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Writing not Drowning: an examination of the issues discussed in the novel *The Summer of Love*, and of the creative and contextual research supporting its creation.

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A thesis submitted in partial fulfilment of the requirements of Bath Spa University for the degree of
Doctor of Philosophy

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Abstract

This PhD submission consists of a novel, *The Summer of Love*, and a supporting thesis, '*Writing not Drowning: an examination of the issues discussed in the novel The Summer of Love, and of the creative and contextual research supporting its creation.*'

Together, novel and thesis comprise and address the research inquiry underpinning the novel's creation, namely: how is it possible to write fiction exploring political issues, the UK Government's treatment of disabled people and the associated stigmatisation of welfare dependents, without flattening the story or appearing partisan or divisive? Is it possible for this novelist to capture difficult truths from the political and social landscape in prose that combines humour with insight?

The Summer of Love is a darkly satirical novel in which Alex, a disabled journalist fallen on hard times, uncovers a story that could link the government to a euthanasia programme targeting disabled, elderly and vulnerable people. During her investigation, she inadvertently becomes part of the Ladies' Defective Agency, a group of disabled women running a phone sex company which, in turn, may or may not be fronting for the underground activist gang, BOUDICCA. Alex and her guide dog, Chris, must negotiate a world where anyone reliant on any form of welfare is pilloried, scapegoated and a potential target of hate crime, in order to bring the uncomfortable truth to an oblivious society.

The novel intends to bring forward challenging ideas about compassion, human rights and equality, about disability and normalcy, reflecting my/our worst nightmares about the current welfare changes and their impact on disabled and vulnerable people.

Following extensive research and experiment, several key creative techniques are specified and applied including:

- Immersion in historical texts in order to write scenarios and characters that would create a resonance with the T4Aktion plans of Nazi Germany.
- Conscientious development of a fully rounded, three dimensional disabled protagonist, in order to reflect our shared human experience and not just a 'disabled' experience.

- The use of satire and humour to create further narrative empathy through a shared, cathartic response of laughter followed by understanding and;
- Employment of the notion of 'protective fictionality', allowing the reader to escape into a slightly more fantastical 'Other England', where they can imaginatively inhabit the minds of animals as well as people. This was done in the hope that a more relaxed reader would be a more amenable, empathic and absorbed one.

By applying these creative tactics, I hope, *The Summer of Love* creates strong narrative empathic connections with its readers that may lead to a greater understanding of the current climate of hostility and shame faced by vulnerable and disabled people in UK today, whilst at the same time providing an entertaining and exhilarating read.

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[The section containing the novel 'The Summer of Love' has been redacted in this digitized version due to potential copyright issues]

Introduction

In this supporting thesis I intend to address the research inquiry underpinning the novel's creation and to examine the research process that informed the conception of *The Summer of Love*, including the key creative practice decisions leading from first to third draft. My central research question can be summarised as follows:

How is it possible to write fiction exploring political issues such as the state's treatment of disabled people and the stigmatisation of welfare dependents, without flattening the story or appearing partisan or divisive? Is it possible for this novelist to capture difficult truths from the political and social landscape in prose that combines humour with insight?

Articulating and evidencing the research inquiry

A number of potential methodologies might've been usefully employed for this research inquiry. As a novel constitutes more than two thirds of this PhD, both it and the contextualising thesis will be considered under the framework of 'practice as research in the arts' as described by Nelson:

PaR (practice as research) involves a research project in which practice is a key method of inquiry and where, in respect of the arts, a practice (creative writing, dance, musical score/performance, theatre/performance, visual exhibition film or other cultural practice) is submitted as substantial evidence of a research inquiry. (Nelson, 2013: 8-9)

Both the novel and thesis put forward in this PhD reflect on and react to personal and observed experiences, whilst commenting on the general socio-economic environment in which I, as writer, am currently situated. This places me, the author, as practitioner, participant and observer, and my thesis utilises multiple methods to articulate and evidence the research inquiry at the heart of the creative work. Different sections of the thesis will, therefore, be approached with different observational and critical styles occasionally interweaving.

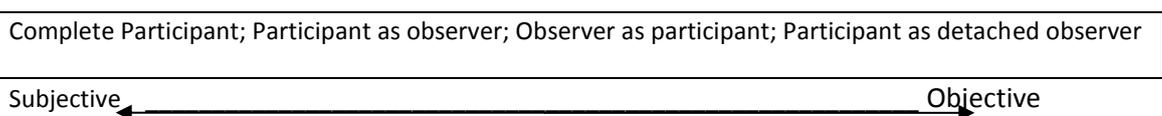
If we take chapter one, section two, as an example, the research and commentary apply both detached and participatory methodologies. Whilst discussing the T4 Aktion Plans of Nazi Germany, I employ the role of detached

observational researcher, citing archive, historical texts, witness testimony, accounts and other authors who have used both memoir and fiction in their diagnosis of these events. However, I also acknowledge the impact that the Second World War had on my Jewish family and show how the accounts of the T4 Aktion events resonate with me deeply, at an emotional level, as both partly Jewish and a disabled woman. Each element was a creative trigger for the novel and its development.

Another example of multiple research modes merging can be seen in chapter two, section two, when discussing the character of Alex and her response to her job interview. Here I take my own experience of the discomfort of unemployment, (participant as observer). I also source academic data, papers and reports on the effects of stigmatization of the unemployed (participant as detached observer) and explore the subsequent fictionalisation of this (observer as participant) and its hoped-for effect on the reader.

If we consider the simple diagram set out by Caulfield and Hill, we can see that the writer-practitioner researcher position, as mooted in this thesis, remains fluid, hovering between all four areas of established researcher roles in the diagram below:

Researcher roles in observation studies:



(Caulfield and Hill, 2014: 118)

It is possible to look at the area of fluidity in the centre of the diagram and suggest that the approach to a novel and thesis, will, in addition, have an autoethnographical angle, as in my chapter two section four, especially as laid out by Ellis in *The Ethnographic, I*:

“What is autoethnography?” you might ask. My answer: research, writing, story and method, that connect the autobiographical and

personal to the cultural, social and political. Autoethnographic forms feature concrete action, emotion, embodiment, self consciousness and introspection portrayed in dialogue, scenes, characterisation and plot. Thus autoethnography claims the conventions of literary writing. (Ellis, 2004: xix)

By designating this novel and thesis as 'practice as research', I may apply the title of writer-practitioner to myself whilst also utilising a fluid model of observer/participant, participant/observer, autoethnographer and qualitative researcher.

Politics and Creative Practice

The Summer of Love is a dark and satirical novel that hypothetically asks what could happen if the UK government sanctioned state-sponsored euthanasia as a social cost-cutting exercise? It is a fiction about the welfare system, about disability and vulnerability; more than that it is a novel about power and powerlessness, about love, courage and freedom. Given the weight of the issues being discussed in the novel, can it be crafted into a worthwhile and readable work of literary fiction?

There are many 'political' novels that comment on the public affairs of a country or on its government, e.g. *The Prince* by Machiavelli (1532) and *Primary Colours* by Klein (1998), while other novels may comment, less specifically, on the human condition or on society in general, e.g. Orwell's *1984* (1949), Levi's *If This Be A Man* (1959), Gee's *The White Family* (2002),) etc. Some novels are polemical, others may be depressing and distressing, some are riddled with horror, violence and depravity. There are novels that alienate, twist the known world into knots, and some that even make their readers physically sick. A few of these disquieting novels are highly successful, issue-laden, combative, sometimes satirical, irritable, rummaging through the endless 'what ifs' that plague our daily lives. Kafka's *Metamorphosis* (1915), Huxley's *Brave New World* (1955), Burgess's *A Clockwork Orange* (1962), Ballard's *High Rise* (1975), Bret Easton Ellis's *American Psycho* (1991), Atwood's *Orynx and Crake* (2003), and Macarthy's *The Road* (2006), to name but a few, have sold in their thousands.

With my own novel, *The Summer of Love*, I too wanted to hypothesise, to examine difficult and disturbing issues arising in the England I was living in and to consider the 'what ifs'; i.e. what if disabled and vulnerable people became society's scapegoats and what if this led the way to social cleansing and euthanasia? I needed to find a way, through craft and imagination, as well as applied research, to convince a reader that the power of my novel would carry them through the difficult terrain of politics, of socio-economics and of my own personal, furious, interpretation of the intricacies of contemporary England. To address my research inquiry, my novel had to resonate on many different levels with many different readers, not just be a single aggrieved political tract.

As Atwood responded to the *New York Times* when her dystopian novel, *The Handmaid's Tale*, was accused of being a feminist polemic:

"Novels are not slogans...If I wanted to say just one thing I would hire a billboard. If I wanted to say just one thing to one person, I would write a letter. Novels are something else. They aren't just political messages ..."
(Rothstein, 1986)

It is with this in mind that I propose, through the writing of my novel and this contextualising thesis, to articulate and evidence my research inquiry into the challenges of writing a politically charged satirical fiction.

In Chapter one, entitled 'Drowning', I will lay out the key aspects of the socio-political backdrop that inspired the novel and examine my personal response to it, and how it triggered the first drafts of *The Summer of Love*.

- In section 1.1, I discuss the changes to the welfare system in UK during the initial conception of the novel and the language of blame that became a key feature of the government and media discourse on disability.
- In 1.2, I go further into the role of this language of propaganda and its capacity to instil fear and prejudice. I begin to highlight how this language resonates with Nazi propaganda in the lead up to the Aktion T4 plans and the euthanasia of disabled and vulnerable people in Germany, and discuss how this might have influenced the emergence of key issues within the novel.
- In 1.3, I look in more detail at ATOS and the system of Work Capability Assessments that were being applied during the writing of the novel and the effect of these on myself and other disabled people. I ask the question, where and what was the response of the government and the medical establishment during this time?

In Chapter two entitled 'Writing', I look closely at the development of my craft and style with reference to the research inquiry and the direct and indirect experiences that fed into the fiction.

- I begin Section 2.1 by discussing the doctors behind the T 4 Aktion experiments, the issue of complicity and complacency and how and why I created the character of Dr Binding, Nurse Dyer and the other 'functionaries'.
- In 2.2 I seek out a genre and a gender for my disabled protagonist and begin to tease out the nuances of authenticity versus 'inspiration porn' when writing, specifically, a disabled character.
- In 2.3 I scrutinize the failings of the first draft in light of the research inquiry.
- In 2.4 I source the elements of resistance and deliberate on active resistance and sexuality in my creations of BOUDICCA and the Ladies' Defective Agency and the role of humour, specifically satire and the affect this had on refreshing my return to the next drafts.
- In 2.5 I discuss the development of other voices in light of the research inquiry and in particular the discovery of a free spirited canine called Chris.

Finally, in a short section called 'The Book Club Experiment', I analyse initial reactions to the draft manuscript in collaboration with a local book club, the resulting data and its effect on the final draft of the novel, before drawing my conclusions.

Chapter 1: Drowning

*'Meet the Superhumans'*¹

1.1: The socioeconomic backdrop to the conception of the novel and the language of blame.

When I was conceptualising the novel, disability in all its various forms had been the topic of discussion across the UK following an incredibly successful Olympic and Paralympic Games in London, in 2012. Much of the discussion had been hopeful and relatively positive. For example, Channel 4 had run a controversial but successful series of promotional adverts for the Paralympics extolling the idea of the 'Super Crip'/'Super-Human' and even commissioned an excellent late night comedy show, *'The Last Leg'*, hosted by the disabled comedian Adam Hills, which ran alongside the Paralympics and is still running at the time of writing. Between the feats of the athletes and the appearance of disabled presenters, comedians, dancers and commentators on every media outlet, disability seemed, for a while, to be almost sexy.

But by 2012, the UK was already mired in the depths of a recession, enduring what felt for many, including local councils and the NHS, to be endless cut-backs to services, while government cuts to disability benefits, to independent living funds and to welfare were impacting hugely on the disabled and deaf community. (Hastings *et al.*, 2015; Wilson *et al.*, 2013)

In addition, there was a more disturbing layer to this misery; since the previous Labour government under Blair, then Brown, later under the Tory Liberal Coalition, and now, in 2015, under a Tory majority, a trend had become apparent in the government's rhetoric around poverty and welfare. No longer was the pivotal stress on looking into the broader societal factors surrounding perceived poverty or welfare 'dependence'. Instead, public perception of

¹ Tag line for advertising Channel Four's 2012 coverage of the London Paralympics

poverty, bolstered by both media and current government policy, was becoming focused on individual rather than systemic causation (Briant *et al.*, 2011). From the mid 2000's to date, a daily ration of 'dole scroungers' and 'benefit cheats' (Baumberg *et al.*, 2012) has been paraded through the pages of the national media, and various television shows, such as '*Benefits Street*' (2014), '*Benefits: Too Fat To Work*' (2015), and '*Undercover: Benefits Cheat*' (2014), have been produced and edited to highlight the degradation, 'deliberate' ignorance and connivance of benefit claimants, portrayed as making a life-style choice of "living off the state".

Reports and data analysis compiled by Warwick University's 'Centre for Human Rights in Practice' from a variety of organisations including the Joseph Rowntree Foundation, (Hastings *et al.*, 2013), The Centre for Welfare Reform (Duffy, 2014) and a particularly damning report from Manchester Citizens' Advice Bureau (Manchester CAB Service, 2013) among others, has shown that the greatest impact of the welfare cuts, leading up to and including the 2012 Welfare Reform Act, has been on the most vulnerable people in society and on those, especially disabled people, who rely on benefits to access work, care, education and independent living.

By 2012, slashes to welfare and local government had begun to directly affect the people who needed help most. In a report entitled 'Counting the Cuts', the Centre for Welfare Reform explained that:

The reason these cuts have been targeted in these areas is not moral or economic - it is political. It is easier to scapegoat disabled people and people in poverty. Few people understand social care or local government. Benefits and social care are highly means tested and stigmatised...Disabled people and people in poverty have no effective political representation. (Duffy, 2014: 21)

The language of blame filtered down from the speeches in Parliament to the tabloid press. "75% of People on Incapacity Benefit are Fit To Work", ran the headline in the *Daily Mail* on October 22nd, 2006, and was just one example. Exposure of benefit fraud became a key component for the national newspapers (Briant, *et al.*, 2011; Baumberg *et al.*, 2012).

In 2011, Amelia Gentleman posted in the *Guardian* that:

The Salvation Army and a number of other charities have written to the prime minister pointing out that the £5bn figure highlighted by the chancellor was "a threefold exaggeration of the true government estimate of benefit fraud". The frequently cited figure is achieved by adding the estimated amount of fraudulent claims (approximately £1.6bn) to the estimated total of claims made as a result of an error either by the claimant or the official handling their claim. (Gentleman, 2011)

Indeed, although in truth only a 0.05% fraud had been reported by the Department of Work and Pensions (DWP), the idea that disabled people were 'faking' took hold across the UK. Investigation by journalists and researchers into why the statistics were being so thoroughly miscommunicated led to Patrick Butler's conclusion that the Department of Work and Pensions itself was often to blame.²

Butler argued:

MPs have criticised the Department for Work and Pensions for a series of rule breaches in which official statistics were used inaccurately, inappropriately, or to "spin" stories about benefit claimants...In one case, the Conservative party had put out a press release which quoted party chair Grant Shapps citing DWP figures that purported to show nearly a million people had dropped their benefit claim rather than face a work capability test. The UKSA [UK Statistics Authority] found that two sets of figures had been erroneously and misleadingly conflated...In a separate case, Duncan Smith was officially reprimanded for claiming that the threat of the benefit cap had directly persuaded 8,000 of claimants to get a job. This clearly demonstrated that the cap was working, he said. But the UKSA ruled that there was no statistical evidence to support this. (Butler, 2014)

On 5th November 2011, the University of Glasgow's Strathclyde Centre of Disability Research published a report concluding that:

Much of the coverage in the tabloid press is at best questionable and some of it is deeply offensive...These [disability fraud] claims are made overwhelmingly without evidence and at no point are the media reporting the very low levels of fraud that occurs overall in relation to these benefits. We would further cite the use of pejorative language, the failure to explore the impact of the proposed cuts on disabled people's quality of life, the reluctance to criticise government policy on these issues and the

² This has been supported by a report into abuse of statistics by the Department for Work and Pensions and UK Government Ministers by DPAC research team: June 2013.

frequent representation of some disabled people as undeserving of benefits as potentially contributing to what could become a highly inflammatory situation. (Briant *et al.*, 2011: 68)

It should also be noted that the 'culture of worklessness', a formulation championed by Iain Duncan Smith, the Secretary of State for Work and Pensions, as long ago as 2009, has been proven to be another myth by research instigated by the Joseph Rowntree Foundation (Shildrick, 2012).

At the same time investigations began into the proliferation of harassment and hate attacks on disabled people. *Hidden in Plain Sight* was an Equalities and Human Rights Commission investigation published in 2014 which concluded in its executive summary that:

The harassment of disabled people is not confined to just a few extreme cases. The incidents, which reach the courts and the media, are just the most public examples of a profound social problem. For many disabled people, harassment is an unwelcome part of everyday life. Many come to accept it as inevitable, and focus on living with it as best they can. And too often that harassment can take place in full view of other people and the authorities without being recognised for what it is. A culture of disbelief exists around this issue. (Equalities and Human Rights Commission, 2014: 5)

The vilification of disabled people on benefits helped to create a climate where extreme reforms which are now seen to be 'inept and damaging' could be enacted without much public interference, as discussed in Radio 4's '*Analysis*' (2014).

As I am a disabled woman intermittently reliant on benefits, I have been both directly and indirectly affected by these changes in attitude, as well as by the cuts to welfare. In the past I had often wished to explore my own disability and its effect on those around me, and now reasoned that this would be an ideal opportunity to shine a light through fiction into what I perceived as the dark underbelly of the welfare cuts and their impact on the vulnerable in our society.

1.2: Fear, prejudice and the spectral echoes of the T-4 Aktion Plan

In 2012, living in a climate of stigma and aggressive cutbacks, I felt as if I were drowning in negativity and fear. I could see, in the responses and outcries on social media, blogs such as 'Diary of a Dole Scrounger' (Marsh, 2014) and 'Benefit Scrounging Scum' (Franklin, 2013), and through charitable campaigns held by Leonard Cheshire, RNIB and MIND for example, that others were feeling this too. I wanted to address the dehumanising images and language I was seeing and hearing in the media and somehow confront the fear and anxiety that many disabled (and non-disabled) people were experiencing. Was this fear justified? And if it was, how far exactly was this government prepared to go? I looked more closely at the dehumanising process of language and its ominous undertow. I recognised that I was not the only person asking how the current situation regarding welfare stigmatisation reverberated with the recent past, for example with the Nazis' programme of euthanasia for their disabled communities in the lead up to the Second World War, the Aktion T-4 Plan.

In January 2012, I had visited Liz Crowe's installation, *Resistance!*, in which she explored through video, re-enactment and contemporary documentary, how the Nazi's T-4 Aktion Plan had happened in plain sight. Disabled children and then adults were rounded up and 'euthanized' under the public gaze. Buses collected local people deemed 'unfit' and took them to nearby institutions, killing and cremating them on site. Villagers and townspeople could see the smoke from the chimneys and yet there was almost no public reaction or outrage for several years. This installation resonated with me not just because of my own disability but also because my father was Jewish and we had lost many Polish and Russian relatives during the holocaust.

There is an old and useful adage – once you mention the Nazis in any argument, you have lost. I had gathered from general discussion with disabled activists from around the country during the 'Avoidance in/and the Academy Conference' on the 11th and 12th September, 2013, that many, although aware of the issues relating to disability and welfare, had been very careful not to make comparisons between Nazi ideology and the present day, perhaps rightly so. In the 21st Century, attitudes to race, gender and disability are very different

and with global technology, medical interventions, the internet, social media and the like, surely nothing like that could ever happen again?

As I thought about the structure of my novel and as I researched the lead up to the Aktion T-4 plans of the Nazis, I realised that there was a definite pattern that ran along the lines of identifying the so-called 'enemy', separating then isolating them from the wider community, and then exterminating them. With that in mind, I decided to break up the novel into three sections: 'Clearance', 'Disinfection' and 'Disposal', three innocuous words that together represented the appalling Aktion T-4 process of acceleration towards extermination.

Having the manuscript in these three 'accelerating' sections also gave me a specific focus and feel as to what would be the required undercurrent and build-up of energy within each section. With regard to the central enquiry, i.e. how was it possible to fictionalise political issues without the work becoming weighted and flat, I was confident that the escalating action within each section would create a heightened state of expectancy from the reader, giving them a clear motivation and desire to keep reading.

In the section 'Clearance' for example, I would hint at new legislation designed to separate out the weak and vulnerable and isolate them from the rest of society. I would contrive incidents and design characters to further this course. In 'Disinfection', I would weave the plot around the residential centre and Dr Binding. I would intimate that behind the scenes this terrible momentum was gathering pace as the book moved forward from one part to the next, climaxing with the section 'Disposal' and the revelation of the Chiller Beds. I hint early at this plot arc by ensuring that the secret files held by my character Dr Binding and by others, laying out the plans to euthanize the disabled and vulnerable, were titled the 'CDD files, Clearance, Disinfection and Disposal'.

