D'Cruz et al (2007) suggested that there is a lack of clarity about the concept of 'reflexivity' in terms of who is being exhorted to be 'reflexive', when and how, I believe that reflecting on my identity and connecting myself to the development of this story provided clarity and by turning back on myself it helped the story make sense to the reader. For me, this was a wonderful project to engage with and I feel proud of my commitment to the aim and objectives of this project discussed in chapter ten, which I feel were achieved. However, looking back, it did make me think of Joseph's death earlier in 2014 and although it makes me feel sad, Joseph's death reminded me of the great pleasure we had by knowing each other and the great times we had together in making this project and other projects post-Manpower.

The past four years in particular have been a truly reflexive period of my life and as I enter the next stage of my life, I feel a new identity emerging, a new academic life, no longer being a student, I almost feel like a new 'Dr Who', is about to appear and the old character drifting off elsewhere. I am sure life will still come with its difficulties and battles, but I am sure more success will follow as I enter the next stage of my life and hope that the marginalised groups I work with in the years to come will benefit in collaboration with myself to make a difference for the better. To end, the quote below reminds me of this thesis, although it refers to poetry, because certainly for me, this work has extended my knowledge, changed my world and is a contribution to knowledge and reality:

A good poem is a contribution to reality. The world is never the same once a good poem has been added to it. A good poem helps to change the shape of the universe, helps to extend everyone's knowledge of himself and the world around him (Dylan Thomas).

**THE END**

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## List of photographs, figures, tables, comic strips, scenes, vignettes and soliloquies

### Photographs:

Photograph 1 - 'Thought for the month' pictures and captions, displayed at a community exhibition .....	139
Photograph 2 - March 2012 – 'We cook and clean, to be healthy and gleam' .....	140
Photograph 3 - Art about food .....	141
Photograph 4 - Men debating healthy diets .....	142
Photograph 5 - Jack editing his photographs .....	144
Photograph 6 - Jack's super hero – 'Strong man' .....	144
Photograph 7 - Gareth choosing to support other members of the group .....	146
Photograph 8 - Gareth choosing to present his art work .....	147
Photograph 9 - Gareth's artistic viewpoint of Lourdes, France .....	147
Photograph 10 - Gareth being filmed .....	148
Photograph 11 - The community exhibition showing photographs, the comic strip, objects and materials the men felt should be in the exhibition .....	152
Photograph 12 - The community exhibition showing the art the men chose and part of the poem the men agreed should be on display .....	152
Photograph 13 - July 2012 – 'Be seen to be clean instead of being spotty like a teen' .....	164
Photograph 14 - November 2012 – 'Have an annual health check or risk hitting the deck' .....	168
Photograph 15 - April 2012 – 'Talk About your emotions, it saves a lot of bad commotions' .....	171
Photograph 16 - May 2012 – 'Actions speak louder than words' .....	175
Photograph 17 - August 2012 – 'We are who we are, with you on a level par' .....	176
Photograph 18 - Jeffrey's art work depicting himself brushing his teeth .....	178
Photograph 19 - Jeffrey's depiction of his boating trip .....	179
Photograph 20 - Stephen writing poetry .....	181
Photograph 21 - An example of Stephen's poetry .....	182
Photograph 22 - June 2012 – 'Let people be who they want to be, different and free' .....	183
Photograph 23 - The 'low relief' – a pop up art piece capturing the essence of Galaxy and the men's pictures .....	195
Photograph 24 - Caption – 'Celebrating the truth about men' .....	197
Photograph 25 - Caption - 'A men's group challenging disability' .....	199
Photograph 26 - Caption – 'Have fun fun fun' .....	200
Photograph 27 - 'Our journey' picture board .....	201
Photograph 28 - Close up of 'our journey' .....	202
Photograph 29 - Developing a scene together .....	203
Photograph 30 - Discussing issues that arose from a scene .....	204
Photograph 31 - Men waiting for directions .....	204
Photograph 32 - Men 'singing in the rain' and dancing .....	205
Photograph 33 - Stephen and Ken (who joined the groups post-Galaxy) acting out a scene on what sexuality means for a training session for volunteers .....	285
Photograph 34 - Joseph having fun at a local art gallery .....	286

Photograph 35 - Stephen preparing to talk about 'psychology and learning difficulties' on the radio .....	291
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**Figures:**

