# A Dialogical Narrative Analysis of Voice Hearers and Emotions

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A thesis submitted in partial fulfilment of the requirements of Birmingham City University for the degree of Doctor of Philosophy

September 2016

Health, Education and Life Sciences, Birmingham City University

### Abstract

This thesis is the result of a process of Dialogical Narrative Analysis with twelve participants who hear voices that other people cannot hear. It uses the *socio-narratology* of Arthur Frank to examine their stories about their experiences in the context of the complex and conceptually contested fields of knowledge that are considered relevant to voice-hearing.

The 12 voice-hearers present a wide range of ideas and explanatory frameworks about their experiences. Emotions are deliberately part of this thesis and many stories are as moving as they are complex. The author's own experiences of these stories is also acknowledged and explored. Whereas much research about hearing voices is biological, psychological or occasionally sociological, this research has many aspects of political exploration and the field is understood as one of conflicting vested interests and ideologies.

Many ethical considerations come to light, especially concerning forms of power and knowledge within mental health professions and services in the UK, but also within the Hearing Voices Movement, which is seen as a vital movement with a variety of possible histories. One possibility suggested by this research is that voice-hearers are able to tolerate, and benefit from, more dialogical approaches and that those that do may find more successful ways to live with their experiences than those who are subject to the strongly monological emplotments of much professionalised knowledge. Another strong theme is the great influence of neoliberal politics over individuals and notions of 'health'.

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# Section 1

### **Living with Voices**

This work has been undertaken as a research studentship and I have been given freedom to reinterpret the original brief considerably. It was explained at my interview that this research was in certain ways felt to be related to a book co-authored by my supervisors Mervyn Morris and Marius Romme (with Sandra Escher, Jacqui Dillon and Dirk Corstens):

Romme, M, et al., 2009. Living with Voices: 50 Stories of Recovery. PCCS Books in association with Birmingham City University.

This book I knew very well and had encouraged voice-hearers and professionals to read, as well as referencing it in my Masters dissertation. This new research was to be in some ways part of the same lineage as that text, part of the same movement, but might achieve something slightly different; *Living with Voices* is a collection of annotated personal accounts, but is not research following a particular method. It was hoped that my research would perhaps satisfy those that might dismiss that work. The Hearing Voices Movement, (hereafter HVM) both seeks new avenues for research and is simultaneously cautious about it, something acknowledged by their current chair, Dirk Corstens (Corstens et al., 2014, p289). One idea envisaged at that time was something which used validated tools to measure *dissociation*, researching its relevance to hearing voices and emotions.

I began to move away from that idea. Of all of the possible *emplotments* (about which, more later) I encountered it was probably the most attractive single story with which to think about voice-hearing and emotions. It was to the politics of emotions and of voice-hearing that I was drawn; I felt that the heterogeneity of the field demanded it. The method of research I came upon was suited to thinking about vested interests. An academic whose work on mental health I thought highly of, Katherine Angel, often quoted Chris Kraus' 1997 book, "I love Dick": *who gets to speak and why is the only question* (Kraus, 1997); I was fascinated.

### Style

The only non-standard referencing method I have employed in this text is when referencing ebooks. Some helpfully provide the text's paper page equivalent for citation purposes; some do not. Where it has not been possible to provide page numbers from direct citations, I have provided the "location number" under the abbreviation "loc", e.g. (Smith, 2010, loc 368).

#### Me

Stories are "recipient designed" (Arthur Frank, 2012, p90) and I was the recipient. The research method, which will be discussed in this section, requires me to be visible in this research. This is not seen as a weakness:

Dialogical interpretation begins with the interpreter's recognition of being caught up in his or her own stories, which may overlap with the narrative habits of the storyteller or may require a substantial shift in horizons, in order for the other's story to be recognisable (Frank, 2012, p94).

This asks the question of whether objectivity is not only seldom possible, but if it is desirable, since the dialogue between my stories and participant stories is part of what is revelatory. It raises my thinking and my research narrative as explanatory in this work and it is frequently most honest to write in the first person, although there are times when I have wished it otherwise. Primarily, I want to explore the narratives of 12 voice-hearers, and place them centrally within a plethora of strong cultural narratives about them and their experiences. However, I also need their stories to bring out what is relevant for the reader to know about myself; dispersed within that text are some of my stories. Occasionally I get a little *in the way* of the participants' texts, and the stories of others certainly do, and the question for Dialogical Narrative Analysis is not whether this can be disguised but rather to ask why that happens and what it tells us about all stories in question.

I am 40 this year, a man, married with three children. I live in the house my wife's grandfather built. I have a sit-on mower. Most of this thesis has been written looking out onto a garden with a children's sandpit and a small field with our chickens busily being chickens. It is different from the blocks of flats I lived in as a child and teenager in Hong Kong and Singapore.

My children, all under ten, ensure that strong emotions are never far from daily life. Put me in the middle of three children whom I love, bickering about breakfast, and I wonder if I really have any better skills with emotions than I had at 15. Five minutes later we are hugging on the sofa, or laughing at the dog, or shouting about Lego.

Being a mental health nurse, which began in my early twenties, has been utterly energising in my life. I have never become bored. The more I have learned, the more questionable the role of *mental health nurse* has become, so what started relatively simply has become something that, rather painfully, I am not sure I ever want to do again. It will be important for me to articulate the role of this research in that difficulty; it is part of the "findings" of research designed to ask what stories do. Increasingly over the last five years (although it began much earlier) I have become alienated from colleagues and feel most at home with "the mad". This, too, is partly an effect of the stories within this research. Others I have met, some through these studies, have also been inspirational and could not have done this work without the support of other professionals equally skeptical about what we are asked to do, especially without the influence of my friend Joachim Schnackenberg. The two of us have worked hard together to try to continue to understand the questions posed to us by our nurse-training and by our work, especially about *hearing voices*, since we first met in 1997.

In 2010 I left a role as a city community psychiatric nurse and studied for a Masters degree at Warwick University called "The Philosophy and Ethics of Mental Health". I wrote my dissertation about the work of Marius Romme and Sandra Escher, two founders of the Hearing Voices Movement. That dissertation led to this research opportunity.

One last thing to say about me requires a little courage to tell. I have had a life-long relationship with faith with twenty years as an atheist. There is a little of this spread through the thesis.

Although still an atheist, I have become a Quaker in the last three years<sup>1</sup>. I feel very nervous about the word "spiritual" and mostly (not always) still agree with Dawkins, whose book *The Blind Watchmaker* (2013, originally 1986) was like a healing balm in my life aged 24: "spiritual" is often used as a trump-card in the face of which reason is supposed to tiptoe from the room. Has this research pushed me back towards something mystical or religious? I do not think so, but in other ways it is clear to me why I am finding a new home within the Religious Society of Friends. It is a response to what may happen when stories *inflate* (an idea which will be explored). The sense that I was making of the world was leading to that special set of emotions which go with acutely feeling the power differential between myself and the decision-makers, and I was beginning to be difficult to be around, suspicious, angry. "The trouble is that people aren't all that great and I'm one of them", I said to my wife. Sitting in silence each week and trying, as the Quaker "Advices and Queries" have it, to "take heed, dear Friends, to the promptings of love and truth in your hearts" (1995, p5) is therefore a lot about emotions, the subject of this research. Some will see it as a psychological process, but, especially for someone who is interested in "socio-narratology", it is more of an exercise in connecting to stories for a purpose.

<sup>&</sup>lt;sup>1</sup> Approximately a fifth of British Quakers are thought to be atheists, or "non-theists" (Hampton, 2015).

## **Contested Categories**

There is no such thing as philosophy-free science, just science that has been conducted without any consideration of its underlying philosophical assumptions (Daniel Dennett, 2014, p20).

#### Section introduction

This first section is an attempt to introduce some of the philosophy which lies behind this research. After this section, I mostly just allow the work to sit within Arthur Frank's language, the author of the method to which this philosophy led me. Without this section, it may appear that I have chosen an unconventional method of research out of perversity, yet for me it was necessity.

I expect that in reading philosophy for a period of time, perhaps for a period of a few weeks, I will have a few days in which I feel like I am falling apart. This has happened so many times now that I am not frightened by it. Perhaps *having a breakdown* is an essential part of learning about the world and being a person, breaking down previous assumptions and going through the necessary period of rewriting. It is in this sense that "narrative therapist" (a term he did not like) Michael White, an important influence on this research, uses the phrase "rites of passage" (White and Epston, 1990, p7), the re-writing of an old, now unviable self.

In December 2010, during my Masters degree, there was a moment in which the pent up anxieties about the course seemed to come together as I read that, according to Donald Davidson, *reasons were causes* (Davidson, 1963). But then, I have been drawn to what Dennett calls *the zombic hunch* (2014, p283) in one form or another my whole life<sup>2</sup>. I felt I needed to believe that there was something about humans that separated us from nature, that allowed us things like freedom of the will, morality and intentional action, and I made the error (I believe it to be error) that in order to have those things and to have them not as mere illusion (a distinction which I also now feel I misunderstood), we could not be determined. I felt that reasons had to be the kind of thing that allowed us to "break free" from causal nature. I had loved G.E.M Anscombe's *Intention,* I felt at the time that it meant that through living *narratively* we could somehow escape nature, speak back to it, and to discover that she was indeed somehow allied to this Davidson, this... *determinist!* It was more than I could understand. I walked around, I ate, I carried on, but I felt like the living dead.

But that breakdown remains essential. I now understand it differently and it forms part of the philosophy of this thesis. If we can have have something like "freedom of the will" and yet be determined, then it is clear that neither *freedom, will,* nor being *determined* can be as we generally understand them to be. This is relevant because questions of the role of nature in understanding mental phenomena and the very related problems of understanding the idea of human agency seem to be the crux of the arguments between the different kinds of knowledge about hearing voices and emotions, whether acknowledged or not. It is not a coincidence that the two most highly paid clinical members of mental health teams are psychiatrists and psychologists. The role of biology verses the role of psychology in understanding voice-hearing and understanding emotions is defined by questions (often hidden) about being "caused by nature" or being "free to make choices", about "being my brain" or "being myself", perhaps *despite* a "diseased" or "ill" brain. Relationships between psychology and psychiatry are deeply fraught and they are not the only

<sup>&</sup>lt;sup>2</sup> Were science able to create a *perfect* physical replica of me, complete with all of the neurological connections in my brain, it would not be me, not quite: there is some added x-factor that makes me, "me". It would remain "unconscious", a kind of zombie. I have "consciousness". I am an "I", it would be an "It". Of course, people never use these rather unusual terms, we talk about our "humanity", "the will", obscure issues with words such as "holism", or betray a belief in our separation from "the animals", or casually assume that the law must be correct in saying I can be held accountable for my actions (which could not be possible if *determined* meant *inevitable*).

perspectives in this battle. Which diagnoses mark which discipline's territory? Questions abound about whether the psyche is really any different from the soul<sup>3</sup>, evoking all of the same sense of there being a me that sits in my body like a person driving a car, the Zombic Hunch, or the classic mind-body dualism. "My favourite part of the brain is the mind", said David Eagleman (BBC Radio 4, *The Infinite Monkey Cage*, 08/02/2016), described in the programme brief as a "superstar neuroscientist". "Who you are can only be understood in terms of the three-pound organ called the brain" (Eagleman, BBC television, 28/01/2016).