It was very interesting to me that, after making the decision to break down my novel into the three segments building towards 'Disposal', I came across Allport's 'Scale of Prejudice'. I was excited to see that the five point scale first propounded in his book, *The Nature of Prejudice* (1958:14-15), had been developed through analysis of several groups, including the Nazis in the lead up to the Holocaust, and gave a clear and detailed breakdown that in some way

concluded with my own deliberations about the projection of prejudice from verbal insults through to mass killing. Allport's scale runs thus:

- Antilocution: A form of discrimination in which negative verbal remarks against a person, group, or community, are made (in a public or private setting) and not addressed directly to the target.
- Avoidance: Members of the majority group actively avoid people in a minority group. No direct harm may be intended, but harm is done through isolation
- Discrimination: Minority groups are discriminated against by denial of opportunities and services, putting prejudice into action. Behaviours have the specific goal of harming the minority group by preventing them from achieving goals, getting education or jobs etc. The majority group is actively trying to harm the minority.
- Physical Attack: The majority group vandalize, burn or destroy minority group property and carry out violent attacks on individuals or groups. Physical harm is done to members of the minority group.
- Extermination: The majority group seeks extermination or removal of the minority group. They attempt to eliminate either the entire or a large fraction of a group of people³.

Finding Allport's scale gave me greater confidence in my decision to use escalating chapters and a sense that some of my creative choices, especially in light of my three-part structure, were not unsubstantiated. I now felt keenly that I was on the right track and that I must make my novel raise the terrible idea: what would happen if the government sanctioned and sponsored euthanasia of the disabled and vulnerable?

³ The scale here is taken from an edited Wikipedia version of Allport's scale – https://en.wikipedia.org/wiki/Allport%27s_Scale, 10th June 13, as the original, written in 1950, is now dated and more unwieldy than this version. I have included the original as Appendix 1.

1.3: ATOS and the Work Capability Assessment (WCA)

As discussed in the first section, I had done a great deal of reading around the Nazis' T-4 Aktion Plans and was now playing with the frightening notion that in contemporary England we were on a similar trajectory, especially when it came to the language of dehumanisation regarding the vulnerable within society. Certainly it was obvious that the idea of people being 'unfit', 'useless eaters' (Gallagher, 1990) or as Iain Duncan Smith, the Minister for Work and Pensions called them on *BBC Radio 4's Today* programme (15/7/2013), 'economically unviable', pervaded public consciousness still. I became interested in the similarities between propaganda in the lead up to Aktion T-4 Plan of the Nazis and the presentation of disability, the scrounging underclass, the 'parasites' of contemporary, austerity Britain.

ATOS brought an added dimension to the 'dehumanisation' of the disabled community that became integral to the imagining of my novel. ATOS, a French multi-national IT service, has been involved in UK healthcare since the late 1990's. The Welfare Reform Act 2007 introduced the Work Capability Assessments (WCAs) to determine who should receive Employment and Support Allowance (ESA) and at what level. ESA was to replace the Incapacity and Income Support Benefits that were already in place, and which disabled people relied upon when in and out of work. Everyone who was already registered with a disability benefit, or applying for one, would now be required to attend an assessment. This included those with a severe or terminal illness, as well as those with unchanging conditions e.g. blindness or amputation.

ATOS won the contract from the Department of Work and Pensions for the WCAs, a tick-box, point-based system, often, in the initial stages, carried out by non-medical people, including administrators, occupational therapists and technicians. From the outset, disabled peoples' organisations (DPOs) and other charities reported back from clients that there appeared to be confusion about certain medical conditions (Barclay and Pettitt, 2014). ATOS assessors did not seem interested in whether the cumulative stress of a chronic condition was compounded by being assessed, or even to care whether the claimant

understood what was happening. Later investigation (*Dispatches*, 2012; *Panorama*, 2012) was to suggest that assessors were actively encouraged to pass as many people as possible 'fit for work' regardless of their situation or condition.

'Assessments begin outside the assessment room,' begins an online report by Guerrilla Policy (Jones, 2013), based on information from the ex-ATOS Nurse and whistle blower, Joyce Drummond. It goes on:

'...At this point the HCP (Health Care Professional) assesses:

- Did you hear your name being called
- Did you rise from your chair unaided, did the chair have arms or not
- Were you accompanied – assessing your ability to go out alone
- Were you reading a paper while waiting – assessing your concentration
- Did you walk to the assessment room unaided, did you use any aids correctly. Did you navigate any obstacles safely – assessing sight

The HCP will shake your hand on introduction – assessing your handshake, noting if you are trembling, sweating – signs of anxiety. The HCP carefully scrutinises everything you do and say'.⁴ (Jones, 2013)

Many thousands of people who were assessed as 'fit for work' were forced to appeal. This could take weeks and during appeals people could not access their full, or in some cases any, benefits. The outcome of this was inevitably more debt, health crisis and many deaths, as shown in these examples from the Black Triangle website's list of cases, first accessed on October 21st 2013.

...Terry McGarvey, 48. Dangerously ill from polycythaemia, Terry asked for an ambulance to be called during his Work Capability Assessment. He knew that he wasn't well enough to attend his WCA but feared that his benefits would be stopped if he did not. He died the following day.

⁴ The article, 'Fear of the Brown Envelope' (Garthwaite, 2014), demonstrates the general confusion caused by this process, and how the changes it caused created fear and anxiety and began impacting especially hard on the vulnerable and those with mental health issues.

Elaine Lowe, 53. Suffering from COPD and fearful of losing her benefits. In desperation, Elaine chose to commit suicide.

Mark Wood, 44. Found fit for work by ATOS, against his Doctor's advice and assertions that he had complex mental health problems. Starved to death after benefits stopped, weighing only 5st 8lb when he died.

Paul Reekie, 48, the Leith-based poet and author. Suffered from severe depression. Committed suicide after DWP stopped his benefits due to an Atos 'fit for work' decision.

Carl Payne, 42. Fears of losing his lifeline benefits due to welfare reform led this father of two to take his own life.

Tim Salter, 53. Blind and suffering from Agoraphobia. Tim hanged himself after Atos found him fit for work and stopped his benefits.

As late as August 2014, several charities supporting people with various chronic and progressive conditions, including multiple sclerosis, Parkinson's, cystic fibrosis etc., wrote again to the WCA Independent Review Team with several key recommendations. They felt they had been thwarted in their attempt to gather supporting evidence by the DWP:

For the Year 5 Review, we had hoped to include additional recent data. We submitted an FOI request to the DWP to obtain up to date information. However, we are disappointed to report that whilst this was meant to have been received by Friday, 8th August, it has still not been received at the time of submission. However, we still have evidence that the system continues to fail those with progressive conditions and is inconsistently applied, costly, and causes untold distress through repeated and unnecessary form filling, assessments and tribunals. (Medhurst *et al*, 2014)

In addition to this, in April 2015, the Information Commissioner's Office ruled that it could see no 'convincing evidence' for the delaying tactics of the DWP in

publishing the figures showing how many people claiming incapacity benefit payments have died after being found fit for work (Wood, 2015)⁵.

As George Monbiot wrote in his article, 'Cleansing the Stock and other ways Governments Talk About Human Beings': 'On the bright side, if you die while on a government work programme, you'll be officially declared a "completer". Which must be a relief.' (Monbiot, 2014). And what, I contemplated with regard to my novel, of the people who can't cope with the forms and give up, falling out of the system entirely, moving back in with parents or falling into homelessness? Are they, too, 'complete'?

To blot people out of existence first you must blot them from your mind. Then you can persuade yourself that what you are doing is moral and necessary. Today this isn't difficult. Those who act without compassion can draw upon a system of thought and language whose purpose is to shield them – and blind us – to the consequences. (Monbiot, 2014)

These horror stories were public knowledge. Almost every day in the media one could, and still can, find a story about someone who had suffered a terrible injustice or merely fallen through the holes in the system and become homeless, sick or worse. As stated in the Equalities and Human Rights Commission findings, abuse and hate crime was happening in plain sight with no obvious organised outcry from the general public. There was little obvious reaction from those witnessing the impact, the medical personnel, the GPs, the nurses and carers. Why were so many not joining disabled people under their care in forming more organised protest? Were they just overwhelmed or did they feel that they could not risk 'rocking the boat'?

In March 2014, with its brand compromised by its association with incompetence and cruelty regarding the WCA's, ATOS bought its way out of its £400m contract with the DWP. In March 2015 the US conglomerate Maximus stepped into the breach. How Maximus will fare is yet to be seen especially in light of the fact that, as reported in the Guardian on January 18th 2015:

⁵ In July 2015, the government launched an appeal to overturn this ruling.

...analysts warn that the whole system has ground to a halt and is in danger of “falling over”. The Office for Budget Responsibility predicted in December that the backlog would take two years to clear, and that these delays to the process would eat into the savings the government hoped to see, by as much as £700m a year.⁶ (Gentleman, 2011)

⁶ Office for Budget Responsibility: Economic and fiscal outlook Presented to Parliament by the Economic Secretary to the Treasury by Command of Her Majesty Government publications 2014 p215 Table A.2: HM Treasury table of welfare cap policy decisions and OBR assessment of the uncertainty of costings.

Chapter 2: Writing

2.1: Examining the ‘functionaries’: complicity and compliance.

Monsters exist, but they are too few in numbers to be truly dangerous. More dangerous are...the functionaries ready to believe and act without asking questions. (Levi, 1987: 396)

In the first draft of the novel I knew that I would be discussing the issues around welfare, disability and stigma in contemporary UK and, as proposed by my central research inquiry, I would need to discover methods to ensure the novel was not flattened by the weight of these ideas. My research had uncovered a general complacency about the work capability assessments (WCAs) and the effect of the interviews and sanctions on vulnerable people. As mentioned in the chapter above, it appeared that the DWP and ATOS ‘functionaries’ seemed to get on with their jobs in spite of the potential damage they might be doing to a vulnerable or disabled person’s life.

In my novel I would have at least one key medically trained character through whom I needed to convey a very complicated ethical quandary. What is it that makes a doctor allow killing or become a killer himself? I read through the transcripts of the Nuremburg trials and the testimony, in particular of the doctors and nurses who had undertaken to murder their patients. Some seemed unable to accept responsibility for their actions, many citing other figures of authority as the decision makers. Others were unrepentant.

My own father had been a doctor, a GP and specialist in tropical medicine working in Lusaka, Zambia. I had seen at first hand the complete trust his patients had in him. Many of them would see no one else, even when he too became ill and had to do visits in a wheel chair. Ethical debate was essential for my Dad especially as he was faced in Zambia with the HIV pandemic and the terrible fear and stigma surrounding the virus. Through the 1980s and 1990s there was at first no treatment and then no affordable treatment for the majority. People known to have the virus were ostracised, scapegoated and sometimes attacked. Husbands did not tell their wives and continued to have unprotected sex. Wives did not tell their husbands and mother-to-child transmission meant

that thousands of children were also born with the virus. The complexities of the situation had to be addressed almost every month.

I decided that the doctor in my novel would have the exemplary traits of an excellent medic. He would initially appear to be a man to rely on, to trust. Gradually though the slippage would occur. He would be highly idealistic, then full of pride and eventually it would be his arrogance which would cause his own self-blindness. I studied the real-life case of Dr Brandt, a man who was perceived as an idealist.

He was a thoughtful man, an intellectual, and he took his responsibilities as a physician most seriously...He acknowledged his participation in Aktion T-4, made no apology for the program, and declared it to be justified - justified out of pity for the victim and out of a desire to free the family and loved ones from a lifetime of needless sacrifice. (Gallagher, 1990: 257b)

At the time, there had been plenty of warning from others in the medical profession about the danger of this possible 'slippage', about the possible corruption of power. To take one example from among many, Burleigh cites the distinguished Berlin physician Hufeland who wrote in 1806:

[the doctor] should and must do nothing other than maintaining life; it is not up to him whether that life is happy or unhappy, worthwhile or not, and should he incorporate these perspectives into his trade the consequences would be unforeseeable and the doctor could well become the most dangerous person in the state; if this line is crossed once, with the doctor believing he is entitled to decide upon the necessity of a life, then it only requires a logical progression for him to apply the criteria of worth and therefore unworth, in other instances. (Burleigh, 1994: 15-16)

'The most dangerous person in the state...', and so it was that Dr Binding emerged into the world, and alongside him the characters of Nurse Dyer, Robin and of course, Andre; each complicit and each with their own misguided intentions. I took the name for my doctor from the doctor, Karl Binding, who in 1920, along with the psychiatrist Alfred Hoche, had written an academic paper entitled 'Die Feigabe der Vernichtung lebensunwerten Lebens' or 'Permitting the Destruction of Life Unworthy of Living'. This became the blueprint for the Aktion T-4 Plan and the staunch defence of many of the doctors, including a certain Dr

Brandt, who cited Binding and Hoche. Below is a chilling paragraph from the German translation:

But if that is the case – if there are indeed human lives in whose continued preservation all rational interest has permanently vanished – the legal system confronts the fateful question of whether it is called upon to actively advocate their asocial continuation, in particular also through the fullest application of criminal law, or, under certain conditions, to permit their destruction? In legislative terms, the question could also be posed this way: whether the vigorous continued preservation of such lives, as evidence of the inviolability of life, deserves preference, or whether permitting their termination, to the relief of everyone involved, would seem the lesser evil. (Binding and Hoche, 1920: 1)

I knew that my Dr Binding would have been a phenomenal and wise medical man with an almost clairvoyant aptitude for diagnosis. He would be admired. Too much admired maybe, and like a few doctors I have known, he would be a very bad patient, unable to diagnose his own corruption, his own psychopathy, as in these paragraphs from my novel when he contemplates the possibility of euthanasia:

The Good Doctor had searched his soul. He had taken the Hippocratic Oath and felt he had a firm grasp of medical ethics. What Thorpe-Sinclair and Rennes were suggesting meant that many people with genuine medical needs would potentially die before receiving the benefit they were entitled to. On the other hand The Good Doctor had seen hundreds of his patients commit virtual suicide by refusing to take his advice or the advice of any health professional. Time after time the same patient would stagger in to his surgery, a little more yellow, still smoking, still obese, still whining about how the medication made them queasy when in reality it was the ghastly diet and the litres of cheap vodka they were guzzling. He found their deliberate ignorance interesting but exhausting and perhaps, he thought, Rennes and the idiot Thorpe-Sinclair had a point. It couldn't hurt anyway. Not really. These people were unlikely to be much missed.

'It seems to me to be both kind and practical,' says The Good Doctor Binding to the faces around the table. And the faces blink and nod. 'Ward B in Grassybanks Residential Home is already welcoming new clients and we open Ward C this summer.' (*The Summer Of Love: Part 1, Chapter 7*)

I continued to read further historical testament and analysis such as S. Evans; *Hitler's Forgotten Victims – The Holocaust and The Disabled* (2007) and

Michael S. Bryant; *Confronting the 'Good Death': Nazi Euthanasia on Trial 1945-1953* (2005). I found testimony from disabled survivors (a few) of Dr Mengele in Yehuda Koren and Eilat Negev, *In Our Hearts We Were Giants – The Remarkable Story of the Lilliput Troupe – a Dwarf Family's Survival of the Holocaust* (2004) It was hard to read, but as Evans writes;

The Holocaust, which is part of the shared history of people with disabilities, acts as a warning both to the disability community and to all who care about liberty justice and fairness...The conditions that made the Nazi regime's murderous programmes possible in Germany more than half a century ago - apathy when confronted with affronts on human dignity, the presence of a charismatic leader who devalues and dehumanises anyone different, negative attitudes and stereotypes about people with disabilities, and the manipulation of science and technology to achieve seemingly unthinkable goals – persist today in many parts of the world. We thus cannot assume that the atrocities the Nazis committed against the disabled community were a unique event, never to be repeated. Our own self-interest, as well as our human obligation requires us to continue to explore and remember these events and the conditions in which they occurred. (Evans, 2007: 164-5)

In *The Summer of Love*, I wanted the Holocaust to resonate for the reader without being so explicit that the reader might feel obligated to take a certain stance depending on their own associations with that period. As Maggie Gee attested in her 1996 William Matthews Lecture:

...it would be surprising, really, if any of our activities weren't affected at some level by the Second World War, to which we are still so close in time, and which caused one of the great losses of life in 150,000 years of human history. (Kilic, 2012: 14)

To allow my prose to flow, I decided to ensure I was steeped in the eye-witness accounts. I wanted to be able to shut my eyes and picture some of the men and women involved, walking, talking, making decisions. I needed to 'meet' them, 'understand' them, as far as was imaginatively possible. With regards to the research inquiry and the question of how to construct a readable, engaging novel despite the weight of the issues, my ability to sketch characters that felt 'real', recognisable and three dimensional was certainly boosted by this protracted period of research.

I mined the list of doctors, many distinguished practitioners, who had taken part in the Aktion T-4 Plan and had, in fact, been proactive in engineering and

experimenting on the patients, concocting various ways to kill swiftly on the cheap, including:

Professor Julius Hallervorden - department head, Brain Research, Kaiser Wilhelm Institute, 1938; department head Max Planck Institute of Brain Research, after 1948... He used more than six hundred brains of euthanasia victims in his research.

Dr Max de Crinis - professor of psychiatry, University of Berlin, and director, Psychiatric Department, Charity Hospital; author of books and articles, including a respected study of somatic origins of emotions. Killed himself in 1945. (Gallagher, 1990: 196-7)

The list continues with other names and brief biographies. In my novel, several of these have brief walk-on roles, names tweaked slightly, sometimes the gender changed too, as in this extract from *The Summer Of Love*:

The Good Doctor Binding recognises many of the figures around the table already. The tall string-bean of a fellow is Professor Erwin Bore: Chair of Botany at the South West Agricultural College research centre.

The silver haired woman in the Chanel suit is Dr Maxine de Crinis: Infectious Diseases Unit, London Institute.

The boorish Julian Hallywooden, ophthalmologist and brainstem specialist, is new to him. The man's eyeballs bulge slightly and The Good Doctor guesses Grave's disease. Oddly appropriate for an ophthalmologist.

The baby faced man in black is Professor Fred Pansy: Psychiatry, Royal Manchester Hospital. He smiles and winks too often, thinks The Good Doctor. He finds the man a mite sinister. Then there is his close friend, the handsome and warm Warren Hyde: Professor of Law at Ruskin. (*The Summer of Love*: Part 1, Chapter 7)

Writing using this technique was not to test my readers' historical knowledge. I gained personal confidence knowing I was reflecting aspects of 'real' people through my fiction and this confidence transferred to my work, giving me personal pleasure. Readers who got the connections might receive an additional jolt of pleasure too, like finding a key clue to a crossword, a joke hidden within the text, but recognition of the characters was certainly not essential to enjoying the novel fully, and neither was recognition of some real-life material props.

For instance, right at the very beginning of *The Summer Of Love*, I create an opening vision of a grey ambulance. The ambulance was based on the very ones in Germany that had picked up the disabled children and adults for euthanasia, plucking them from their communities in the villages, towns and cities without protest, in the 1930's. I had not forgotten, from both Liz Crow's *Resistance!* and my research, that the buses that were sent in to collect the disabled were known as the Community Patients Transport Service. The windows of these buses were blacked out and the SS staff wore white coats in an attempt to keep the 'processing' of the victims secret. Even so there are reports of children calling the buses 'murder boxes' and teasing each other with the refrain "You're an idiot! You'll be sent to bake in Hadamar!" Hadamar was one of the 'processing centres' (Evans, 2007: 57).

Inside it is still an ambulance but with the new paint job it looks more like a shortened grey bus, with 'Community Transport Ltd' embellished in bright orange along its sides. It is currently parked up at the Willowside Estate; badly parked, its back wheels sticking out over the white lines as if abandoned in a fit of pique. (*The Summer of Love: Part 1; Chapter 1*)

This also, again with the central research inquiry in mind and how to fictionalise the weighty issue of euthanasia, allowed me to research the T-4 doctors' methods of killing and from there, design my own, or should I say, my character Dr Binding's, own, Chiller Bed:

'The Chiller beds,' says the Mouth, as if in a sales room, 'are perfect for reducing body temperature. Why, you might ask? Well for the same reason that these beds are also fitted with sponge-like filler in the mattresses, so that in addition to chilling, the beds can be lightly sprayed with water. The combination of wet and cold is perfect for the Chiller bed.' (*The Summer of Love: Part 3; Chapter 12*)

2.2 A genre for a disabled protagonist and a discussion on authenticity.

I began the first draft of the novel in 2012. Initially, I had decided that in order to address my question regarding the intersection of creativity and politics, I would utilise the thriller genre. The thriller demands pace, tension and suspense, and this, I reasoned, would be what would carry the reader into and through the gritty realism of welfare Britain. If there were enough high-octane action and brutal adventure, with an engaging private eye and obvious villain, the reader might not mind the subliminal, or not so subliminal, discussion about disability and human rights.