Figure 1 - Ecological Levels of Analysis/Nested Systems (adapted from Brofenrenner, 1979 and Prilleltensky, Nelson and Peirson, 2001) ....	57
Figure 2 - A Freytagian structure of a Shakespearian play presenting the structure of this thesis (Adapted from Gustav Freytag's 'Technik des Dramas' 1863) .....	74
Figure 3 - The changing roles and positions I experienced throughout the research process .....	107
Figure 4 - The thematic analysis that was undertaken linking the codes and sub themes to form the main themes .....	119
Figure 5 - A diagram representing how the first theme, 'making choice' was formed using Boyatzis's (1998) ideas on how to code and develop themes .....	120
Figure 6 - A diagram representing how the second theme, 'sharing knowledges', was formed using Boyatzis's (1998) ideas on how to code and develop themes .....	121
Figure 7 - A diagram representing how the third theme, 'participation', was formed using Boyatzis's (1998) ideas on how to code and develop themes .....	122
Figure 8 - A diagram that represents some of the choices the men made accompanied with examples of the complexities and limitations that came with making choices .....	134
Figure 9 - A diagram that represents some of the knowledge the men shared within the project accompanied with examples of when the men's knowledge appeared to be devalued .....	155
Figure 10 - A diagram of a continuum that places different examples of participation in the middle, indicating that participation occurred at different times and levels .....	187
Figure 11 - A diagram that connects disability studies and critical community psychology .....	273

**Tables:**

Table 1 - A table comparing and contrasting disability studies and (critical) community psychology (Goodley and Lawthom, 2005) .....	67
Table 2 - The male participants and brief biographies .....	99
Table 3 - The main volunteers and brief biographies .....	100
Table 4 - Organisational staff (Springfields and Galaxy), other people and brief biographies .....	101
Table 5 - Six phases of thematic analysis (Braun and Clarke, 2006) .....	116
Table 6 - Schedule of radio shows produced by myself, Megan and the men .....	290

**Comic Strips:**

Comic Strip 1 - A drama scene developed by the men for filming .....	150
Comic Strip 2 - Process of designing and creating the sculpture allowing different knowledges to emerge .....	160
Comic Strip 3 - Men in the sewers talking about 'being clean' .....	166

Comic Strip 4 - The group discussing male cancers .....	170
Comic Strip 5 - Group debates and evaluations about the project .....	173
Comic Strip 6 - The process of group development of super heros and their comic strip .....	192

### **Scenes:**

Scene 1 - An example of 'choice' within the project .....	137
Scene 2 - An example within the project of how the men shared knowledge about their lives and memories .....	158
Scene 3 - An example of the men participating in an activity .....	191

### **Vignettes:**

Vignette 1 - An example of how a workshop generally worked with the young men I worked with in the community .....	22
Vignette 2 - An overview of Springfields .....	91
Vignette 3 - An overview of Galaxy .....	94
Vignette 4 - A typical workshop .....	131

### **Soliloquies:**


Soliloquy 1 - My perspective on building up towards the making of the project .....	213
Soliloquy 2 - George's (development worker at Springfields) perspective on the initial making of the project .....	214
Soliloquy 3 - Janet's (community worker at Galaxy) perspective on the initial making of the project .....	215
Soliloquy 4 - Stephen's (one of the men) perspective on the build up to the start of the project .....	216
Soliloquy 5 - My perspective on how the beginning of the project worked .....	218
Soliloquy 6 - George's perspective on tensions within the project concerning facilitation .....	221
Soliloquy 7 - Janet's perspective on tensions within the project concerning facilitation .....	222
Soliloquy 8 - Stephen's perspective on the beginning of this project .....	223
Soliloquy 9 - Stephen's perspective on how workshops worked .....	224
Soliloquy 10 - My perspective on the tensions surrounding Winston being banned from Galaxy .....	227
Soliloquy 11 - George's perspective on the tensions surrounding Winston being banned from Galaxy .....	228
Soliloquy 12 - Janet's perspective on the tensions surrounding Winston being banned from Galaxy .....	229
Soliloquy 13 - Stephen's perspective on the tensions surrounding Winston being banned from Galaxy .....	229
Soliloquy 14 - My perspective on tensions within the project concerning facilitation .....	233
Soliloquy 15 - My perspective on further tensions concerning how the project should work .....	236
Soliloquy 16 - George's perspective on further tensions within the project .....	237
Soliloquy 17 - George's perspective on where the community exhibition should be placed .....	238
Soliloquy 18 - Janet's perspective on further tensions in this project .....	239