Dennett may have mocked my Zombic Hunch but he also says that the "self is the centre of narrative gravity" and "it is a category mistake to go looking for the self in the brain" (Dennett, 1992, p275). He sees no reason at all to say that meaning, purpose, choices and selfhood vanish in a world where we are part of causal nature: *compatibilism*. Anscombe and Davidson can work together, after all. When examining the world of mental health one guickly learns that both words mental and health are full of tensely competing ideas, and what is meant by either word is very difficult to be clear about; while mental struggles under the weight of various incarnations of the mind-body problem and philosophies of personal identity, health struggles as an uneasy hybrid between notions of physiology and normative, ethical and political questions that some choose to characterise as fact and value (Ross, 2007, p108; Fulford, 1989, p36; Fulford in Radden, 2007, p206). Arguments about the difference between the words disease and illness abound, and their relationship to terms such as function and action (Fulford et al., 2006, p131). Hence, we should never expect to say anything very precise with the term *mental health*, certainly nothing uncontroversial; the stories in this research may cause the reader to wonder if it is useful at all. They may also wonder at its growing acceptance in the UK generally. Adding the words and wellbeing compounds with further mysteries, perhaps illustrating little more than dissatisfaction with the original. It follows that *mental illness* suffers from all of the same problems. It begs questions about objective measurement, the location of what is the be measured, the validity of subjective (personal) experience, the discipline most suited to make that measurement, the technology most suitable to make it, teleological conundrums, and ethical questions including responsibility and blame. Yet the experiences that are described in terms of "mental illness" are not, and have never been, merely an invention of language, or simply imagined. The moving experiences of the twelve people in this work are generously given and they are suffering a lot more than "semantics".

Already in this description, the stories I have used (phrases such as "freedom of the will" and "the mind body problem" have started to steer this discussion in ways which are non-neutral, forming questions which entail their answers. What Arthur Frank labels "emplotment", of central importance to this work, is taking place (2012, p136). This emplotment could be characterised in a number of ways, but one way is to notice that so far it has not seemed relevant to ask about communities of people, but only individuals. As will be seen, this work uses a research method which begins with the understanding that this is an omission and that it is a crucial one. Frank's use of "emplotment" describes different kinds of narrative pressure, especially the pressures of groups upon individuals. Here, I include the idea that fundamental philosophical problems and the common stories we use to work with them are also emplotting hearing voices and emotions.

#### Three sets of terms

There are three sets of terms which need to be introduced, and for the purposes of this work I am going to treat them as if they are more or less synonymic. I feel I must make that choice in order to move on without too much delay, an exploration of the differences would involve a great deal of precision (words). Deconstructing them in detail might move this PhD firmly into a straight philosophical exploration, leaving too little for participants. I do not think that work would be especially valuable. The three sets of terms are:

#### universal/parochial

<sup>&</sup>lt;sup>3</sup> Except that the two can be said to represent a major historical exchange of entitlement between the church and medicine, one of ownership of persons (Jones et al., 2015, p181)

#### natural/interactive ahistorical/historical

The first is from mathematician Ian Stewart and and biologist Jack Cohen. In their work, especially the seminal *The Collapse of Chaos* (1994) and elsewhere (e.g. 2001), they suggest that were we to rerun evolution there are certain things we should expect to occur a second time, indeed every time (vision, for example). These may therefore be thought of as *universals*. There are other things which we should not expect to occur twice (the rather odd juxtaposition of trachea and oesophagus in mammals, for example), and may therefore be thought of as *parochials*. Parochial is therefore a temporal and a geographic term.

In this research, emotion itself is, as Dennett would undoubtedly agree, universal, but the particular words and meanings and attitudes and morality we have about different emotions are almost certainly parochial. A crude example of this would be to say that the sensations associated with revenge and with justice are probably universal; no organism with the necessary organs of perception could be indifferent to the discovery that others in its environment have found ways to gain at its expense. However, the differences between those two are highly parochial; revenge and justice are perhaps two different *stories* which emplot the sensation, they are not universal/natural/ ahistorical. Treating revenge or justice as being something which can be understood as universal/ natural/ahistorical will lead to error. In this work it is often not differences between emotions or experiences.

The second terms are from philosopher of psychiatry Ian Hacking (1995, p353 - 354, for example), his suggestion for deciding whether something occurs in nature and is unaffected by our way of thinking about it or if it is something else, more interactive<sup>4</sup>. The "interactiveness" of certain kinds is key to the "narrative turn" of philosophy and humanities disciplines of the past few decades; that narratives create as well as reflect reality (Grant et al., 2015, p280, for example), and if there is one idea that this research stands upon, one key reason for the suitability of the method chosen, it is this. At a lecture I attended in 2013, Hacking described his work as being in some ways trying to understand the interface between the "natural sciences" and the "humanities". Hacking sees humans as biosocial rather than reductively biological (Hacking, 2000: 101-110), and in many ways seeks to notice when interactive kinds are "biologized" (1995, p353). An implication of this is that there may be no study of mental phenomena which is not to some extent culturally and historically specific. Natural kinds are stationary, but interactive kinds are moving targets (Khalidi, 2010, p342).

The third is taken from correspondence with my Masters degree tutor, Jon Rubin, in 2014. In some ways I feel it is merely derivative of universal/parochial and follows from natural/interactive, but there does seem to be something valuable about including the word "historical" in this exploration of kinds. History is a subject which, from school age, is taught as something for which *causality* and *fact* are seen as less suitable than *argument* and *perspective*. My GSCE history teacher told me that "history is an apex not an average". I have been unable to find a source for that quote but it remains one of the cleverest things I have ever heard about society, narratives, power, the present and indeed the self.

According to this perspective, medical knowledge is regarded not simply as an incremental progression towards a more refined and better knowledge, but as a series of relative constructions which are dependent upon the socio-historical settings in which they occur and are constantly renegotiated (Lupton, 2012, p9).

The relevance these three sets of terms to this project is this: I believe that much of the debate about the experience of hearing voices, emotions and of the field which frequently concerns itself

<sup>&</sup>lt;sup>4</sup> As a compatibilist, Dennett would say that it is not necessary to imagine that interactive kinds are separate to nature.

with both (i.e. "mental health") is conducted as if dealing with universal/natural/ahistorical kinds. It is the beginning point of this research that most of these concerns are instead parochial/interactive/ historical kinds, or, that they are sufficiently so (because objects can be a sort of hybrid) to make them (a) impossible to treat simply as universal/natural/ahistorical and (b) open to the exciting and dangerous possibilities of what here is termed emplotment, following Arthur Frank. This divide (and exactly what one imagines to be found under each column) is also one way of explaining the astonishing heterogeneity of the field, which is by far the most remarkable feature of research about hearing voices and emotions, arguably more remarkable than any particular knowledge raised and the feature demanding most attention, the reason why a standard review of the literature seems impossible. The study of the narratives of "mental health" is primarily a profound epistemological challenge. I am not, of course, the first to realise this, although I hope this analysis, which continues through both of these introductory chapters, is both personal and fresh. When members of the Critical Psychiatry Network called for a paradigm shift from the *technological* to the hermeneutic (Bracken et al., 2012) they were articulating something similar (more on this later). There is no doubt that it is not only epistemology but also politics that are the target of Bracken and Thomas, given their valuing of Foucault (e.g. 2001, p725.), and of Thomas Kuhn (e.g. Thomas et al., 2012, p152 - 162). Paradigm shift! More like regime change! I said to Jon Rubin upon reading the multi-authored piece in 2012. He told me to go back and read my Kuhn (1962): a paradigm shift is a regime change.

## A first attempt

In 2012, I began this research with an attempt at a more standard literature review. I mention it here because I see it as an instructive failed project. A strategic search with a number of search terms of "key" databases reduced eventually to 69 articles about hearing voices which I then tried to categorise as either "technological" or "hermeneutic", following Bracken et al. (2012), and also some ideas about the valuing of voices. I think that the way I was interpreting "technological" or "hermeneutic" was mostly to do with whether I thought the article represented a reductionist/ positivist science, or a non-reductionist stance in which persons were an emergent property of body and world in some way. At the time I thought I should be looking at "coping" (emotionfocussed or problem-focussed, as coping literature often divides it) as a way of thinking about emotions. The highly opposing views or assumptions about aetiology of the experiences was something I expected, but there were so many other "goods" in evidence: management, functioning, recovery, distraction, adaptive vs maladaptive coping, accepting medication or living medication-free. There were studies of transcranial magnetic stimulation. There were other studies which, even with great consideration, were simply unclassifiable under any schema I could label. I felt I had dipped a toe into the heterogeneity, but even though I had begun to think of the need to view the field as being made up of differing narratives, it seemed that trying to sort it into different headings was not the right approach, and that even were I to be able to sort them well that there was still significant heterogeneity within each set<sup>5</sup>.

What this attempt showed me is that, firstly, it is not enough to try to understand stories as schemata. Even if it is possible to make an attempt to classify perspectives under columns, they are not merely collections of facts put together. This is part of the reason that when, some months later, I read Arthur Frank's work, I immediately related to the need to understand what stories *do* rather than simply discovering what they *are*. Likewise, upon later being introduced to Fulford and Colombo's analysis of different models of mental health within professional teams (2003, p1557-1570), although their effort is much more successful than my own, it remains my belief that what is missing is the dialogue between the stories and power, and what virtues they create and all of the other things that I found in the research method I eventually chose.

Secondly, I became more aware that emotion was another much more complicated topic than I had yet realised, and that what I had so far researched, drawing me into the subject through ideas of

<sup>&</sup>lt;sup>5</sup> This piece of work, my first attempt at a literature review, is included as Appendix 4.

"coping", was inadequate. Later, I read a piece which also identified that coping was a problematic concept (Leff, et al., 2008), but it struggles to propose an alternative. I began to see was that emotions were yet another thing that was not simply universal/natural/ahistorical. Reflecting in 2016 upon this second realisation I feel I should ask readers to remember that I have spent many years working as a mental health nurse and that it may therefore seem surprising that I had spent so little time thinking about emotions. Finally, the point that was clear to me at the time is still the most profound: there is simply no point talking about styles of coping if there is no agreement about what is being *coped with*.

# The effects of a shift towards the parochial/interactive historical

In this work I occasionally employ the following approach: I take knowledges which have been articulated as if universal/natural/ahistorical and try to show that they are parochial/interactive/ historical, at least in part, or else I simply point out that others have done this and try not to give it too much space. However, this is not exactly to discredit; it is merely to show that the issues are valid candidates for analysis *as stories*. It allows me to consider things like brain scans, or medication, or diagnosis or psychological techniques or even concepts such as "equality" as storied. As such they are given credibility (or not) based on quite different kinds of judgement, discussed further in the last chapter.

The effects of this shift, placing most key terms of study under the column *parochial/interactive/ historical,* are profound. The first is that it elevates the importance of context. Under this view emotions, voice-hearing and most kinds of experience – and therefore persons and actions – must make decreasing sense as they become isolated from their context, a context which has to include culture, and culture across time; history. The parochial/interactive/historical self is one which is situated, not isolatable, and with this comes immediate choices about the suitability of certain kinds of research. As above, it is certainly interesting to know what happens in brains in fMRi scanners, when the brain is experiencing. What exactly is *explanatory* about the knowledge that is generated is, however, in need of extreme care. The voice-hearer in the scanner may tell us more about the operator of the scanner than about voices. Yet the "technology" is much more extensive than scanners: Nikolas Rose, consciously echoing Foucault, considers it as an apparatus that forms "the birth of the neuromolecular gaze" (Abi-Rached, et al., 2010). Equally, the voice-hearer described in terms of psychological mechanisms is certainly interesting, but once again, the knowledge generated may be as explanatory of psychologists and the culture they are part of than the experiences they describe.