For many years it has become a mark of commonplace courtesy and intellectual rigor to note occasions when racism, sexism, or class bias creep into discourse...Yet there is a strange and really unaccountable silence when the issue of disability is raised: the silence is stranger, too, since so much of the left's criticism has devoted itself to the issue of the body, of the social construction of sexuality and gender. Alternative bodies people this discourse; gay lesbian, hermaphrodite, criminal, medical and so on. But lurking behind these images of transgression and deviance is a much more transgressive and deviant figure; the disabled body. (Davis, 2006: 5)

I needed a disabled protagonist who was not defined by their disability. With regard to this, there were some essential concepts I had to explore in order to deepen my understanding of the current state of play with respect to disability within, and without, literature. It was also important to familiarise myself with work of academics such as Rosemarie Garland Thompson (2002), Rod Michalko (2002), Paul K. Longmore (2003), Georgina Kleege (1998) and David Bolt (2014), amongst others who have analysed representations of disability in art, literature and film. I had to become more informed about both the definitions of 'disability' and the various models of disability, historical and contemporary. These are cogently analysed in the article 'Disability, Definitions, Models, Experience' by Wassermann *et al.* which states:

These different understandings of the relationship of impairment to limitation inform two contrasting approaches to disability, often described as opposing models: the medical and social. The *medical model* understands a disability as a physical or mental impairment of the individual and its personal and social consequences. It regards the limitations faced by people with disabilities as resulting primarily, or solely, from their impairments. In contrast, the *social model* understands

disability as a relation between an individual and her social environment: the exclusion of people with certain physical and mental characteristics from major domains of social life. Their exclusion is manifested not only in deliberate segregation, but in a built environment and organized social activity that preclude or restrict the participation of people seen or labelled as having disabilities.

In their extreme forms, the medical and social models serve to chart the space of possible relationships between impairment and limitation more than to reflect the actual views of individuals or institutions.
(Wasserman *et al.*, 2011: section 2)

I concluded from much of the literature I read and from academic commentary on the texts (Bolt, 2013; Garland Thompson, 1996), that female disabled characters were vastly under-represented in literature. This helped me decide on the sex of my own protagonist. She must be female, and, given my initial concept of a novel in the thriller genre, it seemed appropriate to make the protagonist the narrator, as was regularly the case in this genre (Keene, 2006).

My protagonist should be the sleuth, the private 'lady-dick', the voice-over in the reader's head. I had visions of V I Warshawski, Rebus, Kay Scarpetta and Jack Reacher boiled up and distilled into a single, 'ordinary' woman. My heroine was going to be as smart, tough, and 'sassy' as any of those hard drinking, quick thinking, villain bashing characters, but rooted in the real world of 2013 Britain.

Her disability? I decided to bestow on her the gift of blindness. Not complete blindness. She would see as I did, therefore she would have tunnel vision, and use a guide dog. This would ensure that I could get the essential detail of her disability right. Being visually impaired (VI) myself, I would be able to draw on my own physical and mental experiences and processes swiftly and accurately.

In this role of writer-practitioner (here at the participant researcher end of the spectrum, as discussed in the opening to this thesis p5), and by using my own understanding of living day-to-day with a degenerating sight condition, I was not just thinking of gritty realism or authenticity *per se*. My protagonist would be authentically visually impaired, yes. But for a writer 'authenticity' is more nebulous as a concept.

As I grappled with this concept, I began to realise that the real impact on the novel from utilising my own direct experience is perhaps more to do with empowerment than authenticity. It can be seen as a reaction to my disability being 'written about' by others in the past who may, consciously or not, have exploited it in order to add significance to their own fiction. As the author and winner of the Pen/Bellweather Prize for socially engaged fiction, Susan Nussbaum, notes about her own beautifully crafted debut novel *Good Kings, Bad Kings* (2013), set in an institution for disabled teenagers in the USA:

None of those people writing books and movies that exploited their disabled characters as "symbols" were disabled themselves. And who were these glamorous stars dying to catch that juicy disabled role, to do their best imitations and take home their Oscar? They knew little if anything about the experiences of real disabled people. I knew the world, the jokes, the words, the underground details. I knew all three dimensions, not the tired one dimension they put out there for the public to eat I knew the struggles, the brutality of oppression, the love that held us together. I was the real thing, the authentic article. A genuine crip writer, writing about crips. (Nussbaum, 2013: 303)

I would emphasise that, although I have a visual impairment, I am not a 'blind' writer. Imagination has no physical impairment. I am a writer, full stop. The visual impairment gives me access to a different experience and different viewpoints that I can utilise to further my profession. In *The Summer of Love* I did want to work with a visually impaired character, partly to test my ability to channel my experiences and partly because visual impairment is a fact of life, like having green eyes or dark hair. It is not so exceptional and should not be treated as such.

However, in an ocular-centric world, blindness still evokes a certain ancient response, even in societies that purport to have an enhanced understanding of the human body and a more inclusive attitude. Bolt and Stein, among others, have written extensively on the subject, exploring both ancient mythologies surrounding the blind and the continuing vindication of blindness 'tropes' in contemporary literature and arts and their effect on societal consciousness (Bolt, 2014; Kent, 1989).

It is relevant that my visual impairment, known as Retinitis Pigmentosa, was first diagnosed when I was 21 years old. At the time, I knew no one who was either similarly visually impaired or blind, apart from the occasional Zambian beggars of my childhood, who used to be led from door to door by young children asking for hand-outs, the objects of terrible pity. My response to the possibility of my own total sight loss (as can occur with this condition) was abject, unmitigated, fear. What had I learnt about blindness from literature? Visions of hell from *The Day of the Triffids* (Wyndham, 1979) and *Blindness*, (Saramago, 1997) cavorted with the gnarly one-eyed Fates of Greek mythology and filthy eye-patched pirates in *Treasure Island* (Stevenson, 1883). The blind were to be pitied or avoided, exploited or even hunted like animals. Many authors refused to even contemplate a normal life without sight. It's better to be dead than blind, intimates Kipling in *The Light That Failed* (1891) and Conrad in *The End of the Tether* (1902), where, faced with the onset of blindness, their heroes commit suicide. My future as a globetrotting free spirit suddenly became untenable, unimaginable. When I thought of the blind community I would be joining, I imagined a line of groping, lurching, repulsive beggars, one behind the next, stumbling across my future landscape, and eventually I would have to grasp a shoulder and follow. No one would ever love me. I would end up in a dark corner weaving baskets, head shorn, a thing of pity and horror.

My ignorance of the reality of living with sight loss was hardly my fault given the circumstances. There were no obvious role models for someone with my condition and not even the ophthalmologists could offer any encouragement. They often saw me as 'a condition of the eye' not as 'a person'. Beyond the anatomy, physiology and diseases of the eye, they seemed uninterested in the daily life of their patients.

Blindness itself is, of course, a natural condition, and as a natural condition it knows little change. (It goes without saying that the rapidly changing developments in the medical treatment of blindness are not part of the condition itself.) But, while blindness as such remains unchanged, our understanding of blindness, our views concerning its "meaning", are matters of culture. So is the attitude toward the blind that is largely a result of what people believed that blindness meant. As matters of culture, the interpretation of blindness and the social attitude toward the blind are, of course, prone to historical change. (Barasch, 2001: 3)

By 2012, however, I was over twenty years on from my original diagnosis and had enough experience of living with chronic sight loss to know a new literary model had to be written, a new paradigm sought. People are not defined by their condition. My VI protagonist would not be either.

I investigated further with help from Bolt's book on *The Metanarrative of Blindness: a Re-reading of Twentieth Century Anglophone Writing*, in which he examines representations of blindness in more than forty literary works, including works by Kipling, Joyce, John Millington Synge, Orwell, H G Wells, Sontag and King, describing his work as shedding light on the deficiencies of these representations and sometimes revealing an uncomfortable resonance between these texts and the Anglo-American science of eugenics. (Bolt, 2013). This seemed appropriate given the issues of stigma, separation and potential euthanasia that I would be exploring in the novel manuscript.

His analysis led me to discover a remarkable absence of partially sighted characters in literature and on film. People are either 'blind' or 'sighted'. They may 'go blind' and therefore experience vision impairment on their journey, but there are very few people represented with a chronic condition, stable or not. According to the Royal National Institute for the Blind (RNIB) website, of the two million people with severe sight impairment in UK, only about 4% are totally blind (Slade, 2012), and given that one in every nine people over 60 is living with sight loss, it occurred to me that this left a vast swathe of people unrepresented in fiction and film, myself included. This was a gap I determined to fill with my novel.

I did find some interesting representation of visual impairment when it came to memoir, both in films like *Blue* (Jarman, 1993) and *Black Sun* (Tan, 2005), and in autobiographical writing. There are many examples of excellent disability memoir, Christy Brown's *My Left Foot* (1954) and Jean-Dominique Bauby's *The Diving Bell and the Butterfly* (1997), to name but two. However, with regard to the experience specific to sight loss, and perhaps because I am searching for a deeper connection when reading these, I have found less well-rounded, less active and more passive writing. John Hull's *Touching The Rock* (1990) was given to me by a friend when she heard that I might lose my sight. She said

that the book had moved her greatly but personally I found it rather dull and depressing and quickly lost interest. I suspect that my friend had only glanced at it but presumed that I would find something more powerful within it due to my own circumstance. The book is about Hull's journey to blindness and mixes memoir and flashback, dreams and contemplation, all weighted heavily towards the Christian ideals of 'bearing up' and 'being one with Christ'.

If blindness is a gift, then death is a gift. What shall we give in return for our death? Whatever we are able to give it must be in anticipation for when we receive that final gift, we will have nothing left to give.

But if blindness is a gift and death is a gift, what have we to fear? If darkness is light, then light is darkness....The world, life or death, or the present or the future, all are ours, and we are Christ's... (Hull, 1990: 108)

Need I go on? I strongly suspect that *Touching The Rock* is the kind of book given to people 'like me' i.e. people with a degenerating sight condition, by well-meaning 'normal' friends. This raises the question of who these memoirs are written for. Are they written to give non-disabled people an empathic experience of disability, or to give people becoming disabled a supporting shoulder squeeze? Are they written to shock or shake up the reader, or purely to reaffirm a status quo with a novel-length outpouring of depressing but possibly reassuring 'coming to terms' with being a 'crip'? This confusion can be a problem for a reader, especially within memoir, when someone else's experience, viewed through the lens of their personality, may irritate more than inform. Candia McWilliams, for instance, wrote her memoir *What to Look for in Winter* (2010) when she was blinded with blepharospasm, a condition which causes the eyelid to remain permanently shut. Her writing is sumptuous, lucid and poetic, but her all-consuming, self-pity renders her a lugubrious Eeyore:

That we each invent a world I do not deny...Mine feels unwhole to me at present, without sight and without a presence to give love to, through with many beloved absences, but I know that when I write fiction, I can make something external to myself that is whole. If one cannot daily build love, one must make something. I am digging a hole through the dark.

...and one of the reasons, I am sure, that I have been so imprisoned by my blindness is that I was my eyes, my eyes were how I got to being me. My eyes saw the edges of things and the insides of things and permitted me to write novels about these matters. My eyes gave me jokes that led

me to friends who enjoyed my company. Without my eyes did I still believe?(McWilliams, 2010: 275-6)

There is a tendency for the 'blind' memoir to be either fraught with self-pity or, which in my opinion, is often as bad, plagued by the need to be seen as triumphing over tragedy, with the 'kill or cure' tropes of the disability literary canon casting oblique shadows. Helen Keller, Jacques Lusseyran, Jason Roberts and Ray Charles have all written memoirs about overcoming their 'tragedy' of sight loss to do extraordinary things against all the odds. They may still be disabled, blind 'crips', but they have almost purged themselves of their 'otherness' by their courage and spirit. How, in my own novel, and again referring to the original research enquiry, could I address the issues around living as a disabled person without falling into these traps?

I am grateful to Georgina Kleege who punched a hole in this concept of disabled hero as 'symbol of human fortitude' in her ingenious examination of Helen Keller's life and work, *Blind Rage: Letters to Helen Keller* (2006). In the book, Kleege opens an intimate and lengthy imagined conversation with Keller through a series of letters asking, in fact demanding, that Keller come clean about how she had really felt and what she had really experienced. Kleege notes 'It was as if her need to be an inspirational icon made it impossible for her ever to express any rage, fear or sorrow, even when her experiences would have prompted these emotions in anyone else. By turns, this baffled and infuriated me' (Kleege, 2006: ix).

Reading Kleege, I get the sense that what starts in anger, in accusation, gradually mellows through the interrogation and the evocative and moving imagined re-enactments of events in Helen's life, to a greater understanding:

The subject now is sex. Another aspect of the Helen Keller Myth is that you had no sex life. It's a myth a lot of people work hard to preserve...They say that the reason you were always so prolific and tireless was that you sublimated or repressed your sexuality and used the excess energy to power your work. They are such pains to promote the idea that you were innocent, pure, sexless. Why, Helen? Why is the idea of your sexuality so threatening? There are several answers. One comes from the impulse to make you a saint. Since blindness, deafness, and other impairments have traditionally been associated with sin, to

make yourself admirable, you had to promote the notion of absolute purity. (Kleege, 2006: 45)

There's more than one way to be a human being – that's what you told the world. On the surface, it seems a pretty innocuous statement, but in fact it's quite revolutionary. It forces people to question everything they take for granted as normal. It's a message that needs to be spoken still. (Kleege, 2006:182)

This need for proof of self-worth has morphed into another cultural stereotype occasionally affixed to disabled people and often associated with the Paralympics, the 'super crip' or 'super human'. And from 'super crip' it is not too big a step to 'inspiration porn', as natively coined by the actor and journalist Stella Young. An example of this is the quote by Scott Hamilton, the figure skater and cancer survivor, 'The only disability is a bad attitude', which is often plastered over pictures of physically disabled people, usually children, doing ordinary things. As Young remarks:

Let me be clear about the intent of this inspiration porn; it's there so that non-disabled people can put their worries into perspective. So they can go, "Oh well if that kid who doesn't have any legs can smile while he's having an awesome time, I should never, EVER feel bad about my life..."

In this way, these modified images exceptionalise and objectify those of us they claim to represent...it doesn't matter what their names are, they're just there as objects of inspiration. (Young, 2012)

Is it any wonder that so many of us who have a perceived disability struggle with understanding what is expected of us – should we hide or be heroes, be stoic or sob? Self-awareness and self-representation are surely integral issues for all of us, but how can disabled people approach our own stories when feeling constantly under scrutiny and held up to judgement? Kleege's memoir, *Sight Unseen*, contains one answer as she takes ownership of her difference in a captivating, thought provoking song of self.

I have come full circle. I return to the question which began this book; Do I have the right to call myself blind when I see as much as I do?...When I read braille in public and then comment on the colour of the carpet, or when I carry a white cane into an art gallery, some may denounce me as

fraud or traitor. Others, I hope, will revive their image of blindness. And it's about time. That image is older than Oedipus and could use a new coat of paint. This new image of blindness is blander and more mundane, a mere matter of seeking practical solutions to everyday inconveniences. It will force us to abandon the old clichés that equate blindness with ignorant despair and sight with virtuous wisdom. Surely it's time for some new metaphors. In the meantime, you see things in your way and I'll see them in mine. But when we close our eyes maybe we'll see everything the same. (Kleege, 1998: 227- 228)

I wanted my protagonist to be, like Kleege, fearless in her approach to this perceived vulnerability. I needed her to somehow stand for, and yet stand up for, all of us VI and blind women. I wanted my heroine, in the parlance of the American cinema, to 'kick all kinds of ass', but without having to don a mask and cape. To give her authenticity, she would have to have lived a life that toughened her up, that gave her insight and a certain body confidence. My heroine had to have more than attitude, she had to have experience of actual physical tangling, be it wrestling in bed or fighting out of it. She had to know what it felt like to hit someone hard as well as kiss someone hard.

My original protagonist was, in addition and albeit briefly, mixed heritage. I think this choice was more personal. I wanted to keep the character a little more separated, more stand-alone, 'betwixt and between' all things, and I knew, from experiences of mixed heritage family members, that being 'non-white' in England could still be an alienating factor. I proudly named my heroine Chay Saeed, a play on 'She Said', and a homage to my older sister, which no one understood but me. But by the second draft, Chay had become Alexandra Lyon, no specified background, but named for lions and conquerors!

'...I grow, I prosper:' shouts Edmund in *King Lear*. 'Now, gods stand up for bastards!'(Shakespeare, 1:3)

I knew this woman, Alex, would need a similar shout. 'Now gods stand up for the disabled!'

2.3: A faltering first draft

The first draft of the novel began with Alex in the Job Centre in Cambridge where she is abused by the staff and flummoxed by the interview. At the Job Centre she befriends a young man called Donald. Donald has Asperger's and a dead mother. The dead mother, Alex and her guide dog discover, is still in her bed at Donald's house. Donald had been nursing her through the last stages of cancer and they had discussed the fact that when she died Donald would have to go and get a job, which is why Donald had gone straight to the Job Centre when he couldn't rouse her that morning.

Alex helps him notify the authorities and sort the funeral. To look after Donald, she moves temporarily into Donald's eerie, enormous house. Alex gets work part time as a journalist and Donald finds work as a care assistant at an old people's home where he inadvertently uncovers a government-sponsored scheme to euthanize the elderly. He tells Alex about it and Donald's house becomes the secret centre for a group of activist disabled campaigners led by Alex who set about uncovering and exposing the scheme.

The construction of the plot had been simple to begin with. In light of my research inquiry into the difficulties of writing 'issue heavy' fiction, my aim was to establish the main character as an independent free thinker in a dystopian world of circular interviews and confusing legislation. Alex, as protagonist and the 'voice' of the novel, was intended to lead the reader through, commenting on the world around her as she did so. However, as the first draft was first person and seen from the perspective of someone who was well-educated, middle class, savvy and tuned in to the world, I felt I needed another main character to balance the cynical 'knowingness' of Alex.

As Donald had been outside the system for years nursing his mother, he could be seen as almost an 'innocent', in that he had lived separately from other children and teenagers and was now forced to return to the world of work. With his Asperger's, I thought he might, possibly because of the difficulties he would have with communication and certain forms of imagination, become the person who showed up the inconsistencies in the system. I knew that I was 'using' Donald's disability in a rather heavy-handed way but I hoped that the complexity

of his character, his personal quirks and wit, would nevertheless allow me to construct a multi-dimensional character.

I wrote sixty thousand words before flinging (metaphorically, as it would have been an expensive waste of a computer) the manuscript at the wall.

Why wasn't it working? There were four key problems:

1. Writing in the first person was, in this instance, becoming very limiting.
2. The novel was becoming issue-led and humourless. I wanted to convey the problems I had encountered with the welfare system for instance, through an almost documentary-style confrontation at the Job Centre, based word for word on my own experience. However, when written as a scene with Alex's nervous, earnest narration, it was mere whinging, humourless and irritating.
3. Alex's visual impairment was a hindrance for a first person narrator. It meant that every time she entered a scene or interacted with anyone, I had to spend endless minutes explaining what she could and could not see so that the reader would find her visual impairment convincing. Yet at the same time, as narrator, she had to find ways to give an overview, paint pictures, source clues, notice expressions and so forth. If one of Alex's key chores as a disabled protagonist was to show the world that she wasn't defined by her disability, she was failing abysmally.
4. So too was Donald's character. Although I knew people with Asperger's and autism, I did not feel relaxed about using the condition as a foil to Alex's worldliness. When writing him, the spontaneity disappeared and I felt almost shy, almost rude. I wondered about dropping his 'diagnosis' completely and just allowing him to be an eccentric, unexplained by neurology. Again, if I wanted to write characters who were disabled not merely in terms of their disability, neither confined nor designed by it, Donald was heading in the wrong direction.

I include an example, from the first draft, of Alex's first person narration working unnaturally hard to 'audio-describe' everything for the reader:

We are half way down the elegant avenue when Donald turns left and disappears behind a huge ancient hedge at the corner of one of the larger houses. Chris pulls me forward and into the gloom of a short dark alley. I can smell tree sap and hear insects buzzing past my face but see nothing until I take off my dark glasses. My eyes grab glimpses of sun sprayed through thick overhanging branches. On my right is an ivy-coated wall and dense shrub and trees to the left. I can barely make out my feet and the stony path broken up by tree roots. I stumble and a thin branch whacks my face narrowly missing my eye.

‘Hang on....!’ I say feeling a little like I have just walked into a Grimm fairy tale without even a breadcrumb trail but Donald has disappeared.

‘Eh? Where did he go Chris?’

Chris’s ears are perked but he too seems to have lost sight of the kid. We both stand disorientated. All is quiet, the birds sing, the leaves rustle and then Donald pops back out and says, ‘Why are you standing there?’

It turns out that Donald gets into his house via a large crack in the wall. I have no doubt it is a crack rather than just a hidden entrance. I run my hands along the edges of the gap thick with ivy and feel the loose crumbling brickwork...

I decided that for the next draft of the novel I would cut Donald’s character out entirely as I felt my understanding of his condition was far too limited and his character was becoming a crude and wooden version of the young man I had intended to write.

I would also explore a different access point for the protagonist. She would no longer have to carry the weight of the novel by being the sole narrator. I would set her free by experimenting with multiple voices and perspectives, and in this way re-evaluate my idea of creating an ‘authentic’ single character to connect with the reader. This decision, I felt instinctively, would feed into the research inquiry as a key craft methodology.