Soliloquy 19 - Stephen's perspective on the tensions within the project .....	240
Soliloquy 20 - My perspective on what I have gained from participating in this project .....	241
Soliloquy 21 - George's perspective on what Springfields gained from participating in this project .....	242
Soliloquy 22 - Janet's perspective on what Galaxy gained from participating in this project .....	243
Soliloquy 23 - Stephen's perspective on what he/the men gained from participating in this project .....	244

## Member’s Forum Questionnaire

1. What kind of activities would you like Springfields to provide for you and other service users? Please mark box or boxes


**ART**




**COOKING**



**MUSIC**




**ART GALLERIES**




**DEBATES**




**PHOTOGRAPHY**



**THEATRE**



**MUSEUMS**




**DAY TRIPS**



**GAMES**



**EATING OUT**



2. Any other activities you think might be a good idea?

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3. Do you think having separate male and female groups is a good idea? Please tick.

Yes

No

Don't mind

4. How can Springfields improve its service for you and others?

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5. Do you have any ideas about how to make the AGM more fun and enjoyable?

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6. Where would you like service user forum meetings to take place? For example, do you know any places near to where you live like church halls?

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7. Please tick

YES, I will be attending the Focus Group meeting on August 11th at 10:30am

NO, I am unable to attend this meeting

NAME: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

TELEPHONE NUMBER: \_\_\_\_\_

Springfields value your input.

Joseph, Cheryl and Jonathon will feedback your opinions and suggestions to the Board of Trustees

From your feedback, an action plan will be put together to work out how to deliver the services you want.

Useful transport information:

Local Bus Service 0845 6884398

Local Link 0845 6059905

## Appendix 2 – Proposed structured timetable

Date	Location And Time	Activity
6 <sup>th</sup> January	Springfields	Consultation.
<b>13<sup>th</sup> January</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
20 <sup>th</sup> January	Cinema – 17pm.	Trip – Cinema.
<b>27<sup>th</sup> January</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
3 <sup>rd</sup> February	Springfields – 17pm.	Photography – favourite things.
<b>10<sup>th</sup> February</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
17 <sup>th</sup> February	Bromhead central – 17pm.	Trip – Eating Out/Pub/Snooker.
<b>24<sup>th</sup> February</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
3 <sup>rd</sup> March	Springfields – 17pm.	Cooking/Create a cook book – healthy meals and drinks.
<b>10<sup>th</sup> March</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
17 <sup>th</sup> March	Springfields – 17pm.	Art – create a large collage.
<b>24<sup>th</sup> March</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
31 <sup>st</sup> March	Springfields or hired building?	Social Evening? – dance.
<b>7<sup>th</sup> April</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
14 <sup>th</sup> April	Bromhead central – 17pm/19pm.	Music – Jazz Night/Disco?
<b>21<sup>st</sup> April</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
28 <sup>th</sup> April	Springfields Entrance – 17pm.	Trip – Walk in local park.
<b>5<sup>th</sup> May</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
12 <sup>th</sup> May	Bromhead – 13pm.	Air Raid Shelter/Art Gallery.
<b>19<sup>th</sup> May</b>	<b>Galaxy – 13pm -15pm.</b>	<b>Film</b>
26 <sup>th</sup> May	Full Day or Weekend?	Trip – local seaside town.

## Appendix 3 – Ethics form and consent form



### ETHICS CHECK FORM FOR UNDERGRADUATE, TAUGHT POSTGRADUATE AND RESEARCH STUDENTS

This checklist should be completed for every project. It is used to identify whether a full application for ethics approval is required.

If a full application is required, you will need to use the 'Application for Ethical Approval' form, or, if your research falls within the NHS and social care, you will need to obtain the required application form from the Central Office for Research Ethics Committees available at [www.corec.org.uk](http://www.corec.org.uk).

**Before completing this form, please refer to the University's Academic Ethical Framework** ([www.rdu.mmu.ac.uk/ethics/mmuframework](http://www.rdu.mmu.ac.uk/ethics/mmuframework)) **and the University's Guidelines on Good Research Practice** ([www.rdu.mmu.ac.uk/rdegrees/goodpractice.doc](http://www.rdu.mmu.ac.uk/rdegrees/goodpractice.doc)) .

***This checklist must be completed before any research starts.***

#### Project and Applicant Details

Project Title:	A community psychology approach working with men and learning difficulties: Improving the relationship between men and poor health.
Name of Researcher: (applicant)	Michael Richards
Status: (please circle as appropriate)	<b>Postgraduate Student/PhD Student.</b>
Email address:	MICHAEL.L.RICHARDS3@stu.mmu.ac.uk
Contact address:	
Telephone Number:	
Programme of Study	PhD
Supervisor's Name: Contact address/telephone	Dr Rebecca Lawthom
Supervisor email address:	r.lawthom@mmu.ac.uk

**Supervisor:** Please tick the appropriate boxes.

 Yes

The student has read the University's Academic Ethical Framework and Guidelines on Good Research Practice.