Therefore, the shift changes the kind of engagement this work has with huge swathes of literature about voice-hearing and emotions, much of which relies on DSM categories, which either attempt to classify, or are in practice treated as, natural kinds. Such research is still relevant to this work, but mostly interesting for the extent to which it has been able to proliferate, to find recruits, but not as "findings" to build upon. Now it becomes clear what is really meant by a *paradigm shift*: we may have to bracket enormous amounts of prior scholarship and dedicated research. In this work I am going to try to not have the almost ubiquitous separate chapter providing a critique of DSM psychiatry. At some stage it will have to be accepted that it has been done too many times already, and that the question of why we still have it is more important than its internal credibility, a point David Pilgrim was already making in 2007 (Moncrieff, 2010, p371). Katherine Angel's work on the history of "female sexual disfunction" is superb *because it is history*, and shows that the DSM makes sense as history (Angel, 2010, p536 - 541), and this again is the key starting moment of this research: one should not engage history as if natural science. And, as Angel intends us to see and has been the contention of philosophers of history such as Hayden White, narrative structures are imposed upon history for a purpose (cited Carr, 2008, p27). Histories are therefore political.

What else does this do to the Grail of a strategic review of the literature? A shift to the parochial/ interactive/historical massively widens the field of relevance. This means that even if I were able to

improve on literature reviews such as Schnackenberg and Martin (2013) or Longden et al. (2012), both of which would serve as an excellent chapter in a PhD (both were, I believe), neither are the right approach in this work. This work would view neither as 'objective' in the sense that a strategic review of literature is often thought to be, although it would not view that as a problem, just as more texts to be placed in dialogue (as will be seen). Instead of trying to replicate these, therefore, it just seems better to state from the start that this research cannot possibly avoid accusations of all kinds of things which are often thought to be poor quality in academic work: subjectivity (as already raised); incompleteness; breadth rather than depth. It may be that the work cannot help but appear to be politically partial, for reasons which will be explored in the next chapter. Completeness of explanation is not possible when categories are too contested to so confine the subject as to render it objective, to finalise it. There are profound questions about the possibility of any quantitative work at such a moment. Instead of completeness one can only hope for *coherence*, and through coherence for a knowledge which is sufficiently transferable, applicable and resonating, a utility, to contribute towards... towards what? For Frank, the purpose of this research is an opening up (2012, p110). When I started this project I do not think that I realised this. Looking back, I think I believed I might be able to contribute towards solidarity. After four years of study for this research, a full time Masters degree and some 12 years of nursing, I feel increasingly confident in saying that solidarity is all there ever was in this field, but now it seems that as soon as solidarity comes it is, like every unifying story, both enabling and at once dangerous, as participants here will testify. So "opening up" it is, rather than solidarity. "Opening up" also prevents a charge of attempting to create a phenomenology of experience which ignores the biological. Any theory made through phenomenological exploration alone could not escape the accusation of "vertical incompleteness" (Graham, in Radden, 2007, p98), the "missing body" (Boyle, in Coles et al., 2013: p6); however, the other charge, that phenomenological accounts also suffer from horizontal incompleteness, I hope my work can satisfy.

#### **Hearing voices?**

What to call the phenomenon which features in these narratives: is it "hearing voices", just "voices", "psychosis", "auditory hallucinations", "schizophrenia" or something else? In choosing the term "hearing voices" this work is already establishing itself as at least partly recruited into a narrative which has arisen in recent decades. Angela Woods contends it was not possible to be "a voice-hearer" before 1987 (2013, p263). It evokes a certain identity and a stance that has in no small part been formed through the efforts of one of this work's supervisors, Marius Romme (working with Sandra Escher). This will be discussed in relation to the accounts of the participants. It would be disingenuous to write as if neutrality in this regard were possible and that I did not have to make certain non-neutral decisions before this research ever recruited a "voice-hearer". While "Auditory Verbal Hallucinations" is the term of the medical mainstream, it is not found to be neutral (Corstens et al., 2014, p289) by the HVM. "Hearing voices" may appear to be more so (McCarthy-Jones, 2015) given that it seems only to describe an experience without associating it with a syndrome or illness or making a judgement about whether it is a healthy experience. However, the very choice to pull the experience out from under the headings (e.g. "schizophrenia") so often associated with it is itself a political act, a rebellion, and one for which many "voice-hearers" are utterly conscious (and so I do not wholly agree with McCarthy-Jones). For Hacking, with early 20th Century revisions the overarching psychiatric category known as hysteria disappeared into a hundred places in the textbook (Micale, cited Hacking, 2002, p72), and he shows how the fate of a diagnosis, "hysterical fugue", once identified as "hysteria", became a species bound up with the fate of the whole genus (2002, p38). What was once a major section of disorders became a mere sub-feature noted in lists and subheadings. Using the phrase "hearing voices" is like this same process in reverse: pulling out a symptom listed in a number of places and making it a major category of experience. Following Anscombe (indeed, she was once his head of department) Hacking reveals that as descriptions change, so the possibilities of action under that description (Anscombe, 1979) are different: one of the reasons they are interactive kinds. Taking a phenomenon such as "hearing voices" to study already implies dissatisfaction with the current classification. Adding "emotions" into the study has further effects, partly because, as will be seen, emotion itself contains parochial/interactive/historical concepts, and partly because it is likely to

drive forward the suggestion that the two relate to each other, and this is not a neutral thing to say either.

#### Narrativity contested too

As is no doubt clear, part of the purpose for beginning this thesis in this manner, rather than moving straight to participants, is to protect it from certain accusations. The "narrative turn" may be coming late to psychiatry at a time when there are already those proclaiming a "new materialism" elsewhere (Van der Tuin & Dolphijn, 2012). Often what is argued is against what might be called the thin version of narrativity. A discussion in 2016 about Frank's statement, "a life that is not fully narratable is vulnerable to devaluation" (2012, p75) surprised me; members of a "survivor group" felt that this fitted a kind of "empty recovery cliché" that is being used for "oppressive ends": not all the ends of a person's life had to be wrapped up in narrative, explained under a unifying story! The contributor cited (as an example of views she found oppressive) Hanna Pickard and then I understood. I heard Pickard lecture at a narrative psychiatry conference, much applauded, in 2012. It was clear then and now that Pickard's narrative project is one of the "authentic" "owned" biography, of "self-autonomy and self-creation" "allowing us to free ourselves from our pasts and treat our futures as open" (Pickard in Sadler, et al., 2015, p1). I was glad to explain that Frank's socio-narratology could not be more different: although stories are the tools we use to think with, we are not usually in anything like the masterful position Pickard implies. Dennett's stories spin us; Frank's stories are 'socio' and dangerous. Stories direct us, they produce us, the are the means by which vested interests may oppress us; they form desires which "take up residence" in us (Angel, 2012, p200). Pickard and others' thin narrative is a very easy target. The philosopher Gaylan Strawson is a good example (2004), and other writers about hearing voices do find his work important (Woods, 2011). However, if one reduces narrative into biography and a psychological discipline, it is easy to knock it down. Stories are not merely used by people to twist reality or create action either, the relationship is much more enmeshed and subservient than such a view implies. Once again, Carr is very helpful on this point:

Storytelling obeys rules that are imbedded in action itself, and narrative is at the root of human reality long before it gets explicitly told about (Carr, 2008, p29).

Strawson's contribution is welcome but what seems to be missing is the narratives that begin beyond the self, which, for someone such as Arthur Frank, is most of them. I hope that my analysis of the spread of views in the next chapter will further show what is happening in these arguments about narrative.

## **Dialogical Narrative Analysis**

The issue that informs all these questions is: what is at stake for whom, including storyteller and protagonist in the story, listeners who are present at the storytelling, and others who may not be present but are implicated in the story? How does the story, and the particular way it is told, define or redefine those stakes, raising or lowering them? How does the story change people's sense of what is possible, what is permitted, and what is responsible or irresponsible? (Frank, 2012, p74).

Our fundamental tactic of self-protection, self-control, and self-definition is not spinning webs or building dams, but telling stories, and more particularly concocting and controlling the story we tell others — and ourselves — about who we are. And just as spiders don't have to think, consciously and deliberately, about how to spin their webs, and just as beavers, unlike professional human engineers, do not consciously and deliberately plan the structures they build, we (unlike professional human storytellers) do not consciously and deliberately figure out what narratives to tell and how to tell them. Our tales are spun, but for the most part we don't spin them; they spin us. Our human consciousness, and our narrative selfhood, is their product, not their source. (Dennett, 1993, loc 7777-82)

It is already clear in the previous chapter that my understanding of the contested categories which are the feature of the field in which this research is situated indicates some quite specific choices about research method, already making certain forms of research unnecessary for me to consider; when categories are so contested, they cannot form the basis of any knowledge without importing all of their controversy. I had come to feel that this was as true for "emotions" and psychological narratives such as "dissociation" as it was for the more obviously contested categories of diagnosis. Here I want to present an introduction to Arthur Frank's approach, Dialogical Narrative Analysis (hereafter "DNA"), which he describes as being less a *research method*, but more a *practice of criticism:* in fact, in key ways it is an antimethodology (Frank, 2012, p73). I also want to present the preparations I made for doing DNA, which included:

- Consideration of the needs of a narrative interview and tools to help achieve it, further introducing the concept of "emplotment" and my interview style.
- The ways in which the interviews and research as a whole was going to attempt to be 'dialogical'.
- A suitable recruitment strategy.
- A brief description of ethical approval and my handling of transcribed material.
- Three diagrams which became key in exploring, understanding and contextualising the spread of narratives I heard and found within the literature.

Beyond the requirement to "hear stories", there are no set forms for a narrative interview (Emden, cited Kelly & Howie, 2007: 139). However, it does not follow that it should simply be a unstructured conversation. It seemed to me that the most important concern was contained in Frank's *emplotment:* "To emplot is to propose a plot that transforms still incoherent things that are happening into the experience that has meaning...." The word is from the philosopher Paul Ricoeur, "for whom it is the act of making a coherent sequence out of what was simply a succession" (Frank, 2012, pp136-137). This is how a narrative *explains* (David Carr, 2008).

Where possible, I have explored and explained my chosen research method alongside participants' transcripts, so that tenets of the approach and the issues raised are seen together. DNA is the work of one particular author, Arthur Frank, and the vast majority of citations in this thesis about the method itself are from one of his books, *Letting Stories Breathe; A socionarratology* (2012).

Like other research approaches, DNA follows from an understanding of the self and of epistemology. It must be remembered throughout that is a 'soccio-narratology'. This means that it takes a stance that we are partly constituted by stories, and that these stories are significantly emplotted by wider cultural narratives, in processes of which we may or may not be particularly conscious. Since most of these narratives are not written by ourselves, and since they greatly define and provide the meanings and actions available to us for past, present and future, it follows that our narrativity is only partially 'self-authorship', contra to the work of many authors and perhaps a more commonly held public sense. Mostly, our own agency is somewhat relegated; DNA has implications for the many different sets of philosophical ideas which make up theories of action, agency and 'the will', 'freedom', etc. Since narratives have such an astonishing effect on us and, through us, upon the physical world, they can be considered *de facto* actors themselves. DNA is a process of raising awareness of these stories and narratives. The internal logic of stories is interesting, but the project aims firstly to ask what kinds of emplotment may be taking place and where those narratives may have come from.