Indeed, when I considered again the issue of ‘authenticity’, I realised that it was perhaps more relevant to talk about creating connections with the reader through a narrative ‘empathy’. It may, for instance, be impossible to define what makes the character of a dog in the novel feel ‘authentic’, as neither the reader nor author, I feel justified in saying, will actually have lived life ‘as’ a dog. However, we can discuss more easily how the written dog creates a response in us, through reading, that gives an uncanny sensation of ‘dog’.

Chris can tell many things about humans. This one is older and solidly built, although bits of him don't work as well anymore. Parnell has a plastic hip and the cartilage in his knees is frayed. Chris sees this through combinations of vibration, sound and scent. Just as he can hear the multiple textures in Parnell's voice and smell the man's breakfast on his breath. This is, in dog terms, a 'good man', lovely colours and smells all the way through his body and a relatively rare find. He makes Chris feel easy and that makes a dog happy and playful.

'Wanna play?' he asks. Chris is using a technique of 'request' that involves every fibre of his body, from his heart rate to the angle of his tail. Humans get this, but slowly.

Parnell looks down at Chris's posture and cocked ears.

'You wanna play, boy?'

Well duh..., thinks Chris. (*The Summer of Love: Part 2, Chapter 6*)

Keene states that:

Character identification often invites empathy, even when the fictional character and reader differ from one another in all sorts of practical and obvious ways, but empathy for fictional characters appears to require only minimal elements of identity, situation and feeling, not necessarily complex or realistic. (Keene, 2006: 214)

Her research suggests that, when employing a first person narrative, creating an 'illusion of reality...is not the vital key to forming an empathic response in the reader'. She argues the opposite, that in fact, the reader's perception of a text's fictionality' plays a role in subsequent empathic response by releasing readers from '... the obligations of self-protection through scepticism and suspicion...'

She calls this 'protective fictionality' and adds:

While a fully-fledged political movement, an appropriately inspiring social context, or an emergent structure of feeling promoting change may be necessary for efficacious action to arise out of internalized experience of narrative empathy, readers may respond to those circumstances as a result of earlier reading. (Keene, 2006: 220)

With this idea of 'protective fictionality' in mind, I would no longer place my novel in the real city of Cambridge, UK, but create 'another England' entirely. I would also look at the world through the eyes and noses of both humans and

animals and I would give different characters their own versions of events, showing them making key decisions, separately from Alex, and feeling their own way through the plot.

2.4: Fighting Back: the evolution of BOUDICCA, the Ladies' Defective Agency and the move towards a satirical style.

In 2012, in the real world of austerity and welfare cuts, disabled communities wanted to protest but often found formally protesting, marching and shouting, holding banners aloft and facing down counter protest and police was physically difficult or impossible for many of those with severe conditions or mobility issues. Many protesters became sicker after a rally as a result of the physical and mental stress. As a group we were weak, vulnerable and therefore easily ignored. Disabled people's organisations recognised this and decided that a new strategy utilising social media and the internet was potentially the only way to muster supporters. A group of disabled activists banded together through social media and found enough funding to research and produce the 'Spartacus Report', otherwise known as the 'Responsible Reform Report' which went viral and forced a debate in Parliament over benefit changes (Campbell *et al.*, 2012).

Although the report was subsequently side-lined as further swingeing cuts were put forward, the momentum and excitement built up by the minority movement 'I am Spartacus!' had caused a hugely positive wave of energy within the disabled community. People who had previously been isolated in their bedrooms due to illness or problems of access found solidarity and power through their computers. The key campaigners became well known both within and without the disabled activist movement and included the indomitable Sue Marsh and her blog, 'Diary of a Benefit Scrounger'.

She wrote an open letter to the Leader of the House, John Bercow, on 13th November 2014, in which she stated:

Over the last four years, I've learnt that democracy is merely an illusion. I've learnt that a politician can do or say anything he or she likes and no one will do anything about it at all.

In the case of Iain Duncan Smith, we have seen the results of a failure to govern the governors as never before. He has lied – not "misled" or "misdirected" – to parliament repeatedly...

The results of his lies are clear for all to see. Vulnerable people he promised to support go hungry or are left without care or security. Nearly a million people have been driven to foodbanks. Homelessness has risen, the benefits bill has risen and the housing bill has risen... Universal

credit, Employment and Support Allowance, Personal Independence Payments, all have failed, leaving millions stuck in limbo. (Marsh, 2014) ⁷

In my novel, the Spartacus Report got its sea change, morphing into my own creation, the anonymous activist group, BOUDICCA, named after the Iceni Queen who led an uprising against the occupying Roman Empire (with an indirect 'hat-tip' to the other uprising, the 'I am Spartacus' social media campaign led by the people behind the Spartacus Report.)

BOUDICCA, in *The Summer of Love*, were not just an online community, although they were empowered by the internet. They went further. They took to the streets with spray cans of paint and weapons. BOUDICCA were not going to protest within the law. For all the people who had worked on the real-life Spartacus report – including Karen Sherlock who died in 2012 from a chronic illness compounded by the stress of the struggle to be heard – I invented BOUDICCA to take vengeance.

As Lennard Davis pointed out in his seminal book *Enforcing Normalcy*,

Disabled bodies are not permitted to participate in the erotics of power, in the power of the erotic, in economies of transgression. There has been virtually no liberatory rhetoric – outside of the disability rights movement – tied to prostheses, wheelchairs, colostomy bags, canes, or leg braces. (Davis, 1995: 158)

In these evolving political conditions, I went back to my original research inquiry, beginning to feel that I had the tools to start afresh. I still felt compelled to write a novel that would revolve around the current welfare situation and the idea of

⁷ In a stranger than fiction twist, Sue Marsh was offered and has taken, a job with Maximus, the company taking over from the disgraced ATOS. Many of her blog followers and fellow activists were horrified by this defection into the 'enemies' ranks' but Sue defended herself saying 'Crucially, it's a campaigner's job to change things, not just to make a lot of noise. That noise is supposed to lead society, stakeholders and commentators to the point where real change can be achieved. In the last six years I never felt that was the case, but at this moment in time, finding myself in this exceptionally unexpected situation, I simply believe that I can do more good now, here, by doing this, than I can do with all of my other interests' (Marsh, 2015).

state sponsored euthanasia and I would still retain my disabled female protagonist and the group, BOUDICCA.

We have discussed death. Let us return to sex. My key protagonist, Alex, was going to be both visually impaired and female. I wanted to explore how she felt about her sexuality. I was going to give her genitals and see if she would use them. After all, every other visually impaired and blind woman I knew in the real world had them too. You would not, however, think this from literature. (Kleege, 2006).

As previously mentioned, in the *Metanarrative of Blindness*, Bolt analyses the work of several Anglo American authors and scholars including Maeterlink, Graham, Thomas, Kipling, Kelman, Gide, Tagore and others, holding up their representations of blind and visually impaired people against the back drop of the Eugenics movement of the 19th Century which postulated prevention of procreation of the 'unfit' through segregation and sterilization. His final assertion is that, 'It must be acknowledged, therefore, that representational asexuality contains a psychosocially castrating message, defining people with impaired vision as unfit for procreation' (Bolt, 2005: 18). To address the research inquiry, as regards the issue of equality and disability, it makes sense, therefore, to create blind, VI and other disabled characters who resist the idea of sexless 'crip', whether this last emerges from an outdated reference to purity, the error Kleege diagnoses in Keller, or to deviance (Bolt 2005; Garland-Thompson, 1996). In *The Summer of Love* Alex both enjoys and uses her sexuality. She is a physical being, utilising all senses, even the ones that work differently to others, her eyes. In the real world, sadly, VI and blind women are more prone to negative experiences of sex and sexuality.

In her article, 'Desire Denied: A Bibliographic Overview of Sexual Inequality and Blind Women', Deborah M. Allen examines social science research on blind women's experiences with sexual relationships. She posits that 'the findings suggest that socially constructed barriers marginalize blind women, often resulting in blind women being labelled as asexual. The intersection of ableism and sexism positions many blind women as outsiders who do not possess sexual attractiveness' (Allen, 2006).

Allen cites Wilkerson in clarifying that her understanding of 'sexual agency' is 'not merely as the capacity to choose, engage in, or refuse sex acts, but as a more profound good...involving not only a sense of oneself as a sexual being, but also a large social dimension' (Allen, 2006: 1).

A related trope, that of the helpless, blind woman as prey, is recycled endlessly. There are a plethora of horror films based, for instance, around the idea of blind women as victim, *Jennifer 8* (Robinson, 1992), *Blink* (Apted, 1994), *Wait Until Dark* (Young, 1967), *Julia's Eyes* (Morales, 2010) and many more.

Is it possible to resist these concepts? Elsewhere, Reeve argues that the 'psycho-emotional dimensions of disability' must be negotiated in order that they do not impact negatively on 'identity construction.' She uses Foucault's concept of 'technologies of power' and investigates the ways in which these dimensions are created and maintained within society (Reeve, 2010). She concludes:

Disability identity needs to include aspects of both disability and impairment and to be more complex and inclusive if it is to better represent all disabled people in society...Resisting the psycho-emotional dimensions of disability and 'coming out' as a disabled person challenge the conventional denigrated disabled identities and a form of individual political action...(Reeve, 2010: 505)

I had an idea that I could challenge the conventional "psycho emotional dimensions" of disabled identity through my own fiction and as an answer to the central inquiry. The idea came about thus.

An autoethnographical interlude⁸

A few years ago, I was on my uppers, back at home and searching for work, when my mother passed me the local paper and pointed to an advert for 'voice-over' work. There was almost no information except to say the address and phone number and that there would be adult content so applicants had to be over 18 years. I had a past life as a performer, theatre and radio mostly, and so I arranged an appointment and found my way to a row of industrial buildings in the city centre. I rang a bell. After a while, a small child in school uniform opened the door and told me to head upstairs to the studio where 'Dad' was waiting. I passed a kitchenette crammed full of children in a post-school toast-making frenzy and climbed nosily up several flights of metal stairs to a set of studios jammed with mikes, wires and musical instruments. 'Dad', it turned out, was a jolly middle-aged man, informally dressed in jeans and a cardigan, who apologised about the children downstairs, his 'wife was coming to collect them', and directed me into Studio 2. He was in the recording business, he said, and today was the day he recorded hard-core pornography for a phone sex company. We chatted about the problems of half term and co-ordinating child care, my previous job and so forth as we perused a couple of scripts of the most gratuitous filth I had ever read. He seemed rather proud of them, having 'knocked them out' himself to save money on a scriptwriter. That afternoon I was a dominatrix, an air stewardess and one of a couple out dogging. I had more sex than some adults will have in a lifetime and never had to take my clothes off. Bad sex too. The writing was ghastly and I couldn't quite get past the fact that a gaggle of kids were eating toast and marmite and playing video games downstairs. It was an interesting and lucrative (cash in hand) afternoon, and too surreal to be embarrassing, or more than just uncomfortable. 'Dad' was very pleased with the result and offered me several other gigs, but the very next day I got a job with Guide Dogs For The Blind and moved to Reading, so my life as a voice-over porn star was over in one afternoon. It had been eye opening.

⁸ As postulated in the introduction p2.

It would also be the seed that would grow into The Ladies' Defective Agency (LDA).

What had struck me about the experience was the sheer banality of it. It was just a job. None of it was live interaction, it was all anonymous. In the studio, 'Dad' the engineer could tune the voices up or down; a high voice could be lowered, a low voice given a bit of tremulous treble. Pretty much anyone, with a little coaching, could read: 'Dad' had asked me if I knew of any Asian or older women who might need to make some money. 'They are impossible to find but there is so much demand,' he had sighed. 'If only they could see there was nothing to be worried about.'

I had done the recordings in my outdoor clothes, trainers still on, little signal cane folded away in my bag. I could have done it in a wheelchair. I could have done it limbless, with half a face, and still men would have believed they were being chided by an Amazonian goddess in fishnets and leather...Lie back, shut those eyes and ...American Express? That will do nicely.

That afternoon, I conceived the Ladies' Defective Agency (with apologies to Alexander McCall Smith)⁹:

The lift grinds up and rocks to a stop. Alex, still holding on, pulls on the handle and the metal door rolls back to reveal an entirely different setting. The same huge warehouse space as below but bright and white and humming with activity. Rows of small booths line a wide walkway giving an almost end of the pier feeling to the sunny room. Each booth is brightly painted in sweet pastels and gorgeous lush plants flow from pots and hanging baskets, from window sills and ceiling. Alex can make out walls hung with art, photographic, abstract or classical she can't be sure from this distance. As Alex's eyes adjust, in so far as they can, to the change in light, Jules gently tugs her over to a large reception desk manned by a young woman in headphones. All around there is the muted sound of phones and low chatter.

Telesales. Alex's heart sinks. 'I hate telesales'.

Jules nods at her kindly. 'Okay. You are to see Kitty. I think she will be about ten minutes. I hope you do hang around. It's not all about the

⁹ A. McCall Smith, *The No 1 Ladies Detective Agency* 1998.

sex,' she says with a wink and turns on her heel. 'I'll organise us some tea,' she calls over her shoulder.

Alex is left staring blankly at the receptionist. 'What did she mean, "It's not all about the sex?"'

The receptionist glances up from tapping her keyboard. 'Hi, I'm Laverne. I'll just be a minute,' she says to the air next to Alex. *Her eyes think Alex. There is something up with her eyes.* The receptionist is blind. *Oh thinks Alex. Oh and oh.*

Scanning, peering around the space. Yes. Everyone in her tunnel of sight is female *and...and...and...they all have well something...other.* There are women in wheelchairs, lots of women in wheelchairs in fact, as well as on buggies, with crutches, with hearing aids, with scars and with worse. There are little women and twisted women, half women and whole women, there are old women and there are even a couple of who look like children.

'The Ladies Defective Agency?' muses Alex. 'Very bloody funny.'*(The Summer of Love: Part 2, Chapter 3)*

'Very bloody funny,' was definitely a way forward. Humour bubbled up through the descriptions of the LDA and yet there was still a sense of sadness and dark desperation. As I researched this new approach, I came across the phenomenal *This Way for the Gas, Ladies and Gentlemen* by Tadeuz Borowski, a book so dark, so infected with horror, so bloody and terrifying that I could only read a few pages at a time before having to put the book down and walk away. The novel is a collection of short stories based on Borowski's experiences at the Auschwitz death camp, each story narrated in such a way that the reader is twisted into the narrative and forced to confront head-on the worst atrocities with a bitter chilling laugh.

Borowski 'fictionalises' the horror using his alter ego, the prisoner Tadek, as narrator, tricking the reader into complicity with his dancing prose and acerbic sharp wit. Is it satire? I am not sure if the situation he conveys in Auschwitz can be satirised, but there is a very dark, dry humour. Our knowledge that this is not really 'a fiction' adds a further level of deeply disconcerting sickness in the reader. His novel is literally hell to read.

It felt important to analyse the reason why his use of a fictionalised Auschwitz, an 'other' Auschwitz, is, to me, so much more distressing than the

autobiographies, biographies and historical documentation to read. Perhaps because there is no distance, no 'this happened in a time previous' to filter the experience. Tadek, the narrator, is in it right up to his neck, living as a witness, a scavenger, an enforcer and a killer. He is often dead-pan, reporting, watching, and as he watches and bears witness, so do we, the reader.

'So you're still alive, Abbie? And what's new with you?'

'Not much. Just gassed a Czech transport.'

'That I know. I mean personally?'

'Personally? What sort of 'personally' is there for me? The oven, the barracks, back to the oven...Have I got anybody around here? Well, if you really want to know what 'personally' – we figured out a new way to burn people. Want to hear about it?'

I indicated polite interest.

'Well then, you take four little kids with plenty of hair on their heads, then stick their heads together and light the hair. The rest burns by itself and in no time at all the whole business is *gemacht*.'

'Congratulations,' I say drily and with very little enthusiasm. (Borowski, 1976: 114)

Borowitz has created his 'other' Auschwitz. I thought I might use a similar technique to create my 'other' England, freeing myself from the detailed simulacrum of Cambridge I had been working on previously. I could inhabit other voices, other bodies. I could report terror without flinching and without being too obviously partisan or proselytising.

In a somewhat dry academic study it is argued:

...that essence of humour can be categorised as possibilities/obstacles and weapon/protection. Humour has affects and functions on individuals. Empathy is a prerequisite for the use of humour...Humour can serve as a means to bridge the mental and intellectual distance between people of different backgrounds, cultures, etc. Humour is an important ingredient – a 'bridge' – in the close interaction between countries and people. Laughter is indeed a language which can be understood by everyone and efficiently ease difficult encounters (Olsson *et al.*, 2002: 26)

I did want to employ humour, but going beyond just 'spoofing' or being wry and witty meant irony, exaggeration and ridicule, and seemed, although appropriate,

potentially a dangerous route. I was anxious about achieving a balance; neither high farce nor pure vitriol.

My supervisor and I had begun to discuss the possibility of utilising satire in a style similar to Heller's *Catch 22* (1961) or even Spike Milligan's *Adolf Hitler; My Part In His Downfall* (1971). Could I achieve a 'satire' that would encourage compassion? Milligan once said of his own novellas about the war that he wasn't an intellectual so '...(I) can't do satire but I felt violently.' (BBC 4, 2014) I feel he was being a touch disingenuous. Firstly there is no qualification for being an 'intellectual' apart from having and using one's intelligence; secondly does one have to be an intellectual to write a true satire? I certainly 'felt violently', and satire might be the key to allowing that expression safely.

In Megan LeBoeuf's analysis 'The Power of Ridicule: An Analysis of Satire' (2007) she defined satire as any piece 'be it literary, artistic, spoken or otherwise presented' which includes criticism, irony and implicitness. As she writes:

Satire is not an overt statement and it does not come to an explicit verdict, but rather the critiqued behaviour deconstructs itself within the satirical work by being obviously absurd, most often because it is exaggerated or taken out of its normal context. (LeBoeuf, 2007: 5)

She also points to the fact that satire is a very useful tool for voicing criticism in 'unstable' and I would add, unsafe, times. Had Chaucer, back at the tail end of the 14th century, been actively, publically vocal about corruption in the Catholic Church, he might well have been labelled a heretic and a heathen, been excluded, discredited and perhaps worse. Instead he wrote *The Canterbury Tales*. Le Boeuf mentions others who also chose satire over direct intervention, including Thomas Moore, Jonathan Swift and Mark Twain¹⁰. Contemporary

¹⁰ It is Twain who opens his 1884 satire on southern American culture and in particular, religion and racism, 'The Adventures of Huckleberry Finn', with the words "Persons attempting to find a motive in this narrative will be prosecuted; persons attempting to find a moral in it will be banished, persons attempting to find a plot in it will be shot." This is a perfect satirical shot of 'double speak' (Orwell: 1949) which ironically steers the reader in exactly the direction of ethical and moral hide-and-seek that is intended by Twain from the outset.

novelists, including Weldon, Amis, Self, Evaristo, Adams, Pratchett, Palanhuik...the list goes on, have all applied the sharp bite of the pen before the sword.

As the writer-practitioner, grappling with political issues of the day, satire seemed a sensible way forward. It would allow me to target what I saw as cruelty and hypocrisy without alienating my readers, and weaving it into a novel would be a much more playful and possibly cathartic process than chaining myself to the railings of the Houses of Parliament.

And it came easily. The satire immediately found its place in the next drafts of the novel, slicing through various scenes like a scalpel; the banality of Job Central, for instance. The dreaded agency ATOS became...what else? TOSA. How much more enjoyable was it both to write and read Alex's job interview with my poor jaundiced tongue lodged firmly in my cheek:-

Today Alex has a new Motivation and Empowerment Officer (MEO). She is small and plump with a pink face and looks rather sweet although clearly anxious. She reminds Alex of a white mouse released into its first laboratory maze.

'Good Morning. My name's Lucy,' she says and leans over the desk to proffer a hand. 'How are...?' Before she completes that sentence she freezes. Already, in her first twenty seconds she has committed two grave mistakes. One, she has offered to shake Alex's hand. Two, and worse even than that, she has almost asked the client how they are...No, no, no! This is entirely outside of TOSA protocol when dealing with crips. NEVER make physical contact and NEVER ask them how they are! Apparently this implies interest in the health of the crip client which could lead to what they call 'negative empathic stereotyping'. *Crips* by definition have health problems. TOSA does not believe in allowing anyone to dwell on this aspect of the client. Including the client. Positivity is key for the work-shy.

Lucy is still frozen.

'Hi, Lucy. Nice to meet you.' Alex, amused, pretends she hasn't noticed Lucy's extended hand and sits. Lucy glances over her shoulder in case her faux pas has been noticed by her supervisor. It hasn't. She is lucky. She plonks back into her seat and picks up Alex's file.

'Alexandra? Alex? Yes, well what can I do for you today? According to our records you have a placement already. It says here you saw my colleague Ishmael three months ago?'

Ishmael, the previous incumbent, had been a delightful and ineffective man who laughed an awful lot and shook his head in a weary 'haven't we seen it all now' kind of way. He had organised Alex her current part time placement at the local newspaper. For this TOSA had received a large wad of cash from the government. If Alex stays in the job for over six months they will get another large pay-out.

'Is there a problem?' Lucy is rummaging through Alex's file.

'The thing is Lucy, it is a part-time placement.' Alex leans in talking low, as if Lucy is a good friend at a bar. 'I am therefore, still not actually in paid employment. Having previously had actual paid work, I feel I could do a great deal better.'