- Yes      The topic merits further research.
- Yes      The student has the skills to carry out the research.
- Yes      The student has adhered to the ethical principles and guidelines of any external bodies associated with the academic activity.
- Yes      The participant information sheet is appropriate.
- Yes      The procedures for recruitment and obtaining informed consent are appropriate.

### Research Checklist

Please answer each question by ticking the appropriate box:

	Yes	No
1. Does the study involve participants who are particularly vulnerable or unable to give informed* consent? (e.g. children, people with learning difficulties)  (* participants made fully aware of the true nature and purpose of the study and their associated risks)	√	
2. Will the study involve the use of participant's images or sensitive data? (e.g. participants personal details stored electronically, image capture techniques)	√	
3. Does any relationship exist between the researcher(s) and the participant(s), other than that required by the academic activity? (eg. fellow students, staff)		√
4. Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (eg. residents of a nursing home)		√
5. Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (eg. covert observation of people in non-public places)		√
6. Will the study involve discussion of sensitive topics (eg. sexual activity, drug use)?		√
7. Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?		√
8. Will blood or tissue samples be obtained from participants?		√
9. Is pain or more than mild discomfort likely to result from the study?		√
10. Will the study involve prolonged or repetitive testing?		√

11. Will the study sample group exceed the minimum effective size?		√
12. Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?		√
13. Will the study involve recruitment of patients or staff through the NHS, or involve NHS resources?  If so, you will need to complete a COREC application form <b>after</b> you have received academic approval for your project.		√
14. Faculty-specific question:		

If you have answered 'no' to all questions, attach the completed and signed form to your project approval form.

If you have answered 'yes' to **any** of the questions, please describe the ethical issues raised below:-

1. Does the study involve participants who are particularly vulnerable or unable to give informed\* consent? (e.g. children, people with learning difficulties)

Service users at Springfields might not be able to give informed consent. However, through their participation with this organisation, their rights and vulnerabilities are protected. In addition, their families or carers can decide if the study is suitable for them to take part.

2. Will the study involve the use of participants' images or sensitive data? (e.g. participants personal details stored electronically, image capture techniques)

Some of the methods that could be implemented involve the use of imagery i.e. videos, photography. Prior to this, consent will be asked for and it will be made clear what the images are for and how they could be used.

You will need to submit your plans for addressing the ethical issues raised by your proposal using the 'Application for Ethical Approval' form which should be submitted to the Research Ethics Committee.

Please note that it is your responsibility to follow the University's Academic Ethical Framework and any relevant academic or professional guidelines in the conduct of your study.

**This includes:**

- **providing appropriate information sheets and consent forms**
- **providing notification that participants can withdraw at any time from the project**
- **ensuring confidentiality in the storage and use of data**

- **safeguarding the interests and safety of researcher(s).**

Any significant change in the question, design or conduct over the course of the research should be notified to your supervisor and may require a new application for ethics approval.

Signed: Michael Richards

Date: 01.10.2010

Principal Investigator: Michael Richards

Supervisor (where appropriate):

Signed:

Date:



Faculty of Health, Psychology and  
Social Care  
Research Committee

Ethics Scrutiny

**ETHICS CHECK FORM**

Introduction

The Departmental Research Committee has agreed that a completed Ethics Check Form should accompany all proposals for empirical studies.

Undergraduate projects may be approved by supervisors; MSc students must submit signed forms and proposals to the Scheme Coordinator (via the office). In all cases, the convenor of the Ethics Panel should be contacted in the event of any query. For all other projects, see below.

The Director or Supervisor of a particular research project has the responsibility of checking the form, signing it, indicating whether there are any ethical issues which deserve further consideration, and forwarding it to the Convenor of the Departmental Ethics Committee. The form must be received by the Convenor **before** the research is undertaken. If the study is described by the Supervisor as **EXCEPTIONAL** [see question 22], the research must not be started before the Ethics Committee has considered the study and indicated its approval. Proposals for funded research which would not otherwise receive ethical scrutiny, must receive approval from the Ethics Committee **prior** to the commencement of the research.