However, two further aspects are crucial. The first is that to uncover the philosophical work of stories, what they reveal, enable, or diminish and make impossible, or how they resist the infiltration of other stories, one needs to follow a strategy of *placing the stories in dialogue with each other.* In my work I have interpreted this as being the stories performed by participants, the stories I brought to the interactions, and wider stories 'out there' in scholarly literature, in the media, in relevant cultures of professional practice, underground movements, social media; anywhere. I also chose not simply to rely on my own ability to place these stories in dialogue but to invite my participants to do that also. Dialogue is not a mysterious process, but allows comparison between incommensurate knowledges and a greater understanding of what stories achieve. Secondly, since stories alter what is possible, it follows that their proliferation contains and is subjects to vested interests. Therefore, DNA is not merely about where stories come from and what they do, but whom they suit, and how. This makes the work a political exploration of competing ideologies, a realisation that gradually increases throughout my work and this thesis.

Since DNA is not a prescribed research method, but a practice of criticism, it is for the researcher to devise a strategy to enable DNA. My strategy was to meet voice-hearers, hear, record and transcribe their stories, and then present those stories back to the voice hearer to ask them to help me to understand how they relate to other stories, both from other participants and the 'out there' stories I identify. There were many ethical and conceptual challenges in doing this, which I discuss in the main body of the text (for example, the difficulty of this approach appearing to 'denigrate' the participants interpretation of themselves and their experiences to 'mere' stories rather than, as they might see it, 'truths'). Not only this, but there is a strong sense in which my own stories are also in dialogue, and this necessitates a number of pauses for reflection and the presentation of aspects of my own experiences. All of these stories and reflections make up this thesis, a piece of writing that has elements of a narrative structure of its own.

Finally, as Arthur Frank makes clear, the approach may stake a pluralist stance to knowledge, but is not resigned to moral relativism. Stories may be judged as more or less *responsible*, an aspect that, for Frank, hinges on the extent to which they can tolerate dialogue. Many stories only hold together by being monological; working to hide or silence the details or alternative conceptual frameworks that would challenge them. In my work it became clear that there were several strongly monological stories competing, but that more responsible and dialogical knowledge and approaches were also possible (and seemed to be very much to the advantage of participants).

#### Interview design

Emplotment in interviews was going to be unavoidable, because, as has already been seen, stories are not just descriptions of reality but shape it, and (beyond being unhelpful in other ways) even if I were to remain silent emplotment would still occur through the ways in which considerations such as time, place, gender, dress, the presence of a recording device and being the subject of research, etc., would suggest the selection of certain kinds of stories or analyses. As

I began to think about how I might make this research dialogical (below) it was clear that it could not be my intention to remain silent, even with a talkative participant, because I wanted participant assistance in at least beginning the dialogue between stories. Nevertheless, I wanted to create a kind of interview which tried hard to limit emplotment until at least there had been a good opportunity to hear the participant's own stories as much as possible, and then, to try to notice emplotment with the participants in some way. It seemed to me that there were two separate challenges. Firstly, I had to be good at eliciting stories, and yet do it in a way which minimised simultaneously writing new versions. Secondly, I had to make the interviews somehow dialogical, so that the person could reflect upon what they had told me in the context of other kinds of stories, either "out there" or told by other participants. Each participant should be given their transcripts, and then helped to consider what they said in the light of other ideas.

As I considered eliciting stories I realised that the problem of emplotment was even more complicated than I had first thought. I knew that many of the explanations that people have for voice-hearing and emotions are in some ways not narrative explanations. For example, illness narratives may place becoming ill or the course of an illness into a narrative structure of past. present and future, but it could be that the arrival of illness itself and features of it are viewed in largely non-narrative or less narrative ways; perhaps the difference between "I became ill because" and "I got ill". Experience is not simply part of one story or another, and sometimes may not be particularly storied at all: a clear implication through Frank's writing, particularly in reference to illness typologies (1997, for example). A guestionnaire for diabetes patients focussed upon lifestyle would carry a certain emplotment and one about family history, another, but one about coping might imply very little by way of story. Much discussion about emotions has these features also: one can just "have anxiety" (sometimes even described as "free-floating" to denote its independence from circumstance) or one can "become anxious about". This kind of discussion may take different forms and is key in this thesis, but one can see that one of the differences is the extent to which narrative explanation is employed, the manner and extent to which the emotion is storied. Asking questions about what was going on within a person's life prior to reported experiences is already placing that experience into a temporal structure and a framework likely to suggest that there could or should be narrative explanations for the onset of the experience. I needed to find a way of interviewing which allowed participants to narrate their experiences or simply describe them. Once again, it was Michael White who seemed to articulate this best: not all events are storied, and indeed they never could be. Much is left out as "unique outcomes", a phrase he takes from Goffman (White & Epston, 1990, p15) and it is from this rich ground that new narratives are often available. I needed to start the interviews in such a way which did not presume that the experiences we were focussed upon were storied.

#### A narrative tool

My decision to use a set of *Emocards*<sup>6</sup> is wrapped up with another tool, one which I thought I might prefer, called The Tree of Life (Ncube-Mlilo & Denborough, 2016). I report further on this choice in the chapter about Claire, and there it can be seen that the Tree of Life was impressive but too emplotting. It is a narrative therapy tool and not as suitable as a narrative research tool, a distinction I came to see as one of degree rather than of kind<sup>7</sup>. However, through this I came to

<sup>&</sup>lt;sup>6</sup> EmoCards were created by Alan Rowland in 2007, an 'expert by experience' contributor to the EU funded project 'EX-IN' Experienced Involvement project (2005-7), that developed materials and a curriculum for training people with experience of using mental health services to work as service providers. Information can be found at <u>http://www.ex-in.info/virthos.php?en/</u>

<sup>&</sup>lt;sup>7</sup> This testing was done prior to Claire volunteering to take part in the research as a participant. More recently she has confirmed that the two hours we spent testing the Tree of Life tool did indeed radically change her perspective on playing her musical instrument, something of enormous significance for her and she has continued to play in ensembles since that time. Her voice-hearing experience is altered as a result. I think the most suitable description for this is "healing".

understand how useful the *Emocards* were. The stylised pictures could refer to a theme, idea, event, characteristic or experience; past, present or future. I felt they would not push for stories that had not previously existed at all. Using the cards would create structure within the interview, but a very loose one.<sup>8</sup>

I decided upon the instruction "pick three cards that you relate to when thinking about hearing voices and emotions". This was the most ambiguous instruction I could think of which still made sense. I felt that it would leave participants very open to either telling stories or describing ideas, talking about themselves or more theoretically. It did not impose a narrative structure or suggest temporal aspects. Although it raises the possibility that hearing voices and emotions are together in some way, I felt that this was as non-emplotting as possible; it does not suggest a causal link and, in fact, it might be referring to them as two uncorrelated subjects. I also developed a strategy of avoiding words and ideas until they had been used by the participant. This meant that interviews tended to start in a very open way, occasionally with a little difficulty, but could finish with quite precise summaries which several participants seemed to feel very pleased with.

#### How emplotting were my interviews?

I want to address this guestion prior to presenting any of the interview material, so that readers do not have a sense that I tried to be more objective than was possible, and "failed". Despite my hopes to limit the emplotment of my interviews, I suspect they were actually very emplotting. I would like to tentatively suggest three reasons for this. The first is that, with the exception of just one or two interviewees, the participants had fewer stories than might be usual (although I do not know how many stories are 'usual'; this is not really any kind of measurement, just a sense that dialogue between stories was not a common experience for some of my participants). Most had been involved with psychiatry, and several for many years, most had experienced prolonged confusion and/or distress. I believe the dominance of psychiatric stories in combination with the limited range of conversation they had about themselves within psychiatric services (part of the dominance of those stories) meant that the interviews had a pronounced tendency to elicit new stories. This might be unexpected, if the preconception of psychiatry is (as Becky, one participant, put it) "being asked questions on a couch". However, talking about themselves (perhaps rather than being asked questions restricted to "symptoms") seemed novel, with several participants making it clear that they were talking about things in new ways or that they had not been asked about them before. As a result, one might say that they were not generally sharing from an established library of stories but making notes in a relatively clean exercise book.

Secondly, I could not help but co-structure what was being said in terms of past, present and future, asking questions which tried to make phenomenological experiences and events causal of each other. Basic prompts such as, "what was going on for you at that time?", the way in which one person tries naturally to understand another's life as a sort of loose timeline, or simply a question such as "can you say a bit more about that?": these are emplotting. For me, they are also just part

<sup>&</sup>lt;sup>8</sup> I did not formalise or record the feedback that participants gave me about the use of *Emocards*. However, they were universally liked. I anticipated at least one interview would include hastily putting them aside if that way of visualising or structuring conversation did not suit, but that never happened. I thought it was possible that the cards would feel patronising (perhaps it was something about their simplicity or bright colours) but I think that the process was perceived to be validating. I made it clear that they were just conversation-starters, not some kind of test. In the first interview, Becky realised that when she had picked a particular card she had thought that it showed a picture of a cut on a hand, but realised when talking about it that it was a red ant. However, we just talked about it as if it had been what she first saw, and after that, I was careful to allow participants to say if the card could be altered to better fit what they wanted to say. Two of the 12 participants asked if they could get a set of their own. Finally, one of the most useful aspects of the cards to me was that I could draw a section of the interview to a close simply by pausing and saying, "would you like to tell me about your next card?".

of responding in a caring manner. I strongly suspect that at the end of the first interviews, in which I was supposed to be as eliciting but separate as possible, several participants had co-authored some new understandings, or did soon afterwards. Just as with the remarkable moment of change Claire experienced while "testing" a narrative tool, these interviews were not neutral; they promoted change. Voice-hearer Eleanor Londen has repeatedly said that psychiatrist Pat Bracken's request not to hear what others had told her about herself, but her own views, was transformational (Longden, 2010).

Thirdly, I think that being the subject of research was itself emplotting. Perhaps it suggested to participants that there was a story to be told. Perhaps on a very basic level it suggested that they could be made sense of, which, for those deemed "mad", is no small matter. I began to notice that I was having new kinds of conversations as a researcher that I was not quite used to as a nurse, but with, as nurses would say, the same "client group". This has had an important effect on me and is something I will discuss.

#### **Bringing dialogue**

I knew I could write a discussion about the differences between stories and their effects, but I wanted to do more. I hoped my participants could also place their stories alongside others'. In this way they would begin the analysis, and I would be able to see more clearly what stories *do*. It seemed that seeing each participant more than once would be best, so that there was enough time for them to tell stories in a first interview, and then in a second or perhaps a third to take the opportunity to ask whether the telling of those stories had altered any part of their experience, and also focus on the range of stories others had told me, sufficiently anonymised, to gain a sense of what participants thought about them against their own. I could also tell them about other ideas "out there" that I read.

Yet this guickly seemed to me to be the most difficult research design challenge. I might have, through a fairly tortuous route (involving considerable personal crises!), come to the conclusion that "the self is the centre of narrative gravity", but most people do not think in those terms. They do not ask, "what is this story doing for me?", or "what possible action does this story allow?" Instead, they want to know what really happened and what is true about themselves. People do not generally talk of making the self through narrative. How could I get my participants to contribute to DNA without seeming to demote their narrative from being true, the uncovering of a true self, into being another story? There was a difficult personal moment as I began to plan my second interviews in which my Director of Studies told me that sometimes I came across as "aloof": the last thing I wanted to be. However, I think this theme is of critical importance. There are painful elements to "socio-narratology". Stories are required for being but are never complete, true, finalised or safe. Stories are not really our possessions; we do not originate much of our own thinking. I particularly like Frank's approach here: stories may have common threads and may not begin with us, but they are "always singular", not a "mere instance" (2012, p119). Forgetting this would lead to treating others' stories in an "aloof" way, and there are other dangers: In the chapter about Claire, I notice that I am pulled into duplicity between two people whose stories I respect individually but do not sit compatibly, and there is a sense in which feel I am in danger of betraying their trust by hearing and validating their stories without "being recruited" by them.