'Is there a problem?'

Lucy's supervisor has crept up behind her like Nosferatu, only with a clipboard. He doesn't introduce himself but leans over Lucy and picks up Alex's file.

'I am sorry,' Alex says although she isn't. She is irritated. 'You are reading my file so you obviously know who I am, but you? You are...?'

He is wearing gold-rimmed spectacles purely so he can glare at people over the top of them. He does so now at Alex.

'My name is Mr. Timms and I am Lucy's supervisor. I see your file is marked with a silver star. That is excellent. We have already been able to place you in work'. (*The Summer of Love: Part 1, Chapter 6*)

It worked too with the sketching of certain characters, especially the politicians. I had actual MPs in my mind when I wrote characters like John Thorpe-Sinclair and Stella Binding and, like a cartoonist, had great fun exaggerating particular traits in order to create metaphor, not to 'spoon' or 'insult' as below;

08.00am

John Thorpe-Sinclair is on the bog. He has done his morning exercises, the rowing machine, a few pull downs and push-ups, some sit-ups, the usual. He has showered with some ghastly scented soap stuff that Wilma insists on, no shampoo as no point with such little hair. He has breakfasted as he always does on coffee, eggs and toast with Seville orange marmalade and now he is on the bog. All on schedule. He likes to keep to a schedule. He believes it is one of the many things that make him a success in life. Schedules, hard work and damn good bowels. No

chance of colon cancer here, no sir! He squeezes gently, enjoying the sensation of tightness then release. A healthy man. (*The Summer of Love*: Part 3, Chapter 2)

Another style idea that kept coming to my mind was based on the poem by Hilaire Belloc, '*Matilda*' (1907), which I had learnt by heart as a child and which has the subtitle par excellence: 'Matilda, who told lies and was burned to death'. I had always been fascinated by the chilling little satirical poems and cartoons of Belloc. There was something of the creepy horror of *Der Struwwelpeter* by Hoffman (1845), and of the Grimms' fairy stories.

Thinking of 'tales' and stories, I began to write little chapter headings and this again seemed to allow me to write more playfully, even though the subject matter was anything but playful. I would write a chapter heading for instance 'In Which Mosh misses his Baby and Andre breaks several fingers,' and then the scene would shape up quickly and efficiently around the heading. It also seemed to create a 'storytelling' distance and again, a lightness which contrasted powerfully with the often distressing action and description within the chapter.

2.5: Discovering alternate voices

One way in which I trained my creative brain to take leaps and find other foot-and hand-holds on the imaginary world, was by taking time out to 'play'. I experimented by free writing for instance, taking a particular character and/or scene and just letting the visions ooze through my brain and into the computer without editing or even attempting to make sense. This occasionally gave greater insight into the characters I had created or showed me a doorway out of a writing block. Other ways of pushing at the boundaries included writing scenes as if for a screenplay, a kind of visual sketching. This was useful in giving me alternate sight lines, visual twists and a way of reworking dialogue.

We are rushing faster than the wind over an alien white sea; skimming over the glistening, unbroken surface that stretches away to the horizon. Faster now! The horizon is a thin curved black line against the white and pink of the sky but that black line is thickening. There is a far off roar and beneath us the gelatinous surface of the strange sea quivers like jelly. The black line is now a band, now a thick wavering wall, growing in height, clambering into the sky, coming at us as fast as we are pelting towards it. A tsunami and we are heading right into its stomach.

A tear forms in the corner of a fat man's eye and plops out onto his cheek. The pores on his skin are little black dots magnified through the droplet which slides down to commingle with the milkier pearls of sweat on his chin. His lips tremble and his nostrils flare.

GROMOND: HIV!

Droplets fly from his chin.

GROMOND: HIV! I'll take HIV!

TERRY: I knew it. I bloody knew it. Damn he was quick off the draw.

Two people, TERRY overweight, denim jacket, balding with a ponytail and CHAY tall, broad shouldered, large busted and lots of frizzy dark hair - are watching the man on a small monitor in a darkened room. The monitor is on a laptop propped up on a sink. (Bush: experimental writing)

It was during these experiments that I began playing with a voice for the guide dog, Chris, which in the previous draft had not existed. I was looking for different points of view and, finding out that dogs have 225 million scent receptors as compared to our paltry 20 million, thought a dog would experience his or her entire world through stink.

CHRIS: (VO): Are we getting the feeling that these so called 'terrorists' are not what they seem? Boudicca's hammer is real enough and she would use it to. She is on fire with rage and grief. The smell of a certain type of grief is almost exactly like *Stachybotrys Chartarum* and is one of the few stinks we all agree is to be feared because, like black mould on wet hay, it has the potential to be toxic to all who ingest it.

In her brassiere she has an old piece of (tissue?) paper that smells still of Chanel No 5, the same jasmine, rose and aldehyde enhanced spray that Chay occasionally uses. I would guess it is a letter of some sort. It has been against her skin a long time too. The sore, soft pink skin beneath the straps is permanently suffused with the scent of sultry summer nights.

Oh...and take a deep inhale. She is also full of cancer in spite of having post-operative radiation therapy. Her essence smells scorched inside and out, poor woman. (Bush; experimental writing)

Although this did not feel right, not 'dog' enough, too anthropomorphised, the experiment triggered ideas that would later lead to entire sections of the novel given over to 'dog' and to the pulsing, sensual, simplicity of Chris. He was such a pleasure to write, and I only had to turn to my own guide dog Grace for inspiration.

The Dog's Prologue

There is a scuffling, squeaking noise coming from the grate in the gutter. Chris lowers his snout and scents rotting leaf mould, cigarette butts and the less subtle smells of shitty water and rat piss. The rats are freaking out about something...something big floating in the sewer beneath the pavement. He can sense their excitement; their eager little bellies growling with anticipation. They are holding a sort of 'rat forum' or what Alex would call 'a mischief of rats'. She prides herself on the weirder names of animal groups. Chris's favourite is a 'nuisance of cats.' He shakes his head to focus and lowers his muzzle again.

The rats are getting more obstreperous. They only ever get this excited over food or flooding. Chris hasn't smelt rain for several days so he is guessing it's the former.

He whimpers down to the rats but they are too agitated to respond. Rats and dogs can speak to each other although not as humans do. Animals use sound and stink but mostly life fuzz, the electricity that holds all component atoms together. It is a kind of vibration, more than anything else.

'What is it?' Chris asks the rats.

'Scrumptious plenty of! More food, more sex, more babies, more rats!
Scrumptious plenty!'

Chris is happy for them but he is a dog and so there is also a part of him anxious to know what food exactly and if he can get his chops around it too.

And then the rats rush away and in their wake Chris smells the floating thing and he is horrified. His hackles rise and his ears flatten.

'What the hell...?' he whines. (*The Summer of Love: Prologue*)

As a response to the research inquiry of this thesis and the key problems posed by *The Summer of Love*, i.e. would the weight of the political issues that the novel intends to discuss flatten the work or appear partisan or divisive? How is it possible to capture difficult truths from within an ever-changing political and social landscape in prose with both humour and insight? – The dog's voice made a profound impact. As I mentioned, he was a joy to write, and I hoped that this joy would resonate with the readers too, easing them through the bleaker passages of the novel.

But how could I possibly tell if my decisions on style, genre, protagonist, plot, voice were working together to create a novel that was issue-driven but readable, and, I hoped, ultimately, engrossing and powerful?

Chapter 3: The Book Club Experiment

3.1 Incentive:

Until the moment an unpublished novel is read, it hangs in the world like a literary version of Schrodinger's cat (Schrödinger, 1935). Is it a live novel or a dead novel? Will opening the book and reading release poison or release the purring puss? The only way to know if the novel is readable, accessible and engages an audience in the subject matter is to hand it over to an audience for feedback.

However, my novel, *The Summer of Love*, was the key component of a PhD and as yet unpublished. This made sourcing a readership, other than fellow PhD students, more problematic, and I wondered whether there could be another way in which to test the novel's impact on the public whilst still in its third draft.

After contemplating various 'focus group' options and after discussion with my supervisors, I decided to approach a local book club and ask for their assistance. I was lucky to find that my study support, Dr Jennie Brunton, was already part of a local book club. She became the invaluable interface between myself, the manuscript and the participants.

On investigation, I could find no evidence that this experiment had been trialled before by Creative Writing PhD students at Bath Spa University. I decided, therefore, to create my own version of a 'focus group', but adapt it to be more amenable to the informality of the book club.

3.2 Method:

A research ethics approval form was submitted as part of Bath Spa University's Research Ethics Committee approval, with the details of the proposed experiment. When this was signed off, I proceeded. Fifteen draft manuscripts of the third draft of the novel were then printed off and bound into simple A5 'books' with plain white cardboard covers for more accessible reading.

After researching online for examples of generic book club questions, (e.g. Lombardi, 2015), I wrote a cover letter explaining the experiment and how it might assist me in my role of the author, in developing my PhD. I also designed an unstructured questionnaire that included twelve open questions to encourage discussion around some of the characters and issues driving the novel. The cover letter and questions were intended to be read aloud by the book club moderator and used to create discussion. The questions would also be available in hard copy or via the internet so that people could personalise their responses or give greater detail if they wished.

Dr Brunton volunteered to pilot the experiment by reading through the proposed cover letter and questionnaire before moderating at the selected book club meeting. As a result of that initial read through, she requested minor edits to the cover letter and questionnaire in order to keep it more informal.

Fifteen packs containing the manuscript, cover letter and questionnaire were put together and a number of these were taken to the monthly meeting of the book club. Dr Brunton was then able to explain the contents of the packs, run through the questions and offer the packs to those who wished to participate. It was agreed by all that the novel and questions would be discussed at the following book club monthly meeting.

The moderator requested, on behalf of the book club, that this meeting set to review the novel would be kept informal and conform to their monthly method of gathering. The author was not to be present as it was felt this might discourage participants from speaking their mind. The evening was not to be recorded either, for this same reason. As mentioned, in order to ensure privacy and

encourage a more detailed response, the questionnaire was also emailed to all who wanted to participate.

3.3 Participants:

The eventual participants included five volunteers from the book club and seven other local volunteers who expressed an interest. The book club regulars were women over 40, mostly retired and living within walking distance of each other in Corsham, a small town in Wiltshire where the University's Graduate School is based. The others were a mix of professional men and women between 30 and 50 years old, who had expressed an interest in reading and discussing fiction and had been personally invited to participate by the author. All written responses to the questionnaire were sent to Dr Brunton, who kindly compiled the data.

3.4 Responses:

The evening meeting of the book club provided a lively discussion. People had, almost exclusively, enjoyed reading the novel, although they acknowledged the difficult subject matter. The majority admitted they had not read about the issues raised in a fictional format before. They felt the novel engaged them and there was a very strong positive reaction to the detailed visualisation within the work and to both the character of Alex and her guide dog, Chris. In all, 12 of the 15 volunteers sent through their feedback and we were able to compile some useful data from the 150 responses to the proposed questions. (The cover letter, questionnaire and all responses have been appended to the end of the thesis as appendix 2.)

3.5 Analysis:

Given that this was quite a rudimentary experiment, the analysis would be limited in terms of specificity. Some questions were easier to analyse than others. I looked through the feedback and then took specific questions and looked at them utilising this 'cluster of concepts':

- Frequency – How often was a concept mentioned?
- Extensiveness – How many different people mentioned the concept?
- Intensity – How much passion or force was behind the comments?
- Specificity – How much detail was provided by respondents?

- Internal consistency – Did individual participants remain consistent in their views?
- Participant perception of importance – Did participants cite this as an important concept? (Krueger *et al.*, 2015: 147)

The feedback was extremely positive and often passionate. Several participants gave detailed notes in response to each question and others responded with short sentences. When taking the major issues of welfare, disability and politics and each of the key craft developments, i.e. satire and humour, multiple perspectives, 'protective fictionality' and historical resonance, we see responses such as:

Q1A.i: I enjoyed it and the unusual perspective of a disabled person trying to survive in the current UK benefit regime. I have been there and I believe it accurately portrays the absurdity and power games that go on. I also liked the honesty about being a woman in the West, having sex without shame.

Q1A.I: I found it exhilarating and emotional; I think that the narrative was so informal, hilarious and chatty that sometimes the weight of the subject matter really crept up on you.

Q2.h: Degradation of the welfare state, exploration of human relationships/humanity, individual characters, euthanasia, power of human action/civil society, scary power and the brutality of the mob, 'group-think', extreme nationalism, scapegoating... Love in all its different forms was explored in the relationships the different characters have with each other etc, but it was more of an apocalyptic, dystopian tale for me; a warning of what the future could be, a stark reminder of where we are, what has been before. (I'm from a German Studies background so it was reminiscent of a warning from history for me re: euthanasia and other related policies) and what can easily be in the future if citizens aren't informed, blindly follow, don't act/protest, oppose the state etc.

Q4.i: I found Alex to be very realistic; forget about disabled characters in books. Alex was like the real life disabled people I've met, full of dark humour and courage... I thought she was very authentic. I definitely related to her as a genuine person.

Q5.e: Tanvi's writing of Chris is – for me – completely credible, except she has thought so deeply into his character, his perceptions and thought processes that he is fully formed and as strong as Alex herself: several times I had welling tears. Never come across such a serious and honest, compassionate depiction of a dog.

Q7.b: Probably would not have read it at all without the humour.

The response to Dr Binding was divided: eight very positive, three negative and one neutral. There were mixed feelings too about the ending, with the ratio of

seven positive responses, three negative and two neutral. This was consistent with the individual participants' relationship to the book:

Q6.h: Sinister, cold, self-serving, cowardly in the end although initially we are given to believe he is kind, good willing to help. Kind of like a mild Demon headmaster, with power/reputation to influence others.

Q10.i: I liked the 'performance' inside the hospital and the storm, but the fact that politicians and Dr Binding got off Scott free – however realistic because none of those bastards seem to pay for what they do – takes the joy off the ending. Even Alex runs away in the end. I guess I wish I could see things change, but they are unlikely to do that for a while and I've done my fair share of running away: that's all you can do when you don't have the power to implement lasting change. So the ending is realistic but sad.

Although this feedback had mostly been extremely positive, the experiment did result in some mixed feelings from me, as author. Initially, on handing out the manuscript, I became very anxious that people might not enjoy the book, find it gruelling to read or badly written. I became nervous about reading the responses and was very glad when Dr Brunton volunteered to help me compile all of the feedback.

3.6 How did the feedback affect the writing of the manuscript?

The feedback was, as mentioned, overwhelmingly positive and gave me, as writer-practitioner, a greater sense of confidence and a deeper belief in the multiple perspective approach and satirical take on the plot and characters. I understood, as a reader myself, that the novel would be more accessible to some than others; perhaps due to background, shared experience and political inclination and so forth. Questions raised in the feedback about characters or style were considered but in the end there was only one minor adjustment I felt I wanted to make, namely to tie up a loose end of plot involving the dead body Chris smells in 'The Dog's Prologue'. On balance, the feedback showed me that *The Summer Of Love* was indeed answering the research inquiry positively.

The research inquiry asked the questions: Would the weight of the political issues that the novel intends to discuss flatten the work or appear partisan or divisive? Is it possible for this novelist to capture difficult truths from within an ever-changing political and social landscape in prose with both humour and insight? The answer, from the Book Club Experiment, I felt strongly, was 'yes'.

Later, when attempting to assess the results, it became clear that an early partnership with a social scientist on the project might well have made the data analysis swifter and more effective. Certainly the questions could have been better designed to tease out more specific feedback and potentially there could have been more than one reading group, reflecting a broader community.

In the long term, I found the experiment both exciting and positive but I was lucky. Had there been a very aggressive response or a general antipathy towards the book, it may well have caused me to mistrust my own instincts as a writer and rethink the novel.

Conclusion

The hegemony of normalcy is, like other hegemonic practices, so effective because of its invisibility. Normalcy is the degree zero of modern existence. Only when the veil is torn from the bland face of the average, only when the hidden political and social injuries are revealed behind the mask of benevolence, only when the hazardous environment designed to be the comfort zone of the normal is shown in all its pitfalls and traps that create disability – only then will we begin to face and feel each other in all the rich variety and difference of our bodies, our minds, and our outlooks. (Davis, 1995: 170-171)

The Summer of Love, I believe, rises to the challenge of the original research inquiry. I asked how is it possible to write fiction exploring political issues such as the state's treatment of disabled people and the stigmatisation of welfare dependents, without flattening the story or appearing partisan or divisive? Is it possible for this novelist to capture difficult truths from the political and social landscape in prose that combines humour with insight?

I had set out to write a novel that would bring forward challenging ideas about compassion, human rights and equality, about disability and normalcy. I wanted to reflect my own worst nightmares about the current welfare changes and their impact on disabled and vulnerable people, whilst also commenting on the current climate of shaming, blaming and scapegoating others. I needed to find creative ways to engage and connect with readers from multiple backgrounds and cultures. My intention in writing a political novel was to create understanding and potential shifts of perspective from my readership.

Through utilising my own personal experience, through extensive research and by experimenting with plot, style, genre and character, I hope I was able to draw out the integral issues without flattening the work whilst also retaining humour and pace to ensure an exhilarating read. Key to this, were the four major craft decisions identified through research and experimentation:

- Research of and immersion in historical texts, archive and witness testimony in order to write scenarios and characters that would create an

disturbing and eerie resonance with the T-4 Aktion plans of Nazi Germany.

- To conscientiously develop a fully rounded, three-dimensional disabled protagonist, full of flaws and fears but engaging and believable, in order to reflect our shared human experience and not just a 'disabled' experience. She would resist and negotiate the stereotypes normally ascribed to a visually impaired character.
- The use of satire and humour to create further narrative empathy through a shared, cathartic response of laughter followed by understanding.
- And finally, employing the notion of 'protective fictionality', allowing the reader to escape from the colder 'real world' of 2013 Britain and relax into a slightly more fantastical 'Other England', where they could inhabit the minds of dogs, crows and storms as well as people. This was done in the hope that a more relaxed reader would be a more amenable, empathic and absorbed one.

If indeed, as the results of the book club experiment encourage me to think, *The Summer of Love* manages to create empathic connections with its readers while also keeping them entertained, this may lead to a greater understanding of the current climate of hostility and shame faced by vulnerable and disabled people in UK today. To quote Fay Weldon, 'In essence that's all a novel is. Something to be proved, which, once proved, satisfies both writer and reader' (Weldon, 2015).

Appendices:

Appendix 1:

Allport's Scale of Prejudice, from: The Nature of Prejudice: Gordon W. Allport (1954)

Acting Out Prejudice...

1. *Antilocution*. Most people who have prejudices talk about them. With like-minded friends, occasionally with strangers, they may express their antagonism freely. But many people never go beyond this mild degree of anti-pathetic action.
 2. *Avoidance*. If the prejudice is more intense, it leads the individual to avoid members of the disliked group, even perhaps at the cost of considerable inconvenience. In this case, the bearer of prejudice does not directly inflict harm on the group he dislikes. He takes the burden of accommodation and withdrawal entirely upon himself.
 3. *Discrimination*. Here the prejudiced person makes detrimental distinctions of an active sort. He undertakes to exclude all members of the group in question from certain types of employment, from residential housing, political rights, educational or recreational opportunities, churches, hospitals, or from some other social privileges. Segregation is an institutionalized form of discrimination, enforced legally or by common custom.
 4. *Physical attack*. Under conditions of heightened emotion prejudice may lead to acts of violence or semi violence. An unwanted Negro family may be forcibly ejected from a neighbourhood, or so severely threatened that it leaves in fear. Gravestones in Jewish cemeteries may be desecrated. The Northside's Italian gang may lie in wait for the Southside's Irish gang.
 5. *Extermination*. Lynchings, pogroms, massacres, and Hitlerian program of genocide mark the ultimate degree of violent expression of prejudice.
- (p14)

Appendix 2: Book Club Experiment: Cover Letter, Questionnaire and Responses

Cover Letter:

Dear Book Club friend,

Dec 2014

Thank you so much for agreeing to have a read of my new novel 'The Summer of Love.' I am hugely grateful because any response you have to the manuscript, good OR bad, will be invaluable in helping me evaluate the book's impact and will feedback into my PhD thesis.

I have included in this pack a hard copy of the manuscript and a list of questions for you to consider once you have read the book. Please do not feel you have to answer each and every question – (although, of course, that would be great!) And I don't want you to feel that you need to respond in great detail. Even a one word response would be useful.

Some of you may find the book isn't really 'your thing' or that you couldn't get through it. That too is absolutely fine. Just let me know.

And, if you would rather just discuss the questions verbally at the book group meeting, that would work too.

Remember that this is a third draft and not close proofed, so there may be (will be) a few mistakes. You may find some you want to point out but please DO NOT mark on the actual manuscript as we will need them returned for reuse. (We will collect them at the next meeting or you can drop them at Corsham Court reception or at Jennie's.)

And finally, as the novel is as yet unpublished and in draft form, please don't share it with anyone else.