## ETHICS CHECKLIST

1. Name(s) of Investigators: Michael Richards
2. For Postgraduates: Degree: PhD.
3. Collaborating Organisations: Springfields
4. Title of Research: A community psychology approach working with men and learning difficulties: Improving the relationship between men and poor health.
5. Research Director/Supervisor: Dr Rebecca Lawthom
6. Give a brief statement of the aim and method (max. 100 words):

With Springfields aims and values and what action research and community psychology aims to do, I want to take a community psychology approach to enable men with learning difficulties to be able to develop their own group, in which they feel empowered and be able to take control of their lives in a positive way daily.

I propose that in collaboration with the relationships I build with service users alongside other advocates and their service users, that a participative approach can be created to develop activities that will enhance their well-being.

7. Describe briefly the arrangements for briefing potential participants [note that briefing must ensure that participants are aware of their right to withdraw from the study at any time]:

I have agreed with Springfields to produce a flyer and cover letter to be sent to service users at Springfields to explain what I hope to achieve. In addition to that, when the group or groups are formed, I will explain in writing and verbally to service users, staff and carers my intentions and hopes for this study. I will make it clear that they can withdraw at any time.

8. Describe briefly the arrangements for obtaining participants' consent. Include a copy of the information they will be given before the study and of a written consent form where this is appropriate. [For Speech Pathology projects, the College of Speech and Language Therapists' Guidelines state that a consent form is **ALWAYS** required from every participant.]

In discussions with Springfields, we have agreed to use diagrammatic consent forms, which will obtain consent. They will be supported by carers and workers to do this, as well as myself.

9. Are the participants able to provide informed consent?

YES/NO \*\*

If the answer is **NO**, what arrangements have been made to obtain approval from parents, representatives or advocates?

Some participants will not be able to provide consent; therefore, in collaboration with Springfields, carers and their families, we will discuss what the work is about and make it clear that withdrawal can be done at anytime.

10. Does the research present any risk, other than expected in the course of normal life, for the physical or mental well-being of the participants?

YES/NO \*\*

If you answer **YES** to this question, the Ethics Committee will require you to give a full explanation, before the research is approved and before it is begun, of what the risks are, what steps are taken to minimise them, what arrangements are made for being available to participants after the study is completed. ***Note that even if you answer NO, this does not absolve investigators from responsibility if a risk is found when the research begins.***

N/A

11. Does the research present any risk to you as the researcher?

YES/NO \*\*

If **YES**, please complete a Risk Management Form [available from research supervisors].

N/A

12. Is deception [including withholding information] involved?

YES/NO \*\*

If the answer is **YES**, explain why it is needed, and how it will be achieved.

N/A

13. Is invasion of privacy involved?

YES/NO \*\*

If the answer is YES, explain why it is needed.

N/A

14. Describe briefly the arrangements for debriefing participants:

The participants are central to the research process actually happening, therefore, they are always aware of what is to be done and what is happening. When the research is complete, I will make my findings available to them, in whatever format they feel comfortable with.

15. Will the data on every individual be anonymous?

YES/NO \*\*

If the answer is **NO**, explain briefly:

(i) why the data cannot, or will not, be anonymous:

If there is the use of film, videos or pictures and this is used to disseminate my research, then participants cannot remain anonymous.

(ii) what steps have been taken to warn participants before they take part in the study?:

I will obtain their consent when this is the case and make it clear they can withdraw at any time.

16. Research data cannot be kept entirely confidential because it must be available for discussion within the research team. What steps have been taken to warn participants before they take part in the study?

I will be clear from the start that this will happen and that if they disapprove they can withdraw at any time. This will be highlighted in the consent form.

17. What secure storage of data has been arranged?

I will not have direct access to personal information on Springfields records. Any information I obtain, will be stored at Springfields in a safe place.

18. What other arrangements under the Data protection Act has been made?

N/A

19. In order to gain access to participants, will you have to gain clearance from an external Ethics Committee?

**YES/NO \*\***

If **YES**, please explain how this will be achieved.

20. Are your results likely to be of interest to your participants?

**YES/NO \*\***

If **YES**, please explain how your research findings will be communicated to your participants.

I will give a presentation of all the things we have done together of the course of the research process.

21. Please outline the composition of a project advisory or steering group (if appropriate)

N/A

22. Statement by Supervisor/Research Director

[Studies can be categorised as ROUTINE, NORMAL, or EXCEPTIONAL. ROUTINE includes studies which have been previously classified by the Ethics Committee as NORMAL. NORMAL involves non-controversial studies. EXCEPTIONAL refers to studies judged by the proposer or supervisor as entailing ethical difficulties.]