As I began to interview participants for a second time I realised that there was a way of exploring with them what stories are doing without being so direct about their nature. I asked participants *what they thought the future held*, and whether the new ideas they had, or the ones I had laid before them, changed the way they might think about the future. This seemed to be a way of unlocking something of the internal workings of stories without requiring more. I think I may found this idea in Michael White's work: "Since all stories have a beginning (or a history), a middle (or a present), and an ending (or a future), then the interpretation of current events is as much future-shaped as it is past-determined" (White & Epston, p10). However, I feel that this only partially resolves the problem. It would have been possible to ask the same question about the past, too, but this I felt should be more gentle; people are probably more willing to consciously reimagine the

future than the past. I suspect that the present is the one that is the least comfortable of all and if the present is seen too clearly as a product of narrative, then surely identity must be close behind.

The following table is a little artificial, but it shows the spread of my ability and my participants' abilities to engage jointly in DNA. In the case of the first two columns, the participants only saw me once and that was the most they were able to offer the project. Their DNA was up to me, and if possible, the other participants. The three participants in the third column all were able to consider other stories, either naturally as they explored their own, or with help from me. The three participants in the last column, perhaps especially Ross, were *narratologists*; they understood that new stories led to new realities, and all had therefore learned or were learning to be consciously strategic in connecting to stories. They engaged enthusiastically in conversation about the complex interplay of stories.

No dialogue	Information about others' stories	Discussing the relative merits of others' stories or considering recruitment into others' stories	DNA
Steve, John, Jenny, Rosie, Amber	Matthew,	Becky, Lisa, Mel	Claire, Angela, Ross

The intimacy of the interviews I present here could not have been possible if participants actually found me to be aloof. Yet I still feel that this tension between the DNA researcher and those researched is very complex and I feel that there are moments when some of the "aloofness" has found its way back in as I have tried to write about the stories told to me. Some will see this as a personal failing, and perhaps it is. However, I also think that it is a product of a tension between stories being viewed as something beginning outside of us and simultaneously as "always singular".

#### **Recruitment Strategy**

The twelve participants in this study represent a rich diversity of stories, yet I feel the recruitment strategy was one of the aspects of this research which worked least well. I did not set out to interview so many people who were exploring the dialogue between medical stories and the stories of the Hearing Voices Movement, something which may be difficult for readers to believe given that Marius Romme was a supervisor and instigator of this work. That I did probably says something about the importance of this current interface, although my sampling was in no way designed to create a representative group. I am not sure that what eventually emerged was problematically limited, just not quite as planned.

My intention was to meet voice-hearers within the NHS and outside of it. What actually occurred was that despite only recruiting four voice-hearers directly from the NHS, all of the others except one had extensive histories of contact with services. As my initial plan, through advertisement in the mainstream media, started to fail (see below), I turned to non-NHS community projects, which almost certainly led me to find people who had been in the NHS but were now considering alternatives. This was a rich place of storying and re-storying. Becky, Lisa, Steve, John, and Jenny fell into this category. Claire was a chance meeting at a conference, someone who I got to know as a colleague who then volunteered to participate. Angela was someone I met at a Hearing Voices Congress (an annual HVM event). Rosie, Amber, Mel and Ross were recruited from two different community teams in the NHS. Matthew was my attempt to find someone very different: I went to a spiritualist church.

In the 1980's, Marius Romme and Sandra Escher had placed articles in the press and asked for voice-hearers who had never been in contact with mental health services to step forward, also

conducting a television phone-in that was successful. A 2011 published review of 17 pieces of research into the possibility that voice-hearing exists in the general population concluded that the prevalence might be 13.2%, although this was achieved as a median between vastly differing findings, from research that struggled to be precise enough about the phenomenon to be clear about who was counted (Beavan et al., 2011). The Durham University project, Hearing The Voice, has recently published an internet-based survey about the phenomenology of voice hearing (Woods et al., 2015), but this focussed on people who either identified as voice-hearers through connection to "clinical populations", or to the Hearing Voices Movement. McCarthy-Jones et al. (2015) recently concluded that the prevalence of voice-hearing in the general population was likely to be a "low single-digit percentage", a figure which attempted to capture not just occasional experiences but "extended" ones. I hoped to copy Romme and Escher's approach, which I do not think has been tried in the UK before, but by the time I met my first participant this was already proving strangely difficult. Even with the support of my university press office, who (along with Romme and Escher) helped me with the wording of my release<sup>9</sup>, no one wanted to publish it without there being some kind of topical news item to lead with. Since hearing voices is often in the press, I did not think this would be difficult, yet what news items there were were often highly "emplotting", making a mockery of my carefully worded neutrality. I hardly wanted my release to go out with a report about a voice-hearer committing a violent crime or on the back of some other, guite different research, such as Julian Leff's Avatar Therapy (2013) which was in the news at the time; I went to hear Leff at a conference and I felt it was ethically, conceptually and methodologically flawed. I did not want the piece to be associated with medical terminology, either. Eventually, I did get a shortened version of my release into the Birmingham Mail (who neglected to inform me that it had gone out). I had one respondent: a lady in her seventies who wanted to tell me all about a haunted hotel where she had once stayed (some thirty years ago) on holiday in Portugal, because, "hearing voices, that's like the paranormal, isn't it?". She had no ongoing experiences of anything like voices. I therefore failed to engage this "low single digit" percentage, or the "13.2%", and, although I have heard many lectures and conference talks which rely upon the idea of voice-hearing in the general population, it may fall into the category of reasonable conjecture at this time.

#### Ethics

Therefore I visited non-statutory organisation support groups and asked to meet voice-hearers, while also going through the process of becoming the holder of an honorary contract to work as a researcher in an NHS trust. For both of these and for University indemnity insurance, it was necessary to have my work approved by the National Research Ethics Service (NRES). Although initially seen as a "proportionate review" by one Research Ethics Committee (February 2014), it was decided that the risk of distress to participants required a full review, which took place in May 2014 in Leicester<sup>10</sup>. In my opinion, the focus of the ethics committee on the support needs of participants was valid but somehow suggested that even in a study about emotions, emotions were not to be encouraged. Significantly, the ethics panel did not in any way approach the idea of emplotment as an ethical issue, that the telling of stories is not a neutral thing to do and that there is an ethical element to hearing stories. In that I planned to introduce people to new stories which might make it more difficult for their current stories and related cast to "hold their own" (about which, more follows), it was up to my supervisors and I to ensure that we took great care of our participants' narratives, and not make this research a cause of confusion and contradiction for them. In this way we found ourselves to have an extra responsibility to them. I feel that this set of concerns turns on the notion of gualitative research and "intervention" research being separate. Narrative is not simply about events, but part of them (Overcash, 2014, p15). Rather than discuss this idea further here. I hope to show how my choice of a "narrative tool", helped by Claire, opened up this concern for me.

<sup>&</sup>lt;sup>9</sup> Appendix 1

<sup>&</sup>lt;sup>10</sup> See Appendix 3

My interviews were audio-recorded, transcribed verbatim, and copies were given to participants with an opportunity to discuss their their anonymity (for example, removal of idiosyncratic details). The transcripts and audio recordings were kept in a locked filing cabinet in accordance with university data protection policy.

#### **Preparing for DNA**

One of Frank's key questions about stories is to ask *who is holding their own* in the story (2012, p77). This simple question makes it impossible to take the "D" out DNA. DNA cannot be merely a dissection of the inner workings and meanings of stories. Asking in effect *whom they suit* brings stories into dialogue with other stories to ask not only how the story works internally, but what it does for those who are caught up in the story as they relate to others caught up in different stories. Yet once again it is not right to imagine stories as the tools we use without also thinking of that relationship as reciprocal. It is not just people "holding their own" with stories, but stories hold their own with us, too. It is not just that they have an internal cohesion, nor even that they tightly resist efforts to be infiltrated or disintegrated, but that there may be aspects of stories which "go after" other stories. There is something about the most successful stories which includes an inoculation against dissent. Political philosopher Michael Freeden uses the word *decontests* in his work on the subject of ideologies: "groups of decontested political concepts" (1994, p158). I think this is perfect for describing the way that stories (and not just the people telling them) hold their own: they hide their contested nature, they *decontest* themselves.

This is also pure Foucault: knowledge-power and processes of subjugation and disqualification (White & Epston 1990, p19; Foucault, 2004 [originally 1975], loc 531). Stories, says Frank, are performed for a purpose, a goal (2002, p115). The space of stories in dialogue is a minefield of vested interests, perhaps it is *the* minefield of vested interests. Could there be a clearer illustration of why the "personal is political"? *For the most part we don't spin them; they spin us.* One could say that stories are both utiliser and utilised. Frank cites Law in saying that *there is no important difference between stories and materials* (2012, p43).

The following, and indeed much of the thesis, is unapologetically presented as a research story. Since the contested nature of the field brings questions about the possibility of a kind of pure objectivity into doubt (which I hope will be considered as even more questionable by the end of this chapter), and since this places the subjectivities of the researcher unavoidably into relevance, I am using narrative to explain my theoretical journey during these three years (that, and the "relational endeavour" that is the larger part of this research (Josselson, in Clandinin, 2007: p537). Another part of the reason is that the contested nature of the field makes it very difficult to say what is and is not relevant. I have come to believe that what might be called its profligacy towards relevance makes DNA a problematic PhD (although, not as problematic, I hope, as something more conventional). Resources demand a closing down of the range of reading, but DNA demands an opening up. This means that one never finishes the work, an outcome endorsed by Frank: "dialogue refuses what monologue aspires to... finalisation" (2012, p97). One allows that the selection of material is going to be partial, and that the partiality is going to be idiosyncratic. As a result this research does not contain a review of the literature (a phrase banished to the same place as the evidence), however unusual that might be for doctoral research in health (I am not sure that this is health research, as will be seen). Under a project already described as one with an aim of coherence rather than completeness, there can only be some literature, and the selection of that literature is driven by the narratives of my participants, my relationships with the participants, and my own research journey.

I followed Deborah Lupton's advice:

For scholars interested in medical discourses, texts to examine may include medical textbooks, hospital records and admission forms, popular self-help manuals, novels, television programmes about health issues, articles in medical and public-health journals and popular newspaper or magazine articles, blogs, websites and social media pages as

well as the transcripts of conversations between doctors and patients or interviews between researcher and subject. When applied to sociocultural analyses of medicine, the analysis of discourse has the potential to demonstrate the process by which biology and culture interact in the social construction of disease, and the ways in which western culture uses disease to define social boundaries (Lupton, 2012, p3).

With this in mind, is it possible to map out the space of these many stories-with-vested-interests? I began to do this in 2014. At this point I should say that I am aware that for some qualitative approaches, I should not have done. For example, my attempt to understand a "big picture" view like this would be a heresy for, say, Grounded Theory, in which I ought not to do anything until I had transcripts to provide source material. However, it is essential to the dialogue of DNA to hold the research stories against wider narratives - the range of narratives "out there" - as well as against each other, and I wanted to ask my participants what they thought of ideas other than their own. I have found the balance between using the collected narratives of my research participants to view the wider narratives, and using the wider narratives to view the collected narratives to be a constant tension. I think this is an implication of Frank's approach: neither are taken as primary, but held together in dialogue, although the structure of this thesis reflects my hope to place the 12 people who contributed to it as participants centre stage, apart from in these brief introductory chapters. What follows is therefore my version of "the literature review", one arrived at through a process of DNA and used as tools in the later analysis too. However, it does not *contain* my reading, most of which is spread across all the chapters and much not included directly at all.