I really hope that you enjoy it and thank you so much once again,

Tanvir Bush

[Contact details redacted]

Questions:

1. How would you sum up your experience of the book?
 - 1a. How did you feel reading it – amused, sad, disturbed, confused, bored... or some other reaction?
2. What in your opinion are the main ideas or themes that this novel explores? Was the title a clue to a theme? Do you feel it is a good title for the book?
3. Were you engaged immediately, or did it take you a while to 'get into it'? Is it a plot driven book, a fast paced page turner? Or does the story unfold slowly with a focus on character development? Were you surprised by the plot's complications or did you find it predictable, even formulaic?
4. Disabled people often complain that books written by non-disabled writers can't authentically represent disabled characters. How do the disabled characters in this book compare with disabled characters in other books you've read? Did you find the character of Alex authentic, could you relate to her? How about the women of the Ladies Defective Agency?
5. What does Chris's perspective bring to the book? Is he just light relief or does he bring a deeper resonance to the story?
6. What do we learn about the character of Dr Binding? Does he grow and change through the book? Is he a three dimensional character, would he be recognisable in the real world? How about Andre, Mosh, Jenny...?
7. Did you find the humour made the novel a better read? For instance, some of the issues around welfare cuts and euthanasia were presented satirically. Did this enhance or detract from the underlying issues and themes?
8. In terms of the way the book is structured, do you feel the shifting view points were helpful in reflecting different perspectives?

9. Are there passages that struck you as insightful or profound? Perhaps a bit of dialogue that's funny or poignant or that encapsulates a character? Maybe there is a particular comment that states the book's thematic concerns?

10. Is the ending satisfying? If so, why? If not, why not...and how would you change it?

11. If you could ask the author a question (and you can!) what would you ask? Would you want to read more of her work?

12. Has this novel changed or broadened your perspective? Have you learned something new or been exposed to different ideas about people or a certain contemporary issue?

Although in my thesis, you will be anonymous, it would be very helpful if you could tell me a little about yourself.

- Name and contact: (If you wish)
- Age:
- Present or previous profession:
- Would you consider yourself to be disabled?
- Do you care for someone who is disabled?
- Ethnicity:

Responses:

1. How would you sum up your experience of the book?

a) Enjoyed the book and found it interesting and engrossing.

b) –

c) –

d) –

e) –

f) Really enjoyed it.

g) Initially amused – then it got darker...

h) I did 'enjoy' reading the book, but it was shocking and made me think, made me sad with the state of the world and human nature most of all.

i) –

j) –

k) –

l) –

m) Good beginning, held my interest most of the way through due to interesting twists and introductions of new characters. Got very attached to Alex and Chris!

1A. How did you feel reading it – amused, sad, disturbed, confused, bored... or some other reaction?

a) Very sad and depressed at the thought of a society that cares so little about others.

b) Amused, entertained, concerned and confused. I read it very quickly so the confusion is probably my own fault.

c) Slightly irritated initially but once into the book and the characters found I had mixed reactions – disturbed at the thought of this dystopian world, the impact on the individuals, despair at the futility of individual lives. The subject was depressing really but this was balanced by the thread of humour throughout the book and the usual approach taken by the dog's viewpoints.

d) I found it far fetched and though to the left myself I found it OTT and too extreme.

e) A riveting, compelling powerful book – often quite scary in the first part – hard to read at bedtime. All the more frightening relating to the hardship this govt. has forced upon people who have ‘failed’ their fit to work campaign.

f) Couple of moments was pit of the stomach scared about what would happen, thought denouement both very clever and satisfying.

g) At different points – amused, saddened, disturbed but also engaged & enthusiastic to read on.

h) Mixed. It was interesting and enlightening. Took me into worlds and situations I don’t have much experience of, also inspired fear, horror, sadness, very tense, disturbing and uncomfortable in places, but also moments of light and humour. I very much liked the emphasis on the natural world / secret world of animals through the character of Chris et al – sights, light, sounds, smell, textures etc. and an animal’s-eye view of the human world and behaviour.

i) I enjoyed it and the unusual perspective of a disabled person trying to survive in the current UK benefit regime. I have been there and I believe it accurately portrays the absurdity and power games that go on. I also liked the honesty about being a woman in the West, having sex without shame.

j) Read 70 pages but not really my kind of thing, I’m afraid.

k) I speed-read it somewhat so I could respond to these questions, and that’s never too satisfying.. so apologise for the sketchiness of this. But I did get hooked by the spirit and energy of it all and got immersed in powerful scenes like Alex’s night with the poet and Boudicca’s final expose of the home.

l) I found it exhilarating and emotional; I think that the narrative was so informal, hilarious and chatty that sometimes the weight of the subject matter really crept up on you.

m) Amused by the deliberate snippets of humour in the writing and the humour was definitely appreciated as the story was very bleak in places. Felt sad and worried when some of the anti-welfare rhetoric/policies/attitudes reminded me of real life situations. Initially frustrated by the ending as the ‘performance’ didn’t seem to have changed anything but after thinking on it further realised that it would have been unrealistic to have expected such a massive change in government policy/people’s attitudes. Above all, happy that Alex was in a better situation both geographically, mentally and employment-wise by the end.

2. What in your opinion are the main ideas or themes that this novel explores? Was the title a clue to a theme? Do you feel it is a good title for the book?

a) Title seemed unrelated to the story. To me the main theme of the novel is how to treat each other.

b) Outsiders, the excluded, how easy it is to fall through the net. Political manipulation/journalistic manipulation. Co-incidentally I was reading a book about the Nazis Aryan program at the same time. The parallels were quite chilling.

c) The potentially increasing intolerance to perceived "burdens" on taxpayers' contributions and the overreaction of the authorities in dealing with it. The title did not reflect the themes in this book and could actually be misleading –ie- might be interpreted as a romantic novel. So I would not think the title is a good one in that respect.

d) No. I thought from the title it would be a romance but it was far from that.

e) No it's not helpful title – weak & not fitting for such a powerful theme. Main ideas: we're all people – some have more obvious disabilities than others. Human resourcefulness – that people with disabilities are usually seen as disability and its problems first & the value of the person seems to be ignored.

f) How we so easily can turn to hatred of others. Disability/difference awareness. Title – only sort of – not sure it's the best title.

g) Disability – government cuts – bias – victimization – the inconsistency of the press & media – euthanasia. Title was not a clue & did not feel totally apt.

h) Degradation of the welfare state, exploration of human relationships / humanity, individual characters, euthanasia, power of human action / civil society, scary power and brutality of the mob, 'group-think', extreme nationalism, scape-goating.

I'm not sure whether the title reflects the novel's key theme(s) and lasting impression for me personally, and if it does I'm not sure whether I missed the message!

Love in all its different forms was explored in the relationships the different characters have with each other etc., but it was more of an apocalyptic, dystopian tale for me; a warning of what the future could be, a stark reminder of where we are, what has been before (- I'm from a German studies background so it was reminiscent of a warning from history for me re. the National Socialist euthanasia and other related policies), and what can easily be in the future if citizens aren't informed, blindly follow, don't act / protest, oppose the state etc.

i) To be honest, I have no idea how the title relates to the book. It sounds like something from the 1960's Age of Aquarius. Yes, I understand that the story

involves love and it takes place in summer, but beyond that, it tells me nothing about the story. Far from it. It sounds more like the title to some chick lit that I wouldn't want to read, so I found the title Summer of Love to be quite off-putting.

j) - Is this meant to be blank?

k) To me it's above all a satire about the ugliest attitudes to disability and immigration today, a warning of the way we could be going.

Summer of Love is so much associated with hippies and ravers that I'm not sure it works as a title.. Maybe with the right cover to make people realise it's ironic.

I think you need a title that's closer to the book's theme – but don't have suggestions I'm afraid... or maybe: 'The Chilling Beds'?

l) I would identify social injustice, largely, as the theme for the book. It is very much a book about the contrasting experiences of people within a society. I found the subject matter fairly timeless- Grassybanks as an institution is extremely reminiscent of the Victorian lunatic/pauper asylums that were largely abandoned only over the last 50 years for reasons various (drugs,Thatcher, drugs)... this coupled with the climax was Orwellian, I felt.

The title wasn't a clue to the theme, no, although in retrospect I think that I understand why the novel is called what it is. I do like the title, having read the book, although I don't honestly know if I personally would rush to pick up a book with this title. I loved the building tension of the summer, of the heat. There was a theme of empathy and understanding (love) versus cruelty and judgement (hate). Upon reflection it is reassuring to feel that love may have triumphed over hate.

m) The strongest impression the book made on me was how strong mob mentality and the media's influence is and also, connected to that but on the positive side, how much stronger someone is if they are working with like-minded people towards a common aim, eg. Alex was pretty much powerless by herself (even though she was a strong person) but the Ladies Defective Agency and Boudicca managed to make a difference to many people's lives against very powerful opposition. Wasn't convinced by the title as to me the 'summer of love' is too overused a phrase with already too many other associations with it. I understood that it was being used ironically but would have appreciated the title linking to the plot more, eg. it being obvious that this was all happening over one summer.

3. Were you engaged immediately, or did it take you a while to 'get into it'? Is it a plot driven book, a fast paced page turner? Or does the story unfold slowly with a focus on character development? Were you surprised by the plot's complications or did you find it predictable, even formulaic?

a) Quickly engaged in the story, well paced, adding layers to the characters, built to an exciting conclusion.

b) I was engaged immediately-very good start. Some characters developed, others not so much – some did seem a little formulaic.

c) Not engaged immediately but after a couple of chapters I found it engaging – wanting to know what would happen to the characters and if the book would have a predictable 'happy' ending.

d) I found the beginning odd as I always thought that rats didn't like dogs and always avoided them – I could be wrong. What of the dead body in the sewer? We never heard anymore about.

e) I started quickly but as the book became darker, preferred not to read at bedtime. I think the reading time given by the reader influences the reader's view of a book, & the author has no control over that.

f) Engaged immediately, enjoyed both plot and character.

g) I felt immediately engaged by the characters but slightly confused by some random wandering off-plot (pregnant flight-attendant did not add much to Dr Binding). Mostly it was fast paced & very readable.

h) I was intrigued and engaged immediately due to the unexpected focus on Chris and the rats in what I presumed would be a conventional love story from the title, as well as the mystery of the dead body. The pace of the book varied a lot, attention to detail and minutiae in places and fast paced / leaving you wanting more in others, but it was easy to read / left me not want to put it down. It wasn't predictable or formulaic – unique plot.

i) It took a while. I loved the start with Chris the dog, but then there were a couple of news articles that I didn't realise at first were news articles (do something clever with layout or print style to clue in the reader who is not able at that point to distinguish?) and then I lost Alex with Mr Tunny (who never appears again though he's the focus of the chapter called The Clearances) and Andre. It was somewhat annoying. I was just getting to 'know' Chris and Alex and then they disappear for what seems like quite a while before they resurface. At the time, I wondered if I was mistaken that Alex was the main character. I think the first couple of Alex chapters should be closer together at the beginning so that the reader can judge the importance of, say, Andre or the news articles.

Once I understood a little more about Alex and what was going on, I got into it. As I said, I loved the character's perspective and the tongue in cheek humour about the inner workings of the JobCentre and the ATOS-type organisation. Actually, there could be more character development with some of the characters, such as Dr Binding and The Poet, which might give the story more punch.

No I was surprised a bit by the climax, and the story is far from formulaic. Too unusual to be that.

j) For what it's worth, I found the present tense difficult to engage with and I think it could do with a clearer viewpoint at times. I felt at a distance from the characters, so maybe first person would draw readers in more.

Sorry not to have read more or been able to give more feedback...

k) I got hooked and liked it being plot driven. Would make a great TV drama too, or graphic novel. It's not quite 'my type' of book but I really enjoyed it.

l) I was engaged immediately, largely by the main characters and the writing style. I did find it to be a page turner, although a story in sections- but that may be the way that I read it. (Over 3 sessions).

m) Engaged immediately, it was a fantastic idea to start the book from Chris' point of view. The characters were introduced well, spaced out in the story enough so that I could 'take them all in'. I thought it was an addictive page-turner, not too much time spent lingering on characters who weren't Alex. I was surprised by most of the twists in the story (eg. what the Ladies Defective Agency actually did, the Poet's link to the politics of it all, how far the Doctor was taking his little experiment) but a few were less surprising (eg. Boudicca being made up of women from the LDA). Although the only obvious twist that made me eye-roll was that the old man in the beginning had killed his wife, that was blatantly going to happen and the whole 'It is done' was a bit heavy-handed. The hints were there from the very beginning – you knew this wasn't going to be a straightforward 'collection' and Mosh felt that something was up, less warning signs would have made the section more subtle and more affecting.

4. Disabled people often complain that books written by non-disabled writers can't authentically represent disabled characters. How do the disabled characters in this book compare with disabled characters in other books you've read? Did you find the character of Alex authentic, could you relate to her? How about the women of the Ladies Defective Agency?

a) Characters seemed realistic and were people you could care about.

b) Don't think I've read anything else specifically about disabled people(!) I did think Alex authentic. LDA more comedic.

c) Cannot recollect any other books with disabled characters that I have read (maybe they have just not been memorable). Was not sure if Alex was authentic – bit far fetched perhaps? This could be my limited knowledge of disability issues. In the world portrayed in this book joining the Ladies Defective Agency as a sex worker did seem to be the (only?) option available to these disabled

women but as I am neither disabled or could imagine undertaking telephone sex I did find it difficult to relate to these characters but could empathise?

d) I found it difficult at times to realize that Alex had defective vision as she appeared to notice quite a few physical actions and visual ones.

e) I don't remember reading another disabled character.

f) Loved Alex – I wanted to be her – a rare response to a disabled character.

g) Found the character of Alex very convincing especially in her relationship with Chris. Loved the notion of the Defective Agency & did not find the characters unconvincing.

h) I could definitely relate to Alex and thought her character was authentic and not defined by her disability - I was much more interested in the type of person she was, her opinions, forthrightness etc. I didn't really feel I got to know the women in the Ladies Defective Agency quite so well, some of them are key players so it would have been nice to get to know more about some of them perhaps.

i) I found Alex to be very realistic; forget about disabled characters in books - Alex was like the real-life disabled people I've met, full of dark humour and courage. I thought she was very authentic. I definitely related to her as a genuine person.

Now this is another place where the book might benefit from more characterisation. Although I wish there was something like the LDA (and Boudicca), it was clearly a fictional device. It might have been a good idea to delve deeper into the women's individual stories if it could be accomplished without making the overall story too scattered. For example, I'd like to know more about Kitty and what she went through from model to cripple. Or Helen's story could be brought out more in its own right, rather than waiting until the end when the link with her daughter comes out.

j) -

k) The characters are larger than life, but feel very authentic too and that's good. I loved their toughness and wit. Alex is a proper storybook heroine.

l) I'm struggling to think of characters in books that are disabled, which is telling in itself. The physically disabled are often portrayed as damaged, likely bitter, invalid, and those with learning difficulties or neuro-differences as either simple and angelic, or deeply suspicious and 'other'.

The difference here is that the disabled people are portrayed as capable, humorous, drinkers of alcohol- 3d, distinctly human.

I *loved* Alex- she is brave and unapologetic, and why shouldn't she be? Hugely relatable, a heroine with foibles and weaknesses. She was presented as a *fait accompli*- there is no wrenching back story or harrowing tale of how she came to be in the body that she is (in contrast to the very necessary stories behind some of the other characters) or where she came from, and I liked that.

Kitty Fox was a bit of a mystery to me... the other ladies of the LDA warm and funny with the exception of the twins, who I found to be a wonderful contrast and completely riveting.

m) I'm ashamed to say this but at this moment I can't remember if I've read many other books with physically disabled main characters. The only ones that come to mind are 'My Left Foot' and 'Emma and I' but they are memoirs, not fiction. I will probably remember more once I've handed this in! The disabled main characters who made more of an impression on me are the ones who had different ways of thinking because this created very unique reading experiences style-wise, eg. 'The Curious Incident of the Dog and the Night Time' or 'The Shock of the Fall'. But even though I haven't read many blind protagonists before, I really identified with Alex and found her very authentic. She was ballsy and went after what she wanted. Her optimism and determination were uplifting at times when the novel really needed a bright spark but equally the fact that she had darker moments and issues with alcohol made her much more realistic and well-rounded a character. I was incredibly angry with her when she took the money the Doctor left her and did exactly what he wanted her to do with it, ie. drink too much booze! I didn't want her to fall into his trap but it was completely understandable that she did – she didn't come across as weak for doing so, merely human. As for the other characters in the LDA, I liked them and they came across as being an interesting range of people but I didn't really identify with them, mainly because any hints of complexity for their characters weren't explored further as the book was very much Alex-based (nothing wrong with that!). I can only think of one bad point about Alex. Her sex scene was funny, realistic and added more layers to her character but the last line of that section really didn't sit well with me – it was something about "acting like a whore". That line didn't seem to fit with the very sex-positive vibe I got from the rest of the scene. I understand that she was upset that she'd accidentally slept with a married man but I felt that she was judged too harshly for it by the authorial voice.

5. What does Chris's perspective bring to the book? Is he just light relief or does he bring a deeper resonance to the story?

- a) This was a quirky aspect of the book which made you think about human/animal relationships in general but didn't see to add to the story but did give some humour.
- b) Excellent I thought – completely different perspective from him.
- c) See 1A. Chris's perspective did provide the viewpoint of the responsibility of a carer – the loyalty and dedication required.
- d) I think Chris was an essential part of the book given that Alex had visual problems and needed a guide dog.
- e) Tanvi's writing of Chris is – for me – completely credible, except she has thought so deeply into his character, his perceptions & thought processes that he is fully formed & as strong as Alex herself; several times I had welling tears. Never come across such a serious & honest, compassionate depiction of a dog.
- f) Both [to both aspects].
- g) Chris's perspective is absolutely fundamental – not only enjoyable but as a contrast to the vanity and folly of some of the humans.
- h) It brings a lot. I really liked it. It did add light relief in places - I liked the reference to him flicking his ears at Alex! But he does bring a deeper resonance to the story – his judgement of people, individual characters, the situations presented and the state of humanity was generally spot on.
- i) I LOVE the parts with Chris! There aren't enough to my taste. Chris is in the unique position of being an independent but sympathetic voice. I think more could be done, more chapters with Chris, that could add resonance and detail to the story. Dogs instinctively know about the people they meet, which could help with characterisation. I think his part should be developed more.
- j) -
- k) I like the dog, definitely brings resonance. I wonder if you could go even further in describing a dog's eye view of the world of smells and food and walks with owners. Can dogs see the TV? I had a feeling they couldn't, but maybe that's a myth.
- l) The Chris parts are brilliant and I found a lot of them hilarious. His insight was valuable, and his perspective was so valuable- not least because it conveyed his importance in Alex's life. I liked that he had relationships beyond those that strictly Alex developed- ie Parnell.

The part where Alex gets the train without him, with the umbrella, terrified me. I worried.

m) He was definitely not just light relief but he did that job very well too! I really liked reading his slant on what was happening. His interactions with other dogs and the descriptions of his senses were really imaginative. The bond between Alex and Chris was explained well and the love/devotion on both sides felt true. Showing Chris's thoughts on what was happening made him more real and therefore heightened the tension when he was attacked later in the book. Also, widening out this question a bit, I thought that all the mentions of animals in the book were fantastic, especially the crows and their early warning system about the storm. It showed a wider perspective on what was happening and added another layer of goings-on, expanded the world view and emphasised the limitations of the humans, eg. Mosh being dismissive towards the crows when really they are way ahead of him in terms of what's going on to happen next (one of my favourite little sections).

6. What do we learn about the character of Dr Binding? Does he grow and change through the book? Is he a three dimensional character, would he be recognisable in the real world? How about Andre, Mosh, Jenny...?

a) Characters all seemed identifiable, however Dr Binding did seem in the end to become a larger than life figure – bit of a James Bond Baddie!

b) Dr Binding = pantomime villain.

c) All the characters would be recognizable in the real world – there are those that care, understand and stand up for their beliefs – those in power that take advantage, misunderstand and those in between.

d) Andre would have had more than 1 person supervising his behaviour so I didn't find his reasonably long stay in the ambulance service gradible. What happened to him after waking in the kennel? Mosh seemed real and gradible but Dr Binding didn't.

e) Andre – thin, an ogre, Dr Binding ...I wonder if there isn't too much black and white – Andre is just bad, and so is the good Doctor. (We know that Andre had a hard childhood, but we see no good facet to his character.)

f) I think I'm a bit like Jenny (in a flattering way). Definitely recognized Andre and Mosh. Dr Binding a bit a type but scary especially at the end.

g) I felt that Andre was the most 'flat' character – but perhaps because he is so unlikeable.

h) Sinister, cold, self-serving, cowardly in the end although initially we are given to believe he is kind, good, willing to help. Kind of like a mild Demon Headmaster, with power / reputation to influence others.

i) No, I found him to be very two-dimensional and flat. Notwithstanding references to him as 'the Good Doctor', he was the bad guy and that was it. Like the Mitchell brothers in the TV show Eastenders, what makes a 'good' bad guy is his humanity, the good parts that make him someone you like and sympathise with ... Just before he turns around and does something nasty. Here we have a doctor, who probably went into the profession to do good, but now he is quite far from that. What was his motivation? Does he have any bouts of conscience? Does he regret the way his daughter turned out? There's no hint of these considerations. The characterisations of Andre, Mosh and Jenny are better balanced for the role they play.

j) -

k) They're stock characters made real and individual, something like the best comic book heroes and villains – it would make a good one. Dr Binding is as chilling as his beds but does develop.

l) Dr Binding was authentic- convinced of his own righteousness throughout, sometimes rightly and sometimes wrongly. He might have ended up disabled but I felt that he (and his circle) would classify his disability as the "right sort" of disability- that of a privileged victim. He had the means to continue to function in his society, but his boundaries were redrawn for him. He won't be bullied into working, an irony lost on him maybe.