I believe that the research proposed here should be classified as:

ROUTINE / NORMAL / EXCEPTIONAL \*\*

I appreciate that all items in the **EXCEPTIONAL** group must be forwarded to the Departmental Ethics Committee, and that under no circumstances must studies in the **EXCEPTIONAL** category be commenced before the Ethics Committee has considered it and issued its approval. All externally funded research must receive ethical clearance prior to the commencement of the research.

Supervisor's/Director's Signature: \_\_\_\_\_

Application Number.....

(facultycoding)

(Sep 2007)

Date.....



**MANCHESTER METROPOLITAN UNIVERSITY**  
**FACULTY OF (INSERT RELEVANT FACULTY HERE)**

**APPLICATION FOR ETHICAL APPROVAL**

**Introduction**

All university activity must be reviewed for ethical approval. In particular, all undergraduate, postgraduate and staff research work, projects and taught programmes must obtain approval from their Faculty Academic Ethics committee (or delegated Departmental Ethics Committee).

**APPLICATION PROCEDURE**

The form should be completed legibly (preferably typed) and, so far as possible, in a way which would enable a layperson to understand the aims and methods of the research. Every relevant section should be completed. Applicants should also include a copy of any proposed advert, information sheet, consent form and, if relevant, any questionnaire being used. The Principal Investigator should sign the application form. Supporting documents, together with one copy of the full protocol should be sent to the Administrator of the appropriate Faculty Academic Ethics Committee. **(Insert contact details)**

**Your application will require external ethical approval by an NHS Research Ethics**

Committee if your research involves staff, patients or premises of the NHS (see guidance notes)

**Work with children and vulnerable adults**

You will be required to have a Criminal Disclosure, if your work involves children or vulnerable adults – **already completed at organisation – Springfields**

**The Faculty Academic Ethics Committee meets every (insert period) and will respond as soon as possible, and where appropriate, will operate a process of expedited review. Applications that require approval by an NHS Research Ethics Committee or a Criminal Disclosure will take longer - perhaps 3 months.**

## **1. DETAILS OF APPLICANT (S)**

**1.1 Principal Investigator:** (Member of staff or student responsible for work)  
Name, qualifications, post held, tel. no, e-mail

Michael Richards BSc (Hons) Psychology MSc Community Psychology.

PhD Researcher.

MICHAEL.L.RICHARDS3@stu.mmu.ac.uk

**1.2 Co-Workers and their role in the project:** (e.g. students, external collaborators, etc)

Details (Name, tel. no, email)

N/A.

**1.3 University Department/Research Institute/Other Unit:**

Research Institute for Health and Social Change.  
Gaskell Campus  
Manchester Metropolitan University  
M13 OJA

## **2. DETAILS OF THE PROJECT**

**2.1 Title:**

A community psychology approach working with men and learning difficulties:  
Improving the relationship between men and poor health.

**2.2 Description of Project:** (please **outline** the background and the purpose of the research project, 250 words max.).

With Springfields aims and values and what action research and community psychology aims to do, I want to take a community psychology approach to enable men with learning difficulties to be able to develop their own group, in which they feel empowered and be able to take control of their lives in a positive way. This I hope will help to improve men's health lifestyles, which according to research is relatively poor (Courtenay, (1998), Rule and Gandy (1994), Boehm et al (1993) and Eisler (1995)).

I propose that in collaboration with the relationships I build with participants alongside other advocates and their service users, that a participative approach can be created to develop activities that will enhance their well-being.

**Aims:**

- To explore how community psychology approaches can empower men with learning difficulties through an evaluation of an action learning project.
- To consider strategies that improves psychological/physical well-being for men using community psychology philosophy as a framework.
- To evaluate a community psychology approach to working with men (with learning difficulties) utilising a range of creative methods.

**Objectives:**

- Use visual methods such as diaries, photography and creative writing, to explore how community psychological approaches can empower men.
- Implement strategies of change in collaboration with men to enhance their psychological well-being.
- Evaluate community psychology approaches to men by critically analysing its philosophy and framework.

My working research question will be:

Does being labelled with 'learning difficulties' have a negative effect on men's health and well-being? What methods can be used to improve this relationship?

Describe what type of study this is (e.g. qualitative or quantitative; also indicate how the data will be collected and analysed). Additional sheets may be attached.

The research will adopt an action research methodology and be situated broadly within a community psychology and disability studies framework.