#### The Location of Experience

What follows is my version of "the literature review". It was formed in dialogue between myself, my research, and the spectrum of heterogeneous literature to which I have already referred. I chose to draw the following map by considering the "location of distress" mostly due to the influence of critical psychologist David Smail, work I read in 2013 (Smail, 2001). It was also influenced by the masters I did in 2010/11 (designed by philosopher of psychiatry Bill Fulford) in which notions of responsibility were understood to be at the heart of concepts of illness, and in particular *action theory*. The division of "personal/sub-personal" is from Daniel Dennett, whom I first read in 2010 and then more extensively in 2014. I called my map a "political map of distress". Over time I realised that it was more than a map of distress: it could equally be a map of happiness, so it might be better thought of as a political map of *experience*.

Here is how my map looked in June 2014:

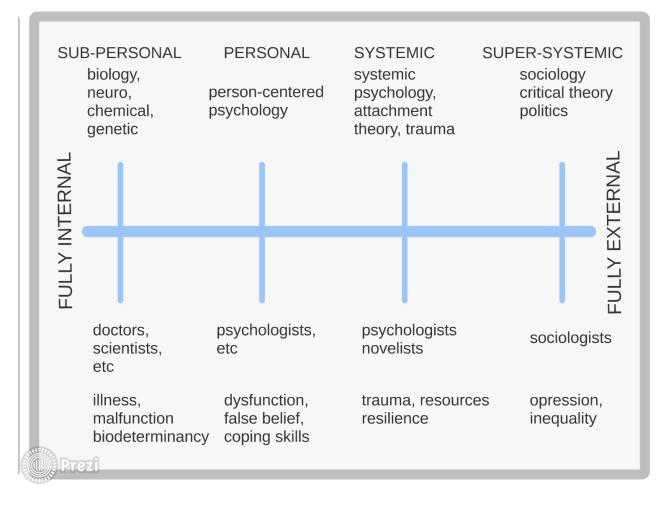


Diagram 1: My 'map of experience'

The logo in the corner, "Prezi" (a presentation tool) is there because this is a screen-shot of a lesson I facilitated for undergraduate nurses at the time. On the left of the map are fully internal locations of experience, and the explanations used here I describe as "sub-personal". Moving to the right the explanations become increasingly external, until on the far right, they are fully external. To help the students, I suggested some of the professions which have found their niches with expertise at different locations, and some of their typical language. All suggestions, both above and certainly below the line are open to debate; they represent stereotypes. It is quite possible to meet psychologists who are interested in neurology, psychiatrists who prefer systemic understandings, and surprisingly medical social workers. More common still are people who seem to drift from one location to another, which could be considered a strength from some perspectives or confusing to the the point of being abusive from others. I asked students to consider where mental health nurses might operate from on the map. The challenge for the map was the centre and I think there could be finer-grained ways of demarcating positions there, although these might not add much to what I hope the map achieves. In later versions of the map I have added "economics" to the left, and my Director of Studies noted that "illness" might be better replaced with "disease".

Mapping the territory in this way makes visible a number of features that I find to be hidden in what is frequently referred to as "biopsychosocial" (originally Engel, G.L., 1977).

 There is something interesting about psychology. The diversity of philosophies called "psychology" exist in two parts of this map, not one. Importantly, it exists across the intriguing centre, which on this map can be seen to divide two halves, leading to

- 2. A sense that there is an important binary shown by this map, between left and right: on the left views give priority to understandings of experience as being *from the inside-outwards*. On the right, experience is *from the outside-inwards*.<sup>11</sup>
- 3. There is no hiding the fact that mainstream mental health services operate on the left side of this map. It is where the money is on the map, in terms of research, professions and numbers of workers. *Biopsychosocial* implies partnerships of equality. Read et al. claim that instead, it is "a colonization of the psychological and social by the biological" (2004, p4), certainly not Engel's original intention. On my map I saw that the place my nursing self imagined to be a kind of fulcrum, a point of balance between biological and psychological, could never be a balancing point. I will return to this idea in the chapter about John. I now see that this speaks volumes about mental health nursing culture.
- 4. Some months later I realised that my map was also a map of concepts about the individual; a map that shows some different ways of thinking about what makes up the individual, or *selfhood*. It became clear that the location of experience was in some way linked, perhaps even predicated, upon one's understanding of the individual. I wish to make only one extra comment in this regard: to recall the 2013 conference on "narrative psychiatry" mentioned in the last chapter, where I was astonished to encounter a uniform sense that narrative was synonymous with *biography*. It is quite possible to therefore speak of the importance of narrative but operate from the left side of my map only, which therefore becomes a further way to understand what have have previously referred to as the "thin" concept of narrative selfhood, against Frank/Dennett's "thick" concept that includes social narratives in forming the self. Frank elaborates that the *authenticity* that Pickard evokes (see page 14) is *intrapersonal* but socionarratology is *interpersonal* (2012, p192).

#### **Smith's Structural Model of Genre**

The map also reminded me of Hacking and Anscombe and agency, as well as older philosophy concerning freedom vs determinism, and I then saw a sort of kind inverted parabolic curve that could be superimposed on may map to represent agency, or at least I wondered whether the relationship would be a parabolic curve. In any case, it seemed likely from my own experiences and my reading that the closer one moved to the extreme left or the extreme right, the less personal agency would be envisaged there. On the left was bio-determinism, on the right was a view which cast individuals as products of society only. This seemed very important because I knew that in my analysis I would be asking what stories do for those recruited into them, and part of what they do must be that they create (or diminish) possible action. This idea of a parabolic curve was somewhat superseded by the discovery of Phillip Smith's Structural Model of Genre, from a book that Frank (2012, p138) describes as an exemplar of DNA. I saw immediately that Smith's chart, which describes the *inflation and deflation* of narratives, was going to be important in my work and now I felt that it could somehow be overlaid on my map. In doing this I realised that Smith's work is related to Anscombe's *action under a description* (1979), and a very useful extension. I also can see that notions of agency and of the individual are linked concepts.

<sup>&</sup>lt;sup>11</sup> It is beyond the scope of this thesis to explore the various positions and various forms of problems that are found at a fine-grained view of this interface. However, it is important to note that Frank, Hacking and other philosophical contributors to this thesis would see the reality that is represented inside of us as itself reflexive, that narratives become embodied actors in our physical world and that the physical word both enables and limits possible narratives. I think this essentially is the backbone of their argument against such dualisms, meaning that this work contains a form of answer to the interface problems of mind/body, and mind/society. I take the view that there is no reason to believe that evolutionary processes should lead to humans mentally representing the world accurately, with many credible questions about our observations and perceptions that suggest we do not. This has implications for what becomes labelled as correct or incorrect perceptions, sane or insane.

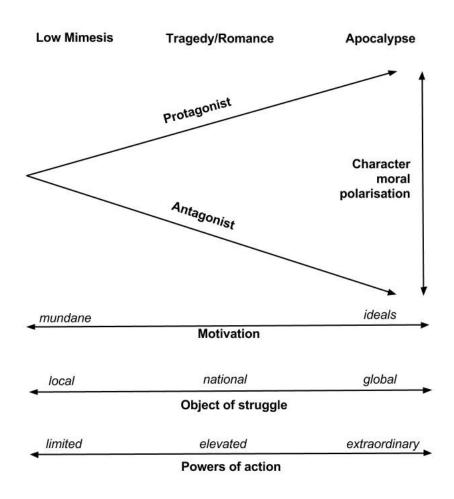


Diagram 2: The Structural Model of Genre, Smith, 2010, loc 340

For me this chart is slightly breathtaking in its elegance. It superseded my idea that there might be a parabolic curve of personal agency by making me recognise that the way I formed the question *that it concerned personal agency* was narrowing my answer. Yes, it might well be that *personal agency* (or the agency made available or attributable to the person) is diminished at the extremes of my map, but the stories which support those positions, far from reducing agency *per se* make it available or attributable to others. For example, one could say that the effort of psychiatry in regards to hearing voices is to reduce them to "Low Mimesis": they are mundane (hallucinations, not messages, for example), they are local (just in your head, just a feature of the present moment) and the voice-hearer has limited powers of action over them. Yet this story concurrently elevates the power of mental health professions who may respond by using the Mental Health Act and everything it entails. Likewise, a view that experience is the result of fully external factors may reduce the agency available to the person, but it massively elevates the perceived role of society, making it contain the morally corrupt forces, able, through ideologies of one kind or another, to enable or oppress. Thus, relevant agency is given to politicians, institutions, perhaps to markets.

This suggested to me that although I expected the people I was going to interview to have different kinds of stories, and ones which seemed to provide more or less agency, the question was not whether agency was made possible or not, but rather *for whom*.

#### The left and right of experience

On the following page is the third chart that became significant, *Left Vs Right* by David MacCandless (2012, p14), and the following section concerns that chart.

I realised my map of experience was yet more than these things. I had already noticed the interesting left/right split, and now saw that it in some ways resembled a chart I had found which outlined key attitudes and goals and institutions of Left and Right wing politics, by David MacCandless (2012, p14). During a conversation, my Director of Studies picked up a printed copy of my first chart, my map, and curled the ends around into a tube: he felt that something at the extremes met each other. This was a little unnerving for me: I instantly recognised it as something said about communism and fascism, but I knew that I did not have much experience with political philosophy, beyond a few "short introduction" style books (Miller, 2003, for example). However, I could see that if there was some kind of significant correlation between distress and its location, identity, and politics, I was going to have to gain more understanding of political views in order to provide the "dialogical" part of the analysis. I also felt I needed to be more precise about how it was that I felt the two were matched.

What intrigued me was that narratives associated with the left of my map, the *sub-personal* and personal locations appeared very similar to that of Right wing politics; the right of my map, systemic and super-systemic appeared similar to the Left of politics. Perhaps I needed to redraw my map in mirror image? On the Right of politics, the values that surround an individual and their place in society are to do with freedom, which leads to a focus on the individual needing to be free from impediment in order to live well, as described so beautifully in Isaiah Berlin's Two Concepts of Liberty (2003 [originally 1958]); human rights are present in order that people may be unimpeded and held responsible, and subsequently this is their achievement; the goal is a self-reliant. independent adult (where "self-reliant" is a synonym for "autonomous agent"). This really did seem to match the left of my map, in which the reasons for illness or wellness lie within a person; either in their actual body/brain, or in the choices they make. They are seen to be an agent, if only the impediments of "biological defect" and "poor thinking" are overcome. Health, freedom, individuality and personal responsibility are therefore inseparable here. Thomas Szasz' critique of psychiatry comes from his right-wing libertarian/capitalist views (Bracken and Thomas, 2005, p221) but my point here is that psychiatry itself may rely upon similar notions of individuality. However, on the right of my map are found ways of thinking about individuals and about responsibility which are much closer to the Left of politics; an emphasis on the family as the grounding of both health or the lack of it, the idea that it is society which can not only impede a person and cause them distress but that it is within society that they find health; health as membership (Goodman, 2015). Agency here is not a personal property, but the result of connection, and through connection fulfilment may be found. So here health, community integration and fulfilling roles are inseparable, and rights exist not so much to make persons responsible but to hold authority to account.