Andre- couldn't stand him which was obviously the point. Truly authentic, an ignorant, basic, bastard.

I really liked Mosh and Jenny. I worked out that they were together as soon as Jenny mentioned what her husband did. The good guys.

Stella- total bitch. Totally believable.

Why did I like The Poet as much as I did? He was utterly pathetic in the true sense, but I was sort of rooting for him.

Kitty- as I previously stated I couldn't really work her out- she wasn't as developed as say Helen, but then she played a different role.

Robin- Ha, at first I was wondering how a yogi vegan could be so totally unevolved. That didn't last long.

m) Binding's capacity for self-delusion really irritated me! But the best villains are the ones who believe that they are in the right so he was an interesting character in my opinion. I'm not sure if he changed at all, I'm writing this a few weeks after finishing the book so most of the characters who weren't Alex and Chris have faded quite a lot in my mind! I definitely believed that his thought processes justifying what he was doing seemed like something that someone in real life would think, scarily enough. Mosh made a big impression and I was surprised when he didn't become a main character, his personality came across well. Andre seemed to be a bit of a caricature, as did the rest of the 'Believe in Better' brigade.

7. Did you find the humour made the novel a better read? For instance, some of the issues around welfare cuts and euthanasia were presented satirically. Did this enhance or detract from the underlying issues and themes?

- a) It helped to make the book more readable, without the humour it would have been very depressing!
- b) Probably would not have read it at all without the humour.
- c) Humour was necessary in the book – without it the book would have been a depressing representation of a dystopian world thus making it a book that would have been difficult to get into.
- d) The humour passed me by as the subject was such a serious matter.
- e) The humour is important – it underlines and enhances themes – it would be a grim read otherwise, and it makes characters more alive – its vital for the Ladies Defective Agency which I loved.
- f) Yes made what otherwise would have been too much, bearable.
- g) The first half of the novel was very amusing & made me laugh out loud at several points. The second half had far fewer comic interludes (in spite of clowns). I would have liked to see the satire sustained as it was an effective foil to the disturbing plot lines.
- h) Yes it enhanced my reading experience and the strength of the issues and themes presented. It provided some light relief, in terms of the tone of delivery – some heavy subjects are discussed and if this was done without humour or satirically it would perhaps be too much - without taking away from the overall serious message.

Humour also strengthened the notion that some of the things described in the book (e.g. government policies re. benefits) are ludicrous. It has more power this way, seems more real and reflects the way that people deal with extreme situations – with humour, wrath, sadness etc.

i) I thought the humour helped to highlight the issues. I enjoyed the humour in the book.

j) –

k) A humorous dystopia, satirising what is happening right now by exaggeration, is tricky to handle, How to make it believable as a fictional world and not too cartoony. I think you get this about right, but that may be what I found off putting at first. You're basing your world on what might happen in ours, but still creating a place where you make awful things happen and then say, "Isn't this awful!" – it's a loaded world, designed to prove your point.

l) Enhanced, definitely. It would have been a sobering read indeed without it- the spoonful of sugar, as it were. Plus it was genuinely funny. How else should we (as humans) deal with adversity?

m) It only enhanced them in my opinion. Making fun of a situation is the best way to criticise it. Also the humour was needed, if something horrific is happening in the plot then it's best to read about it when you are also being distracted by how clever the humour is being.

8. In terms of the way the book is structured, do you feel the shifting view points were helpful in reflecting different perspectives?

a) Definitely makes it more interesting to learn more about the characters' personalities.

b) Yes but I did get quite confused. Own fault for reading too quickly.

c) It certainly helped with introducing the characters and their part in the plot.

d) I found them all too extreme.

e) I liked the different viewpoints eg those that show Alex's frailties, as she is such a strong individual.

f) Yes and also Chris is helpful reminder that Alex is blind/VI (very important).

g) Yes. Particularly like the animal viewpoints

h) Yes, also adds depth / breadth to the themes explored.

i) Yes, I liked the variety of perspectives. As I said, you could do more with the perspective of Chris the dog.

j) –

k) Yes, I liked the voices a lot.

l) Yes, and it varied the pace. This is, ultimately, a book about differing perspectives.

m) Yes, I really liked that this shift in view points kept happening. It also refreshed my interest in the story a few times as perspectives changed and I had to concentrate again on what was going on. It was an effective technique for making the book a page-turner. But also it was done to a degree that didn't detract from Alex's view point, it was obvious she was the main character.

9. Are there passages that struck you as insightful or profound? Perhaps a bit of dialogue that's funny or poignant or that encapsulates a character? Maybe there is a particular comment that states the book's thematic concerns?

a) Helen's story about her daughter near the end of the book was very poignant and made me cry...

b) –

c) The propaganda slogans are impactful in providing the reader very clearly the state of the world as portrayed by this book.

d) I found too much swearing even by professionals which I doubt would happen. I know that is a trend in a lot of modern books but it doesn't lead to good literature. Someone once said that swearing is used when a person is short of meaningful adjectives.

e) I loved the crows, the rats & Chris's awareness of them. I enjoyed Chris and the other dogs – I loved that they are taken seriously & the author 'feels' them so powerfully & presents their realities equally with humans. She is very clever. I like the short chapters – the story moves quickly, the characters are interesting & I want to know what happens. I would like to know more about Alex before her sight changed, and about how she coped with the effect it had on her life, and how she met & learned Chris. The comparisons with politics & real life in small chunks, works well, highlighting the difference between propaganda & reality.

f) –

g) I particularly liked the perspective of Chris and his absolute 'humanity' – loyalty, kindness, compassion, trust in the face of human failings.

h) Lots of it stood out and was poignant, horrific – lots of little moments which added chill, warmth, fun and captured the character of individual characters e.g. Chris flicking the V to Alex with his ears, Alex tying her knickers to the door after sleeping with the artist as a two fingers up to him and his wife, the description of how the chiller beds worked and how it was just a normal task for the nurses ... and lots more.

i) It's been a couple of weeks since I read the book, so I don't recall the detail as well now, but I remember liking the insight given into what goes on in the JobCentre and the homeless shelters.

j) –

k) Alex dealing with nasty guys were my favourite bits.

l) p. 32 As Alex walks home from the hotel, past the multi-storey where Laura committed suicide with the Shop a Scrounger poster.

"The flap of red made Alex nervous. During the day people hang around here, under the poster, absorbing the red energy of the thing..."

And then when Alex throws the shoe back...

These couple of pages are unspeakably brilliant. They tell us so much about the societal landscape, about Alex, about Chris and about their relationship. They are frightening and funny, which is exactly how I would sum up this book in two words if I had to.

p.109 "...The clients are teenagers and young adults with Downs Syndrome and other varieties of learning impairment that Robin rattles through as if reading through a script. ADHD, autism, Asperger's, cerebral palsy, Dyspraxia, hydroencephalitis..."

The kids are not particularly impressed. 'They just look like people,' the nose picker, Johnny, points out. 'They look like they are at school.'

Robin seems a little chagrined by the dismissal of the show. 'Well what about Leo? See? That boy over there, in the wheelchair. He was born without eyes!'

'Ahhh..!' the children rush to the window again, following Robin's pointing finger.'

This floored me. I laughed because it was so ridiculous but it was really poignant.

p. 240 Back at the Movies.

Especially the paragraph which starts "In the night Wayne pulls out his cannula..."

Could not stop crying.

The climax, the protest was electrifying. I could see it, which was extraordinary. Much of the story is told through emotion, dialogue and deed- there are very few visual descriptives until we get to this climax, and that is extremely powerful.

m) I found the dinner party conversation about what new TV show could be created in order to win the majority of the population over to the government's policies to be an unnerving experience to read, especially with the range of people participating in the conversation, eg. from the people orchestrating it to the female guest who watches the shows without realising how she's being indoctrinated. Also the attack on Alex and Rory was a horrible glimpse at how quickly and easily a situation can escalate into something violent and how powerless an ordinary member of the public can be when confronted with someone like Andre who can't be reasoned with or his good nature appealed to. On a more positive note, the reunion of Alex and Chris after his injuries was very moving and just reinforced to me the importance of somebody having connections, even if to "just" a dog – nobody can get by with just themselves!

10. Is the ending satisfying? If so, why? If not, why not...and how would you change it?

a) Not completely satisfying – nothing had really changed despite all their efforts.

b) Yes- it had to be that way really (I mean politically)- though was surprised by Alex's outcome.

c) In that it is not a predictable 'happy' ending but does it show that Alex ultimately also looks out for herself and leaves the country where nothing has really changed despite the efforts to reveal what is really going on.

d) I found the ending unconvincing as the book until that point contained no concerns about 3rd world issues.

e) It seemed not to carry through, although I loved the vicious humour...Although it does with Laura Shandy. On immediately finishing – The ending came too quickly –I would like to know the media interpreted the film of the action at the ceremony – it was on local TV, so how did the international media deal with this. The reaction of Parliament to the return of MP Donaghue seems improbable – but also quite possible.

f) Yes see Q1 [really enjoyed it]

g) It seemed right that the 'protest' at Grassybanks should have ultimately brought about no change (not right morally! But right in terms of plot expectation).

h) No, it was over too soon – the pace at the end was very fast, and I didn't feel that many key issues had been resolved, I didn't know exactly what had happened to all of the characters who had been introduced throughout the novel, although I guess that was the point, made the story more realistic / truthful, or maybe I wanted a happier ending - for the 'Baddies' not to get away with it quite was much as they did and for the 'Goodies' to have more of an impact / triumphed over evil, although perhaps I wanted this more to feel better about myself(?) I think Alex and Chris should have stayed rather than moving abroad – have our heroes given up?

In addition I really thought the mystery of the dead body in the beginning would be returned to in the end – I still want to know who was it? What happened to them? Were they victims of the state-sponsored euthanasia programme or something else entirely?

i) I liked the 'performance' inside the hospital and the storm, but the fact that the politicians and Dr Binding got off Scott free - however realistic because none of those bastards seem to pay for what they do - takes the joy off the ending. Even Alex runs away in the end. I guess I wish I could see things change, but they are unlikely to do that for a while and I've done my fair share of running away: that's all you can do when you don't have the power to implement lasting change. So the ending is realistic but sad.

j) –

k) Like the denouement and the ending is bleak but with a bit of happy ending.

l) In an ideal world the Gallagher enquiry would have resulted in a complete damning abandonment of TOSA, Grassybanks, everything... but we do not live in an ideal world. I did like the ending, with the excerpts of media, and was happy for Alex that she extricated herself from the impossible UK system. She took control of her environment and her narrative. I listened to 'Il Luta Continua!' as I read Chris's Epi-Dogue. I was an emotional wreck, but hopeful that we will get to know what happens afterwards. Will we find out together?

m) It was difficult for me to accept the ending and in fact it was difficult for me to like all of the third act in some ways. I was very used to seeing Alex as proactive and in charge both of herself and what was going on around her so for her to be relegated to a supporting role for the actual 'performance' at the centre was frustrating for me. It was great that she was getting the chance to do her old career of reporting again and I was happy that she ended up doing that at the end as well but for me, she should have been more involved in the action and less passive. I hadn't connected enough emotionally to the members of Boudicca to care much about what happened to them when they were protesting whereas I was very concerned about Alex! Also the whole 'performance' was a great idea but I think it went on for too long, there was no way the police wouldn't have broken in and stopped it way before it ended. About half way through the book I thought that the hints Binding was dropping about Alex's alcoholism would come to something and that she would actually find herself trapped in his treatment centre after being sent there by him manipulating the power of his role as doctor to the long-term alcoholic homeless people. Then I thought we'd get some action with her escaping from Binding's centre with Phil and they would get video evidence of what was going on inside. Alternatively I thought that she would break the story of Binding's centre using her newspaper connection (after getting hold of the photos from that little girl's phone) and then have to go into hiding with Boudicca protecting her before an attack on the centre being the final act. So, in my head I had Alex as more of an action hero rather than a reporter so maybe this was me just getting a little too carried away!

11. If you could ask the author a question (and you can!) what would you ask? Would you want to read more of her work?

a) Why chose this theme? Have you yourself suffered from these bigoted views?

b) I would read more. I like your style.

c) Does the author feel this is the way this country is heading – in terms of the way less able individuals are treated? Is this what prompted the themes of the book?

d) I had a Masters in Health Policy Studies and for the dissertation research and references were expected to be appended. Why not for a Ph.D?

e) Yes I would love to see how her writing develops. What will you write about next? Please keep your sharp edge of insight. (No pun intended)

f) Yes. When is it coming out in print? I'd love to recommend it to people.

g) Yes would love to read more.

h) As above – who was the dead body in the beginning and what happened to them?

What happened to Andre?

Also is the novel set in Cambridge and if so why didn't you use the name 'Cambridge'? There were so many allusions to the city – direct and indirect I'm sure it is, but just don't know if or why it would be un-PC to do this?

Yes, I would read more of this author's work.

i) Yes [I would read more]

j) -

k) I'd like to know what you're going to write next and whether it will be very different from this.

l) Yes, definitely. This is really, really exciting.

m) Who was the body that Chris sensed at the very beginning? And yes, definitely.

12. Has this novel changed or broadened your perspective? Have you learned something new or been exposed to different ideas about people or a certain contemporary issue?

a) Has had a lasting effect on me to feel depressed and concerned that society may head in this direction.

b) I have been reminded of certain issues that people face which I have not considered for a long time.

c) Not really. As a family we often debate the rights and wrongs of issues such as euthanasia, medical interventions on the elderly and seriously disabled – difficult moral and social issues for which there is no one answer.

d) No. No

e) The Defective Ladies – their strength, humour & ingenuity – utterly confounded their name, brilliantly so, reminding me that it's the person, not the disability, that's important. I look forward to your next book Tanvi. I'd like time to read this again, too. Thank you!

f) Yes. Yes made me think re parallels Nazi Germany + us now.

g) Not really.

h) Yes I have learned a lot – my experience of fiction about disabilities is limited and the insight was really enlightening and interesting. I would like to think the novel will act as a warning for me personally to keep me even more alert to things going on in civic society that I can do something about and protest.

i) Having experienced the benefit system first hand, as well as indirectly as an advisor with the Citizens Advice Bureau, I think it's a fairly accurate portrayal of the struggle faced by a good part of the population. I like that it exposes the problems without the condescension or condemnation of most of the other portrayals nowadays. For that reason, I hope the novel gets widespread exposure.

j) –

k) Hmm.. confronted but in a relatively comfortable way for a Guardian reading leftyish type like me. And I think it would alienate very quickly any UKIPper.

l) I personally am big on difference over deficit, and while I found a lot of this satirically presented not-too-distant-dystopia terrifying it did make me think a lot about how we as a society view the disabled people among us.

Apologies for probably sounding like a gushing dickhead but I loved it. It has been a privilege to read.

m) It's made me more aware of how important the connection is between a guide dog and its owner, the bond there is so strong and Alex and Chris really put that across well. Also since reading the book I've been more aware of news stories focusing on issues for disabled people and the government's attitude to supporting the more needy members of society (eg. long term unemployed).

Brief outline of respondees (where supplied)

Although in my thesis you will be anonymous, it would be very helpful if you could tell me a little about yourself.

[Details redacted to retain anonymity of participants]

Bibliography:

Allen, D.M. (2006) 'Desire denied: a bibliographic overview of sexual inequality and blind women'. *McNair Scholars Research Journal*, 2 (1): 4.

Allport, G.W. (1954) *The nature of prejudice*. Reading, MA.: Doubleday Anchor.

Allport's scale of prejudice: Wikipedia entry (2013) [Online] Available from: https://en.wikipedia.org/wiki/Allport%27s_Scale [Accessed 10th June 2013]

Analysis: inside welfare reform (2014) BBC Radio 4, 27 October, 20:30pm.

Asch, A. (2001) 'Disability, bioethics and human rights'. In: Albrecht, G, Seelman, K and Bury, M eds. *Handbook of Disability Studies*. London: Sage: 297-327.

Auster, P. (1999) *Timbuktu*. London: Faber.

Aveling, H.A. (2009) *Unseen childhoods: disabled characters in 20th-century Books for girls*. London: Bettany.

Bachrach, S. (2007) 'Deadly medicine'. *The Public Historian*, 29 (3): 19-32.

Ballard, J.G. (1975) *High-rise*. London: Cape.

Barasch, M. (2001) *Blindness: the history of a mental image in western thought*. London: Routledge.

Barnes, C. (2014) 'An ethical agenda in disability research: rhetoric or reality?' In: Mertens, D. M. and Ginsberg P. E. eds. *The Handbook of Social Research Ethics*, London: Sage: 458–473.

Bauby, J. (1997) *The diving-bell and the butterfly*. London: Fourth Estate.

Baumberg, B., Bell, K. and Gaffney, D. (2012) 'Benefits stigma in Britain'. Kent: University of Kent and Turn2us.

Beckett, A.E. (2009) 'Challenging disabling attitudes, building an inclusive society': considering the role of education in encouraging non-disabled children to develop positive attitudes towards disabled people'. *British Journal of Sociology of Education*, 30 (3): 317-329.

Beckett, A.E. and Buckner, L. (2012) 'Promoting positive attitudes towards disabled people: definition of, rationale and prospects for anti-disablist education'. *British Journal of Sociology of Education*, 33 (6): 873-891.

Belloc, H. (1973) *Cautionary tales for children*. London: Duckworth.

Benefits Street (2014) Channel 4, 21:00pm.

Benefits: Too fat to work (2015) Channel 5, 14 January, 20:00.

Binding, K and Hoche, A, 'Permitting the destruction of life unworthy of living' (1920) [Online] German History in Documents and Images (GHDl). Available from: http://www.germanhistorydocs.ghi-dc.org/sub_document.cfm?document_id=4496 [Accessed 8 December 2014]

Black Sun. (2006) [DVD] Director: Tarn, G. Passion Pictures.

Black Triangle Campaign Website. Available from: <http://blacktrianglecampaign.org/2014/10/21/uk-welfare-reform-deaths-updated-list-october-21st-2014/> [Accessed 21 October 2013]

Blane, D. and Watt, G. (2012) 'GP experience of the impact of austerity on patients and general practices in very deprived areas'. Glasgow: University of Glasgow.

Blink. (1994) Director: Apted, M. New Line Cinema.

Blue. (1993) Director: Jarman, D. Channel 4 Films.

Bolt, D. (2005) 'Castrating depictions of visual impairment: the literary backdrop to eugenics [penultimate draft of article]' *Journal of Visual Impairment and Blindness*, 99: 141-50 [Online] Available from: <http://disability-studies.leeds.ac.uk/files/library/bolt-Castrating-Depictions.pdf> [Accessed 8 December 2015].

Bolt, D. (2007) 'Saramago's blindness: humans or animals?' *The Explicator*, 66 (1): 44-47.

Bolt, D. (2014) *The metanarrative of blindness: a re-reading of twentieth-century anglophone writing*. Michigan: University of Michigan Press.

Bolt, D., Rodas, J.M. and Donaldson, E.J. (2012) *The madwoman and the blindman: Jane Eyre, discourse, disability*. Columbus: The Ohio State University Press.

Booth, A., Papaioannou, D. and Sutton, A. (2012) *Systematic approaches to a successful literature review*. London: Sage.

Borges, J.L. (2010) *Selected fictions*. [Audiobook] Penguin Audiobooks.

Borowski, T., Vedder, B., Kott, J. and Kandel, M. (1976) *This way for the gas, ladies and gentlemen*. New York: Penguin.

Boston, L.M. (1964) *The chimneys of Green Knowe*. London: Faber & Faber.

Briant, E., Watson, N. and Philo, G. (2011) 'Bad news for disabled people: How the newspapers are reporting disability'. Strathclyde Centre for Disability Research: University of Glasgow

- Brown, C. (1954) *My left foot*. London: Secker & Warburg.
- Bryant, M.S. (2005) *Confronting the "good death": Nazi euthanasia on trial, 1945-1953*. Boulder: University Press of Colorado.
- Burgess, A. (1962) *A clockwork orange*. London: Heinemann.
- Burleigh, M. (1994) *Death and deliverance 'euthanasia' in Germany c. 1900 - 1945*. Cambridge: Cambridge University Press.
- Burns, C. & Arana, M. (2008) *Off the page: writers talk about beginnings, endings, and everything in between*. New York: W. W. Norton.
- Butler, P. (2014) *MPs criticise DWP for 'spin' on official statistics and benefit claimants* [Online] Available from: <http://www.theguardian.com/politics/2014/mar/18/mps-criticise-dwp-spin-statistics-benefit-claimants> [Accessed 8 December 2014].
- Callahan, J. (1991) *Don't worry, he won't get far on foot*. London: Vintage Books.
- Campbell, S. (2012) *Responsible reform: a report on the proposed changes to disability living allowance: independent report from sick and disabled people, their friends and carers: diary of a benefit scrounger*. [Online] Available from: <http://www.rcpsych.ac.uk/pdf/Responsible%20Reform.pdf> [Accessed 8 December 2014].
- Cattaneo, Z. (2011) *Blind vision: the neuroscience of visual impairment*. Cambridge: MIT Press.
- Cattell, G.M. and Carroll, R. (2013) 'Dialogue on the uses of expressive writing for individual, relational, and community change'. *Journal of Poetry Therapy*, 26 (1): 41-59.
- Caulfield, L. (2014) *Criminological research for beginners: a student's guide*. Oxon: Routledge.
- Centre for Culture and Disability Studies (2013) 'Avoidance in/and the academy: the international conference on disability, culture and education. Liverpool Hope University, UK.' 11th-12th September 2013. eds. D. Bolt, C. Penketh and C. Lowry.
- Charles, R. (1979) *Brother Ray: Ray Charles' own story*. London: Macdonald and Jane's.
- Chatwin, B. (1988) *The songlines*. London: Picador.
- Collins, K., Costelloe, C., Kador, T., Maroukis, T. and Reyher, K. (2015) 'Austerity, sanctions and asylum: some asylum seekers' diet comparable to pre-welfare state conditions'. *British Medical Journal (BMJ)*, 350.