**MORE NEEDED.**

**2.3 Are you going to use a questionnaire? YES/NO/N/A**

In the course of collaborating with participants, questionnaires may be used, but for now it not applicable.

**2.4 Start Date / Duration of project:**

January 2010 – June 2014.

**2.5 Location of where the project and data collection will take place:**

The data collection will take place at the premises of Springfields. In addition, to this it is likely I will be running the group in different locations, with the use of different activities, therefore, location will change.



## **2.6 Nature/Source of funding**

Personal funds.

## **2.7 Are there any regulatory requirements?**

NO.

## **3. DETAILS OF PARTICIPANTS**

### **3.1 How many?**

### **3.2 Age:**

21 years and over.

### **3.3 Sex:**

Men.

### **3.4 How will they be recruited?**

Already based with Springfields

**3.5 Status of participants:** (e.g. students, public, colleagues, children, hospital patients, prisoners, including young offenders, participants with mental illness or learning difficulties.)

**3.6 Inclusion and exclusion from the project:** (indicate the criteria to be applied).

**3.7 Payment to volunteers:** (indicate any sums to be paid to volunteers).

N/A.

### **3.8 Study information:**

Have you provided a study information sheet for the participants? YES/NO/N/A  
Please attach a copy of the information sheet, where appropriate

### **3.9 Consent:**

(A written consent form for the study participants MUST be provided in all cases, unless the research is a questionnaire.)

Have you produced a written consent form for the participants to sign for your records? YES/NO/N/A

Please attach as appropriate.

#### **4. RISKS AND HAZARDS**

Please respond to the following questions if applicable

##### **4.1 Are there any risks to the researcher and/or participants?**

(Give details of the procedures and processes to be undertaken, e.g., if the researcher is a lone-worker.)

##### **4.2 State precautions to minimise the risks and possible adverse events:**

##### **4.3 What discomfort (physical or psychological) danger or interference with normal activities might be suffered by the researcher and/or participant(s)? State precautions which will be taken to minimise them:**

N/A.

#### **5. PLEASE DESCRIBE ANY ETHICAL ISSUES RAISED AND HOW YOU INTEND TO ADDRESS THESE:**

#### **6. SAFEGUARDS /PROCEDURAL COMPLIANCE**

##### **6.1 Confidentiality:**

(a) Indicate what steps will be taken to safeguard the confidentiality of participant records. If the data is to be computerised, it will be necessary to ensure compliance with the requirements of the Data Protection Act.

(b) If you are intending to make any kind of audio or visual recordings of the participants, please answer the following questions:

a. How long will the recordings be retained and how will they be stored?

b. How will they be destroyed at the end of the project?

c. What further use, if any, do you intend to make of the recordings?

## 6.2 Human Tissue Act:

The Human Tissue Act came into force in November 2004, and requires appropriate consent for, and regulates the removal, storage and use of all human tissue.

a. Does your project involve taking tissue samples, e.g., blood, urine, hair, etc., from human subjects?

NO.

b. Will this be discarded when the project is terminated?

N/A

If NO – Explain how the samples will be placed into a tissue bank under the Human Tissue Act regulations:

## 6.3 Insurance:

The University holds insurance policies that will cover claims for negligence arising from the conduct of the University's normal business, which includes research carried out by staff and by undergraduate and postgraduate students as part of their courses. This does **not** extend to clinical negligence. There are no arrangements to provide indemnity and/or compensation in the event of claims for non-negligent harm.

Will the proposed project result in you undertaking any activity that would not be considered as normal University business? If so, please detail below:

N/A.

## 6.4 Notification of Adverse Events (e.g., negative reaction, counsellor, etc):

(Indicate precautions taken to avoid adverse reactions.)

Please state the processes/procedures in place to respond to possible adverse reactions.

In the case of clinical research, you will need to abide by specific guidance. This may include notification to GP and ethics committee. **Please seek guidance for up to date advice**, e.g., see the NRES website at <http://www.nres.npsa.nhs.uk/>

SIGNATURE OF PRINCIPAL INVESTIGATOR  
Michael Richards

DATE:  
01.10.2010

.....

.....  
SIGNATURE OF FACULTY ACADEMIC ETHICS  
COMMITTEE CHAIRPERSON:

DATE:

.....

.....

## Consent Form

**A community psychology approach working with men and learning difficulties:  
Improving the relationship between men and poor health.**

**Researcher: Michael Richards**

**PhD Student at Manchester Metropolitan University.**

I would like to invite you to take part in a study.