Thinking about mental distress in terms of the logic of Freedom vs the logic of Equality seemed to be an important thing to do in DNA. At this point, having recognised this apparent link between politics and experience, I then got absorbed by my research interviews. I believe I should have read more politics, more about freedom and equality. This lack had the effect of making me more recruitable into certain stories (not necessarily my participants' stories but the ones I was reading) than it might have done if I had been more knowledgeable about politics. I do not see this as a weakness of this research: readers will be able to see what the stories produced in me as further examples of what stories do.

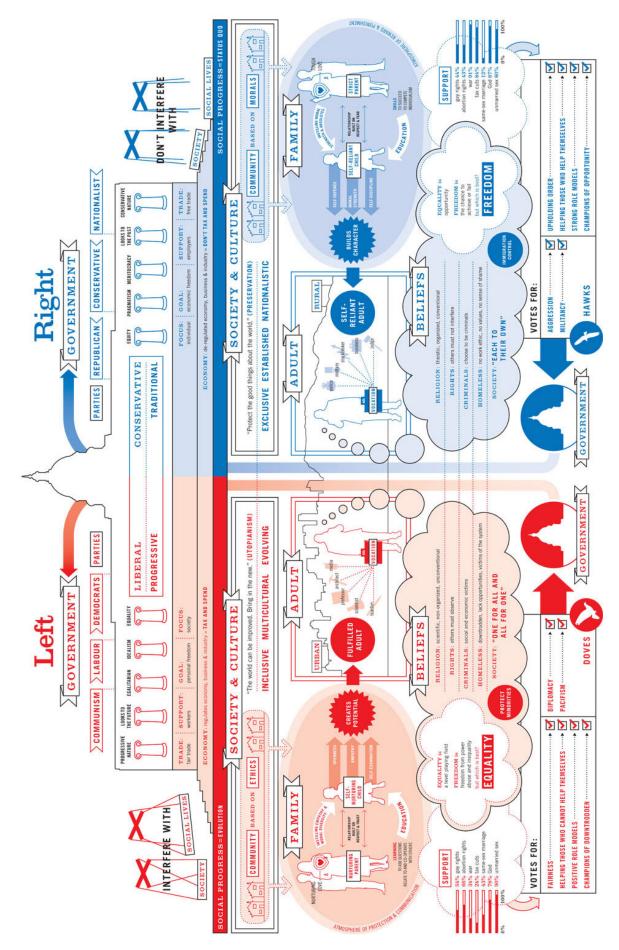


Diagram 3: Left Vs Right by David MacCandless (2012, p14)

#### The emplotment of "emotions"

I had now done the necessary groundwork to see that the word "emotion", a key part of my study, was also laid bare on my map, and that using my map I could understand why it seemed so unsatisfying when addressed in terms of "coping and resilience" in the influential work of Lazarus and Folkman (e.g. Lazarus, 2000). Now I saw that coping and resilience are not wrong, but my concerns about them I could now understand as being that they may require emotions to be found in only one place on a much larger map. Literature surrounding coping brings out other uncomfortable ideas: state vs trait, for example (e.g. Boals et al., 2011), emotion-focussed vs problem-focussed coping, (one of the major contributions to the field by the prolific Lazarus and Folkman) which seemed to imply a separation that is hard to be precise about and problems which are both easily described and personally solvable, through (often measurable) self-efficacy (Gibbons et al., 2011, for example). The other trouble was that "coping" seemed to cover hundreds of different kinds of activities, a point made in a piece by Schwarzer & Schwarzer (1996), which seemed to contain a rare moment of self-reflection in coping literature. And this was long before I had come across much critical writing about resilience, such as Kristina Diprose (2014). A more recent review concludes that despite the rise of the word "resilience" in nursing research, there is no universally agreed meaning, and that from a piece which does not attempt to view resilience as much more than a personal attribute (Aburn et al., 2016).

If one follows the arguments above (and writers such as Diprose), then coping and resilience are politically Right-wing; useful concepts no doubt, but not neutral. This resonated with Jerry Tew's explanation that not only is the inter-personal political, but the intra-personal also (Tew, in Spandler et al., 2015, p69). I needed a way of thinking about emotions more suited to my method, which led to another realisation: it would be temptingly simple to say that on the left of my map (and the Right of MacCandless') people *are* emotional and on the right of my map (and corresponding Left) people experience emotions *about*. However, I wonder if the whole language of emotions lends itself to a personalised or sub-personalised position; experienced in our bodies, yes, but the words used to describe our most common emotions already contain an emplotment which suggests they begin inside of us. This theme is discussed further with John, a participant who had a very social understanding of his experiences and health. I began to see emotions not as objects but as stories; stories we collectively tell, and just like every story, they are told for a purpose.

I seemed to have had this realisation about emotions twice, in two ways. Firstly, that I felt that having emotions *per se* must be a Stewart and Cohen *universal*, but that the ways that we describe and value them must contain many *parochial* elements. Secondly, that they were not politically neutral (because they tended to pull explanations of experience towards the sub-personal and personal): *probably just the same realisation*. This illustrates another important idea: If there is a tendency for people to create arguments which misconstrue parochials as universals, as I have already claimed, might that tendency itself serve some purpose? The answer, according to those who are on the systemic/super-systemic side of the map, is an emphatic "yes!", but their language is usually that of "false depoliticisation".

I realised that the combination of these three charts was joining up dots in rather exciting ways. I saw conflicts within nursing practice very clearly expressed on MacCandlass' chart. I felt that Smith's chart seemed to promise an understanding of self and agency which was fascinating. I felt that my own simple map had helped me enormously already; it is not complicated, but seemed more revealing than *biopsychosocial*. I am aware that this introduction to the politics of experience is very basic, despite the considerable mental effort it has taken me to come to it. Yet that too is an important realisation. Frank's narratives hold their own and do the work of memory; Foucault's knowledges subjugate other knowledges (1988); Freeden's ideologies work best when they decontest themselves; Smail considers our inability to rate the importance of distal power as being the fundamental paradox of being a human; White finds that we have internalised problem narratives; all of these ideas can be used as stations on the journey that a mental health nurse may require to discover the *depoliticised* nature of their work and understandings.

In the work that follows I will refer back to the three charts in order to help to consider the stories of the participants. I will also consider some suggestions of illness narratives offered by Frank, *Chaos, Restitution and Quest,* (2012, p118) and ask whether in voices and emotions there is another: *Mechanical.* In addition to universal/parochial and that set of three related terms, I will also continue to note that in many ways this work sits in three related areas of philosophy.

- The mind-body problem
- · Freedom of the will/agency/theories of action
- The philosophy of personal identity/selfhood.

Time and again it is seen that without a supporting backstory about "the will" or agency, or assumptions made about the mind, individuals and selfhood, or using a particular political story (which frequently turn on conceptions of the individual and of agency) to act as a moral framework, then understandings, whether it be from "lived experience" or from an "RCT", make little sense. I think it is even fair to say that many of the main stories discovered here, whether it be stories such as "psychology" or "emotions" or "rights" or "illness" and, yes, "voices" are born from these more primal stories and are often spin-offs; one might say they are part of our collective attempts to live with such stories. I think it is sensible to describe psychiatry as part of a conversation we are having between ourselves, and perfectly reasonable to further reduce that idea to say that psychiatry is part of a dialogue between several sets of stories, stories which recruit and mobilise us in their efforts to hold their own. In particular I think that stories about *will*, with its siblings of agency, intention and action are tyrants which seem to lock us into other stories about self that in turn produce problems of left and right wing politics and more.

This thesis cannot resolve those philosophical problems, it cannot resolve *equality vs freedom* (about which, more later); it cannot improve upon others' attempts in those regards. I look at the work of other PhD students and worry that this DNA is a mere scratching of the surface. However, its attempt is to stay on the surface, not to be drawn down into any one story, to be wooed by their apparent easy precision.

#### Can socio-narratology be neutral?

Can I pretend that the method of a "socio-narratologist" is simply a means to neutrally explore the narratives on both sides of politics and all positions on my map? It seems to lend itself to thinking about power and agency in ways which are Left-leaning, experience as situated and not possessed. Those on the Right of politics would perhaps not agree that their *achievement/ characteristic of agency* is better reframed as being in the right social space to be conduits for the *agentic forces* of societal narratives. Arthur Frank, Michael White, David Smail, Michael Freeden and Michel Foucault are arguably the five most significant authors for this thesis and from the above analysis it seems that they generally understand the position of the Right of politics through the logic of the Left. At least, I recognise that the more I have become recruited into the ideologies they espouse, the more my sense of how to understand the mental health system, its critics and the world more generally has shifted to the Left. I cannot see how it could be otherwise, even if I allow the approach to critique all narratives. Tew seems to have recognised this in describing movements such as the HVM:

Such understandings have led to a new form of praxis which may be seen as complimentary to the social model of disability. It represents a very different form of taking power – one which focuses much more on the personal but viewed through a lens that is profoundly social. (Tew in Spander et al., 2015, p75)

I believe that this research is part of this current effort to reexamine the personal through a situated understanding of the self, and thereby reclaim emotions from a site of power relations in which the dominant views in recent history have been individualistic, falsely depoliticised, and, as Tew also describes, *ruthlessly othering* (p69). I therefore hope that this work, which explores the apparently

personal experiences of voice-hearers may nevertheless be favourably received by the authors of the 2014 *Thessaloniki Declaration* (6th World Hearing Voices Congress) who claim:

The experience of voices is not a personal, but a collective matter: it concerns family, friends, professionals, the whole society.<sup>12</sup>

If psychiatry does epitomise aspects of Right-wing thinking, then we should expect that a "practice of criticism" of a field which includes psychiatry is going to contain Left elements. However, I will do my best to show that becoming recruited into these more situated narratives may have undesirable consequences also, an endeavour in which some of my participants will join me.

#### Summary

Before designing this research it was the sheer heterogeneity of the field of hearing voices and emotions which demanded my attention. In exploring the contested categories I found three sets of concepts very helpful: universal/parochial, natural/interactive and historical/ahistorical. I have explained that this alters the possibility of a standard literature review, and have reported on an early attempt to separate literature into schemata<sup>13</sup>, an attempt which helped me to realise that I needed an analysis of what stories do and not merely what they are, and also that "emotions" were not well translated into "things one needs to cope with", but that the variety of ways of understanding emotions are not politically neutral.

After selecting the work of Arthur Frank, I began to prepare for DNA. This increasingly revolved around three charts that became part of a lens through which to view the literature and the transcripts. The first is a map of the location of experience, the second containing the work of Phillip Smith and then finally stumbling upon MacCandlass' diagram showing the ways that perspectives may be spread over the continuum of politics. I felt I was beginning to understand the incommensurability of perspectives. In putting all of this together and using an approach which emphasised the context of experience, I seemed to be being drawn towards the right of my map and the Left of politics; of narrative inflation of its own. I now felt ready to be able to think about the narratives of voice-hearers and understand what they might be doing.