- Collins, W. (1995) *Poor Miss Finch*. Oxford: Oxford University Press.
- Conrad, J. (1995) *Youth; heart of darkness: the end of the tether*. London: Penguin Books.
- Conrad, J., Mosley, F. and Harding, J. (1997) *Heart of darkness and two other stories*. London: Folio Society.
- Corey, P. (1968) *The planet of the blind*. London: Hale.
- Crow, L. (1990) 'Disability in children's literature'. Arts Council of Great Britain, literature department seminar.
- Crowe, L. (2012) *Resistance!* [Installation]. Bristol M Shed Museum: Roaring girl productions. Available from: <http://www.roaring-girl.com/work/resistance/>
- Davis, F. (1961) 'Deviance disavowal: the management of strained interaction by the visibly handicapped'. *Social Problems*, 9 (2): 120-132.
- Davis, L.J. (1995) *Enforcing normalcy : disability, deafness, and the body*. London: Verso.
- Davis, L.J. (1999) 'Crips strike back: the rise of disability studies'. *American Literary History*, 11 (3): 500-512.
- Davis, L.J. (2006) *The disability studies reader*. 2nd Ed. London: Routledge.
- Davis, N.A. (2005) 'Invisible disability'. *Ethics*, 116 (1): 153-213.
- Dickens, C. (2008) *Another round of stories by the Christmas fire*. London: Hesperus.
- Dispatches: Britain on the sick* (2012) Channel 4, 30 July, 20:00.
- Duffy, S. (2014) *Counting the cuts: what the government doesn't want the public to know*. Sheffield: Centre for Welfare Reform.
- Eigen, S. (2006) 'Liebe Perla, memento mori: on filming disability and holocaust history'. *Women in German Yearbook*: 1-20.
- Eisenhauer, J. (2007) 'Just looking and staring back: challenging ableism through disability performance art'. *Studies in Art Education*: 7-22.
- Ellen, L. (2012) *Blind spot*. New York: Houghton Mifflin Harcourt.
- Ellis, B.E. (1991) *American psycho: a novel*. London: Picador Thirty.
- Ellis, C. (2004) *The ethnographic I: a methodological novel about autoethnography*. Walnut Creek: AltaMira Press.

- Evans, S.E. (2010) *Hitler's forgotten victims: the holocaust and the disabled*. Stroud: History.
- Evaristo, B. (2008) *Blonde roots*. London: Hamish Hamilton.
- Filer, N. (2013) *The shock of the fall*. London: HarperCollins.
- Fillingham, L.A. (1993) *Foucault for beginners*. London: Writers and Readers.
- Fine, M. and Asch, A. (1988) *Women with disabilities : essays in psychology, policy, and politics*. Philadelphia: Temple University Press.
- Finlayson, J. (1971) 'The satiric mode and the "parson's tale"'. *The Chaucer Review*: 94-116.
- Gallagher, D.J. (2006) 'On using blindness as metaphor and difficult questions: a response to Ben-Moshe'. *Disability Studies Quarterly*, 26 (2).
- Gallagher, H.G. (1990) *By trust betrayed: patients, physicians and the license to kill in the Third Reich*. New York: H. Holt.
- Garland-Thomson, R. (2002) 'Integrating disability: transforming feminist theory'. *NWSA Journal*, 14 (3): 1-32.
- Garland-Thomson, R. (2011) 'Misfits: a feminist materialist disability concept'. *Hypatia*, 26 (3): 591-609.
- Garthwaite, K. (2014) 'Fear of the brown envelope: exploring welfare reform with long-term sickness benefits recipients'. *Social Policy & Administration*, 48 (7): 782-798.
- Gee, M. (2008) *The White Family*. London: Telegram.
- Gentleman, A. (2011) *Benefit fraud: spies in the welfare war* [Online] Available from: <http://www.theguardian.com/society/2011/feb/01/benefits-fraud-investigators> [Accessed 8 December 2015].
- Gide, A. (1963) *La Symphonie Pastorale; and, Isabelle*. Harmondsworth: Penguin.
- Gillard, L. (2008) *Star gazing*. London: Piatkus.
- Gitter, E.G. (1999) 'The blind daughter in Charles Dickens's cricket on the hearth'. *SEL Studies in English Literature 1500-1900*, 39 (4): 675-689.
- Green, M. (2012) *The travel auction*. London: CreateSpace.
- Hall, K.Q. (2011) *Feminist disability studies*. Bloomington: Indiana University Press.

- Harrison, J. (2015) *Reports on the impact of public spending cuts on different disadvantaged groups within the UK*: University of Warwick [Online]. Available from: <http://www2.warwick.ac.uk/fac/soc/law/research/centres/chrp/projects/spendingcuts/resources/database/reportsgroups/> [Accessed 8 December 2015].
- Hastings, A., Bailey, N., Bramley, G., Gannon, M. and Watkins, D. (2015) 'The cost of the cuts: The impact on local government and poorer communities'. York: Joseph Rowntree Foundation.
- Houston, P. (2005) *Sight hound: a novel*. London: W. W. Norton & Co.
- Hühn, P. (1987) 'The detective as reader: narrativity and reading concepts in detective fiction'. *MFS Modern Fiction Studies*, 3 (3): 451-466.
- Hull, J.M. (1990) *Touching the rock: an experience of blindness*. London: SPCK.
- Hutchinson, P. (1983) *Games authors play*. London: Methuen.
- Huxley, A. (1955) *Brave new world: a novel*. London: Penguin.
- Iacobucci, G. (2015) 'Government objects to publishing how many claimants have died after being found fit for work'. *BMJ (Clinical Research Ed.)*, 350: h3329.
- Ings, S. (2007) *The eye: a natural history*. London: Bloomsbury.
- Innes, C. (1988) 'Selective blindness'. *Third World Quarterly*, 10 (3): 1357-1360.
- Jackson, R. (1988) *Fantasy: the literature of subversion*. London: Routledge.
- Jackson, S. (2004) *Creature of havoc*. New York: Ibooks, inc.
- Jay, M. (1988) 'The rise of hermeneutics and the crisis of ocularcentrism'. *Poetics Today*: 307-326.
- Jennifer 8*. (1992) [DVD] Director: Robinson, B. Paramount Pictures.
- Jernigan, K. (1975) *Blindness, is literature against us?* Clovernook Printing House.
- Julia's Eyes* (2010) [DVD] Morales, G. Antena 3 Films, Canal + Espana. [Accessed August 2015].
- Kafka, F. (1992) *Metamorphosis and other stories*. London: Minerva.
- Keene, S. (2006) 'A theory of narrative empathy'. *Narrative*, 14 (3): 207-236.
- Keller, H. (1996) *The story of my life*. London: Dover Publications; Constable and Co.

- Keller, H. (2009) *The world I live in and optimism: a collection of essays*. Mineola: Dover.
- Kent, D. (1989) 'Shackled imagination: literary illusions about blindness.' *Journal of Visual Impairment & Blindness*.
- Keren, M. (2007) 'The original position in José Saramago's "Blindness"'. *The Review of Politics*, 69 (3): 447-463.
- Kipling, R. (1891) *The light that failed*. London: Macmillan & Co.
- Kittysjones (2015) *What you need to know about ATOS assessments* [Online] Available from: <http://guerillawire.org/disability/what-you-need-to-know-about-atos-assessments/> [Accessed 8 December 2015].
- Kılıç, M.Ö. (2012) *Maggie Gee: writing the condition-of-England novel*. London: Continuum.
- Kleege, G. (1998) *Sight unseen*. New Haven, CT: Yale University Press.
- Kleege, G. (2006) *Blind rage: letters to Helen Keller*. Washington, D.C.: Gallaudet University Press.
- Knighton, R. (2007) *Cockeyed: a memoir*. London: Atlantic.
- Koren, Y. & Negev, E. (2004) *In our hearts we were giants: the remarkable story of the Lilliput Troupe: a dwarf family's survival of the Holocaust*. Carroll & Graf eds. New York: Carroll & Graf.
- Krueger, R.A. & Casey, M.A. (2015) *Focus groups: a practical guide for applied research*. 5th ed. Thousand Oaks, California: Sage Publications Inc.
- Kudlick, C.J. (2003) 'Disability history: why we need another "other"'. *The American Historical Review*, 108 (3): 763-793.
- Kuusisto, S. (1998) *Planet of the blind*. London: Faber and Faber.
- Kuusisto, S. (2000) *Only bread, only light: poems*. Port Townsend, Wash.: Copper Canyon Press.
- LeBoeuf, M. (2007) 'The power of ridicule: an analysis of satire'. *Senior Honors Projects*, 63. [Online] Available from: http://digitalcommons.uri.edu/cgi/viewcontent.cgi?article=1065&context=sr_honorsprog [Accessed: 8 December 2015].
- Lethbridge, J. (2012) 'Impact of the global economic crisis and austerity Measures on Woman'. *Public Services International Research Unit (PSIRU)*.
- Levi, P. (1987) *If this is a man and the truce*. London: Abacus.

- Lombardi, E. (2015) *General book club questions for study and discussion* [Online] Available from: http://classiclit.about.com/od/bookclubs/a/aa_bcquestions.htm [Accessed 8 December 2015].
- Longmore, P.K. (2003) *Why I burned my book and other essays on disability*. Philadelphia: Temple University Press.
- Lorenz, D.C. (1998) 'Man and animal: the discourse of exclusion and discrimination in a literary context'. *Women in German Yearbook*: 201-224.
- Lusseyran, J. (1964) *And there was light: Translated by Elizabeth R. Cameron*. London: Heinemann.
- Macdonald, S. (2006) 'A suicidal woman, roaming pigs and a noisy trampolinist: refining the ASBO's definition of 'anti- social behaviour'. *The Modern Law Review*, 69 (2): 183-213.
- Macgregor, V. (2014) *What Milo saw*. London: Sphere.
- Machiavelli, N. (2009) *The prince*. London: Penguin.
- Malan, R. (1990) *My traitor's heart: blood and bad dreams: a South African explores the madness in his country, his tribe and himself*. London: Vintage.
- Manchester Citizens Advice Bureau Service (2013) *Punishing poverty? A review of benefits sanctions and their impacts on clients and claimants* [Online] Available from: <https://onedrive.live.com/view.aspx?resid=CB5ED957FE0B849F!350&app=WordPdf&authkey=!AJTbB-gzwsSCayQ> [Accessed 20 August 2015].
- Marsh, S. (2014) *Diary of a benefit scrounger: who will watch the watchmen? an open letter to John Bercow*. [Online] Available from: <http://diaryofabenefitscrounger.blogspot.co.uk/2014/11/who-will-watch-watchmen-open-letter-to.html> [Accessed 8 December 2015].
- Martin, G.R.R. (2011) *A game of thrones*. London: Harper Voyager.
- McCarthy, C. (2006) *The road*. London: Picador.
- McKay, M. (1997) 'An interview with Maggie Gee'. *Studia Neophilologica*, 69 (2): 213-221.
- McWilliam, C. (2010) *What to look for in winter: a memoir in blindness*. London: Jonathan Cape.
- Medhurst, N., Cox, J., Nurden, C., O'Brien, D. and Wetherly, L (2014) *Parkinson's UK: progressive conditions dossier* [Online] Available

from: <http://www.parkinsons.org.uk/sites/default/files/progressiveconditionsdossier.pdf> [Accessed 8 December, 2015].

Meekosha, H. (2002) 'Virtual activists? Women and the making of identities of disability'. *Hypatia*, 17 (3): 67-88.

Michalko, R. (2002) *The difference that disability makes*. Philadelphia: Temple University Press.

Miele, K. (2007) *Representing empathy: speaking for vulnerable bodies in Victorian medicine and culture*. PhD thesis. Warwick: University of Warwick.

Milligan, S. (1972) *Adolf Hitler: my part in his downfall* London, Penguin.

Milton, J. (Undated) 'On his blindness'. In: *The Oxford Book of English Verse* [Online] Available from: <http://www.bartleby.com/101/318.html> [Accessed 18 August 2015].

Mintz, S.B. (2002) 'Invisible disability: Georgina Kleege's "sight unseen"'. *NWSA Journal*, 14 (3): 155-177.

Mitchell, D.T. (2000) *Narrative prosthesis: disability and the dependencies of discourse*. Ann Arbor: University of Michigan Press.

Monbiot, G. (2014) 'Cleansing the stock' and other ways governments talk about human beings. *The Guardian*, [Online] Available from: <http://www.theguardian.com/commentisfree/2014/oct/21/cleansing-stock-doublespeak-people-killing> [Accessed 12 August 2015].

Murphy, R.F. (2001; 1987) *The body silent*. New York: W. W. Norton.

Nelson, R. (2013) *Practice as research in the arts: principles, protocols, pedagogies, resistances*. Hampshire: Palgrave Macmillan.

Nussbaum, S. (2013) *Good kings bad kings*. Chapel Hill: Algonquin Books of Chapel Hill.

Office for Budget Responsibility (OBR) (2014) *CM 8966: Economic and fiscal outlook - December 2014* [Online] Available from: http://cdn.budgetresponsibility.independent.gov.uk/December_2014_EFO-web513.pdf [Accessed 8 December 2015].

Oishi, E. (2014) 'Visual perversions: Race, sex, and cinematic pleasure'. *Signs*, 40 (1).

Oliver, M. (1990) "The individual and social models of disability". *Joint workshop of the living options Group and the Research Unit of the Royal College of Physicians*.

- Olsson, H., Backe, H., Sörensen, S. and Kock, M. (2002) 'The essence of humour and its effects and functions: a qualitative study'. *Journal of Nursing Management*, 10 (1): 21-26.
- Orwell, G. (1997) *Nineteen eighty-four*. London: Secker & Warburg.
- Orwell, G. (2013) *Politics and the English language*. London: Penguin.
- Panorama: Disabled or faking it*. (2012) BBC 2, 30 July, 21:00.
- Persin, M. (2007) 'José Angel Valente's blindness and insight: rewriting as discovery'. *Hispania*, 90 (3): 431-442.
- Poore, C. (2003) 'Who belongs? Disability and the Germannation in post-war literature and film'. *German Studies Review*, 26 (1): 21-42.
- Reeve, D. (2002) 'Negotiating psycho-emotional dimensions of disability and their influence on identity constructions'. *Disability & Society*, 17 (5): 493-508.
- Robert, P.M. and Harlan, S.L. (2006) 'Mechanisms of disability discrimination in large bureaucratic organizations: ascriptive inequalities in the workplace'. *The Sociological Quarterly*, 47 (4): 599-630.
- Ronson, J. (2011) *The psychopath test: a journey through the madness industry*. London: Picador.
- Ross, C. (2001) 'Vision and insufficiency at the turn of the millennium: Rosemarie Trockel's distracted eye'. *October*. 87-110.
- Ross, M.L. (2008) 'On a darkling planet: Ian McEwan's "Saturday" and the condition of England'. *Twentieth Century Literature*: 75-96.
- Rothstein, M. (1986) No balm in Gilead for Margaret Atwood [Online] *New York Times*. Available from: <http://www.nytimes.com/1986/02/17/books/no-balm-in-gilead-for-margaret-atwood.html> [Accessed 08 December 2015].
- Sacks, O.W. (2010) *The mind's eye*. London: Picador.
- Samuels, E. (2002) 'Critical divides: Judith Butler's body theory and the question of disability'. *NWSA Journal*, 14 (3): 58-76.
- Saramago, J. (1997) *Blindness: a novel*. London: Harvill.
- Schmiesing, A. (2014) *Disability, deformity, and disease in the Grimms' fairy tales*. Detroit, MI: Wayne State University Press.
- Schneider, B., Austin, C. and Arney, L. (2008) 'Writing to wellness: using an open journal in narrative therapy'. *Journal of Systemic Therapies*, 27 (2): 60-75.

Schrödinger, E. (1935) Die gegenwärtige situation in der quantenmechanik (the present situation in quantum mechanics), translated by John D. Trimmer (1980). *Proceedings of the American Philosophical Society*, 124: 323-38.

Sedgwick, M. (2013) *She is not invisible*. London: Indigo.

Self, W. (1996) *The sweet smell of psychosis*. London: Bloomsbury.

Shildrick, T., MacDonald, R., Furlong, A., Roden, J. and Crow, R. (2012) *Are 'cultures of worklessness' passed down the generations?* York: Joseph Rowntree Foundation.

Siebers, T. (2003) 'What can disability studies learn from the culture wars?' *Cultural Critique*, (55): 182-216.

Slade RNIB - *Supporting people with sight loss* [Online] RNIB. Available from: <http://www.rnib.org.uk/Pages/Home.aspx> [Accessed 13 November 2012].

Spike Milligan: Love, light and peace. (2014) BBC 4, 17 December, 00:25

Stevenson, R.L. (2011) *Treasure Island*. London: Sovereign.

Stoddard Holmes, M. (2003) *Fictions of affliction: physical disability in Victorian culture*. Ann Arbor, Mich.; Bristol: University of Michigan Press.

Szell, R. (2011) *Blind trust*. Brighton: IndePen Press.

The Last Leg (2012) Channel 4, 22:30pm.

The Today Programme (2013) BBC Radio 4, 15 July, 06:00.

Thomson, R.G. (1997) *Extraordinary bodies: figuring physical disability in American culture and literature*. New York: Columbia University Press.

Toombs, S.K. (1997) 'Taking the body seriously'. *The Hastings Center Report*, 27 (5): 39-43.

Undercover: benefits cheat. (2014) Channel 5, 16 August, 21.00.

Wait til dark. (1967) [DVD] Director: Young, T. Warner Bros.

Wasserman, D., Asch, A., Blustein, J. and Putnam, D. (2011) 'Disability: definitions, models, experience'. Oxford: Oxford University Press.

Waugh, P. (1984) *Metafiction: the theory and practice of self-conscious fiction*. London: Methuen.

Weldon, F. (1983) *The life and loves of a she-devil*. London: Hodder and Stoughton.

- Weldon, F. (1992) *The heart of the country*. London: Vintage.
- Weldon, F. (2015) *Mischief*. London: Head of Zeus.
- Weldon, F. (2015) *The cosmic statement* [Online] Available from: <http://www.fayweldon.co.uk/the-cosmic-statement/> [Accessed 12 August 2015].
- Wells, H.G. (2006) *The country of the blind and other stories*. Iowa: First World Library.
- Wendell, S. (1989) 'Toward a feminist theory of disability'. *Hypatia*, 4 (2): 104-124.
- Wilder, L.I. and Williams, G. (1961) *By the shores of Silver Lake*. Oxford: Windrush.
- Willett, J. and Deegan, M. (2001) 'Liminality and disability: rites of passage and community in hypermodern society'. *Disability Studies Quarterly*, 21 (3).
- Wilson, T., Morgan, G., Rahman, A. and Vaid, L. (2013) 'The local impacts of welfare reform: an assessment of cumulative impacts and mitigations'. *London: Local Government Association*.
- Winterson, J. (2004) *Lighthousekeeping*. London: Harper Perennial.
- Woiak, J. (2007) 'Designing a brave new world: eugenics, politics, and fiction'. *The Public Historian*, 29 (3): 105-129.
- Wolbring, G. (2012) 'Expanding ableism: taking down the ghettoization of impact of disability studies scholars'. *Societies*, 2 (3): 75-83.
- Wood, S. (2015) *Reference FS50557638 - Freedom of Information Act 2000 (FOIA) decision notice 30 April 2015* [Online] Information Commissioner's Office (ICO). Available from: https://ico.org.uk/media/actions-weve-taken/decision-notice/2015/1424160/fs_50557638.pdf [Accessed 12 August 2015].
- Wyndham, J. (1979) *The day of the triffids*. Harmondsworth: Penguin.
- Yanagizawa-Drott, D. (2014) 'Propaganda and conflict: evidence from the Rwandan genocide'. *The Quarterly Journal of Economics*, 129 (4): 1947-1994.
- Young, S. (2012) *We're not here for your inspiration* [Online] The Drum. Available from: <http://www.abc.net.au/news/2012-07-03/young-inspiration-porn/4107006> [Accessed 12 August 2015].