Before you decide, I want you to be clear about why the research is being done, what will be done and how you play a part in this research.



Please read the information I have provided and talk about it with family, friends, carers or colleagues.

A. Why am I doing the research?



Health



Men



Changing

and



Listening

I am a PhD student at Manchester Metropolitan University and I am interested in men's health and to find ways to change it in a positive way by listening to you and working together.

I want to collaborate with you in healthy, fun activities to promote healthy lifestyles for men.

B. Why do I want you to take part in my study?



Working Together.

I want you to be involved because you are men connected with Springfields who I feel could benefit from the process of this study.



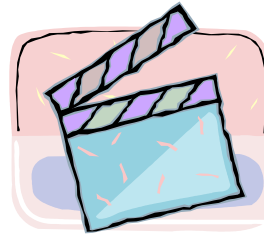
Walking



Eating well



Snooker



Cinema



Day Trips

I will facilitate group work that will cover a range of activities that aim to improve mental and physical health. For example, one week we might go for a country walk and another week could involve learning to cook.



Cameras



Filming

I will use different methods to record the ongoing development of the group.

C. Do I have to take part in the study?



Choice.

It is for you to decide if you want to take part in this study.

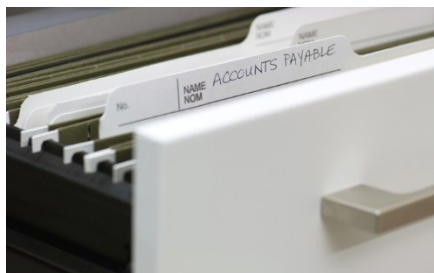


Consent Form.

If you decide you want to take part, I will provide a consent form for you to complete.

If you choose at any point to withdraw from the study you can and you do not need to explain why.

D. Will my taking part in this study be kept confidential?



Confidential.

All information will be kept confidential that I will collect.



You Decide.

Any pictorial or film information will only be used if you consent to it being used. You can view information first before you decide to allow it to be made public.



Safe and Secure.

All recordings and information will be secured and kept safe and will be destroyed when the study is over.



You have access at all times.

You have access to your information at anytime.

E. What will happen to the results of my study?

The results of my study will be presented at conferences, seminars and publications.





Anonymous.

You will remain anonymous to anyone outside the group.

You can contact me for further information.



Contact me.

Michael Richards

- Contact me through Springfields (via Joan, administrator)

01614371111

Thank you very much for taking the time to read this information and I hope you can take part in this study.

**Consent Form.**

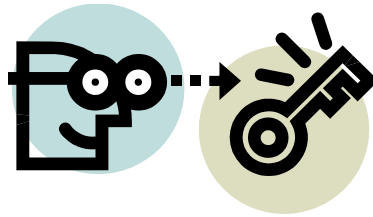
**A community psychology approach working with men and learning difficulties:  
Improving the relationship between men and poor health.**

**Researcher: Michael Richards**

**PhD Student at Manchester Metropolitan University.**

Please circle your answer to the questions that follow:

A. Do you understand what this study will be about?



Understanding.

YES NO

B. If you have had any questions or concerns, have these been addressed the way you wanted them to be addressed?



Thoughts and Feelings.

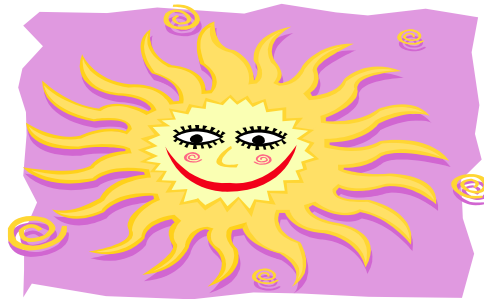
YES NO

C. Do you know you can stop taking part in this study at anytime?



YES NO

D. Are you happy to be interviewed and recorded on a dictaphone and have pictures taken or be on film?



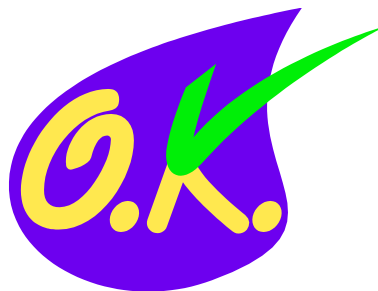
Cameras



Filming

YES NO

E. Are you happy to take part in this study?



Are you ok?

YES NO

If the answer is NO to any of the above questions then **do not** sign your name below. If you do want to take part in this study, sign your name below.

Name:

Date:

Thank you very much for taking the time to read and sign the form.