<sup>&</sup>lt;sup>12</sup> I have decided to reproduce the declaration in full, see Appendix 5

## Section 2

# **Relationships and Reflections**

#### Three reminders:

Placing too much emphasis on verification relegates the storyteller to being a mere source and holds the story hostage to its mimetic value. (Frank, 2012, p101)

1. I will not be checking participant's stories for "factual accuracy".

Rather than carrying the monological message, this is all you are, dialogical research can offer the possibility, this is what else you are connected to. (Frank, 2012, p102)

2. What I hope to achieve will be both speculative and inconclusive.

3. In 2013 I wrote that I "wanted to emancipate the stories of voice-hearers": a politically loaded statement! Does this DNA do this? Throughout the research I have had an idea that as long as I somehow made the participant's stories "central" that I would not be "using them to illustrate my own arguments". Many methods of research do not respect individuality, indeed, they 'control' for it. Where a group has been treated without respect, it is long due, and narrative research is perhaps the most respectful research (Carson, 2002: p22). It has been argued that "snippets of service users" lives have been colonised and presented as "truths" for the education of mental health professionals, and that this has not been emancipating but a kind of theft of narrative control, or transforming narrative into specimen (Morgan et al., 2016, p5). Stories recreated as truths is essentially the dream of power over others (Stivers in Overcash, 2004, p19).

The participants have all received copies of their transcripts, but what follows, DNA, is not *theirs* in the same way, although some were able to make their views more plain than others and I have tried to represent them. In any case, although DNA tries to properly hear stories, it contains the idea that stories are not exactly *ours* anyway, but that we use them to think with. I therefore feel they have the right, should they wish it, to say that what follows is not *them*, despite my efforts. I also hope that both they and I can remember that what follows is not truth and not an attempted mastery over participants in order to say that I know what their stories truly are, what they really mean. I would rather it be thought of as a sort of helpful conjecture, which serves to widen what participants and others have previously thought to be relevant.

In reading the transcripts I looked carefully for several key aspects. How do stories locate experience (with all of the sub questions about responsibility, agency and selfhood)? What actions are made possible by the stories? How does the story relate to my three charts? As much as possible I tried to think as I thought Arthur Frank would, and this included trying to read even the news as I thought he might! My friends wondered why I was always talking about stories. I approached each transcript as a person in a relationship, too. I had met people and been privileged to hear their (often distressing) stories. None of what was said felt like 'data'. These were real people and I had a relationship with them.

#### **Twelve People**

The bulk of this thesis lies in this section. It explores the narratives of twelve people met once, twice, or more times in the course of this research. They are not given equal weight here, because some of their stories brought more other stories into visibility than others, or stories of greater

complexity. The twelve are presented in order, due to previously discussed ideas about research narrative. Despite this choice, the order does seem to make a kind of thematic sense. I have changed all of their names, removed locations and idiosyncratic events. Becky, Claire, Angela, and Lisa introduce, amongst other ideas, *narratives of diagnosis*. Matthew is rather different, he is the only participant to have never been diagnosed, and he stands as someone who further illustrates some of the questions left by such contested categories: he does not seem to fit but it is very hard to be precise about why. Steve is difficult to summarise, which seems to be a part of his profound suffering. John introduces a pivotal chapter, because his narrative forces a new perspective into the research which is a very uncomfortable reflection on notions of responsibility and judgement. He is in some ways the antithesis of a "good" citizen, but does this tell us more about him, or the State? John forces a return to explore the politics of experience and "the will". Jenny and Rosie seem to illustrate lives caught up in others' stories, with Amber's story missing for interesting reasons. Mel's story is a medical success and yet somehow incomplete, and Ross... Ross is simply astonishing.

No matter how many times I have re-written the chapters for Becky, Claire and Angela, the first three, I feel the need to bring in a lot of other material and this makes their chapters slightly less personal. I may have to let them stand as an illustration of how much work needs to be done to actually hear voice-hearers. Perhaps it is a tension between the need to let their stories be heard and the desire to write an academic piece. Nevertheless, I think it was really only after Angela that I began to feel free to just hear the stories, and I think that is partly Angela's achievement. Lisa followed Angela and it may have been under Angela's influence that I began to see that I was trying to emplot Lisa's story, for example. This means that in later chapters I feel more confident that the participants will recognise themselves and view the chapters as primarily comprising their stories, but there is something about the first chapters that makes me feel a little apologetic, even though in other ways I am delighted to present them. It feels as though I do let those first stories breathe (Frank, 2012), but only just.

# Becky

I met Becky at a meeting in a small town in a rural county. It was at the beginning of my recruitment, and I was trying out some different strategies for meeting voice-hearers outside of the NHS, having had the difficulties already described with advertising. I had been given a short slot to describe my research at a community event and immediately afterwards, Becky approached me with enthusiasm. She had been through a lot, she said, and hoped her experiences might help others. We exchanged details and met up twice, with some correspondence in-between to share the transcript of her first interview. The first time was at my university, to which she drove a considerable distance with a friend. The second time was in a bookable room in a city library near where she lived. The two interviews were eight months apart. They introduce themes that will be important throughout this thesis, quickly, in a rush. The first interview seemed to contain the fragments of many competing stories, the second was more strongly emplotted by just one.

### Diagnosis, re-diagnosis

Initially I was diagnosed with depression. For a long time and for many years I kept going to the doctor and saying, "It's not just depression, it's not just depression, there's something wrong, there's something wrong with me... You need to do something about this there is something wrong with me". I kept saying, "I think I'm bipolar" and, all over my medical notes it says I'm "neurotic". Well, last year when I had a breakdown I eventually got a new diagnosis and a psychiatrist said "No, you're right, it's not just depression". I said, "Thank you! Someone finally is listening now!" So yeah, I just always thought it was bipolar, because I'm such an extreme person. It just made sense for it to be bipolar... but it's not bipolar... but I suppose it can look bipolar to people that don't know what's going on inside my head. I look like I go from extreme lows to extreme highs, and that's it... but it's all the other stuff that is going on inside. The way I have come to see it, is that I've always been led to believe that bipolar is a chemical issue, rather than, like a proper psychological problem... Whereas I don't really think mine is chemical... Well it would be nice if it was chemical, because that's fixable problem... It's not that my problem is not fixable, it's like since having the breakdown last year I've learnt a lot more about my life... I see it more accurately now... I've had outsiders trying to help me see things the way that it actually was rather than just being that oh this is the way it actually is, and... I do think I know the stem of the cause of the problems now.

Becky then described to me a process of rediagnosis which has occurred under a new consultant psychiatrist following a "breakdown" a year ago. She acquired two new stories, borderline personality disorder and emotionally unstable personality disorder, taking the tally of diagnostic terms in this interview to five. She welcomes both of these and describes them as making sense. There seemed to be three reasons that she saw these as positive. Firstly, they fitted with the idea that to have a primarily biological disorder somehow did not take full account of her sense that life events, especially her parents neglect and violence towards her, were causal. When diagnosed with a personality disorder, Becky therefore felt due attention was given her past history, but a biological account appeared to invalidate her life experiences. This is a theme that other participants also explored; Claire was also diagnosed with borderline personality disorder after being diagnosed as psychotic and found it more validating of her life events and emotional difficulties (although she later denounced both diagnoses). Secondly, Becky felt that the description of turbulent relationships, self-harm and substance abuse which was offered to her with that diagnosis was a helpful explanation or vindication of her own difficulties in those areas, whereas previously they had been more incidental to illness. Therefore, the new diagnosis not only widened the scope of what what was narratable from the past, but also horizontally, into other areas of her experience. Thirdly, for her the new diagnoses explained the continuing severity of her distress: for Becky, a "chemical" illness is fixable, but having been on medications for years, she felt at best a bit supported, but not better. The new diagnoses provided an answer.

These opening remarks for Becky introduce enormous ideas; her explanation feels like huge stories being moved around like chessmen across the board of her life. There are the stories of *psychotic vs neurotic, chemical vs psychological, biology vs phenomenology,* and questions (it seems from both psychiatrists and from Becky) about the role of experience as either causal in, or secondary to, the mental: choices about how to story the past in order to explain the present. Questions of responsibility flow through all; what or who is the cause of her distress? What seems evident is that there was a period of time in which Becky wanted recognition that there was something further "wrong with" her, that the current set of stories neglected that, and then later she preferred to be rediagnosed in a way that brought other issues into view. Recent *learning about her life* is then described as "the stem of the cause of the problems".

When I was 16, I was living at home. I've had problems though I don't know how long. I've started self harming when I was about 13, and then a really crappy thing happened when I was about 14, and it just got worse and worse and worse. And then I went through a really bad breakup with my first proper boyfriend at the time and that just started a snowballing of events and it just got worse and worse and worse, I was cutting more, I tried to cut my wrist, and then I ended up leaving home...

In thinking about this in terms of my map, one might say that Becky felt the need for stories which were sub-personal, but found they made more personal and systemic ones less visible, less able to hold their own, and that there were parts of those stories she felt she needed too. Yet that makes Becky seem like the author. Another point of view, one more suited to viewing diagnoses as parochial/interactive/historical, says that the real context is that she sought help and these stories were what was on offer. No one narrative seems to quite fit. One of the first examples of this is that, although finding biological explanation a poor fit in the examples above, Becky used a biological phrase which is, at face value, as completely sub-personal as it is strikingly sad. In speaking about her future she said:

# I don't want children, at all. I... really put that down to the fact that I'm poorly. I don't want to give a child my shit genes.

In addition to the "chemical" illness story, Becky's transcript reflects another narrative: that there is something which may be physically inherited about mental distress, genetically driven illness which may be passed on through reproduction. It would be possible to write an entire thesis on the origins, science and poor science which has formed this narrative, and the ways in which it has continued in this post-Human Genome Project era. It seems uncontroversial to say that there is a considerable lag between changes to understandings about the relationship between genotype and phenotype and the ways in which psychiatry often evokes notions of heredity or a "genetic basis". How, for example, are such psychiatrists going to respond to Dias and Ressler's (2014) elegant research which resurrects Lamarckism after all these years with its important implications for the direction of causality between experience and genes?

To the extent that Becky believes that her genes are "shit", this story is very sad. That a woman in her late twenties would believe this of herself, and as a result make a sort of self-imposed sterilisation decision, would be difficult to hear even if there existed good grounds to see that story as well-evidenced and uncontroversial. However, if we are to believe writers such as Bonnie Burstow (2015) on the subject of heredity and the kinds of "mental illness" at stake in Becky's life, then Becky's recruitment into this narrative goes beyond tragic into the realms of human rights violation. For Burstow the origins of the genetic story are thoroughly embedded in a global early and middle 20th Century partnership between psychiatry and eugenics, and, yes, the Nazi Holocaust (2015, p48). The genetic story is essential for psychiatry to take it's societal role in the creation of "the other", the mad unreasonable underclass. Read et al. devote a chapter to this theme of the shared history of psychiatry and eugenics also, with similarly radical conclusions (2004). Current re-examination of often cited twin studies and associated genetic assumptions are likewise drawing conclusions about their dreadful science and political affiliations (Fleming &

Martin, 2011). All the while the media repeatedly and calmly inform us that the gene(s) or "biomarkers" for schizophrenia will be discovered shortly.

Perhaps this genetic story also protects Becky from societal expectations surrounding women, relationships and childbirth (perhaps "uses" is too deliberate; "allows" might be better). Her later suggestion that she would not like a relationship because it does not seem right to *drag another person into my mess* might also be a way of protecting herself from societal pressures and past hurts. Becky did not raise the issue of sexuality and did not further explain the "really crappy thing" that happened when she was about fourteen. In describing two occasions of being discharged from mental health services at times when she clearly felt in need of further help. She alarmingly described this as being "pimped out", a phrase she used in that context twice.

Becky used another internal story too:

...[L]ooking at the rest of my life and knowing that this could be it, knowing that this could be the best I could be – I'm a lot better than I was a year ago – but it's still very frightening to think of my whole life going through cycles of crap, as I usually call it... er... because when it's great, it's great, but when it's shit it's really really shit.... and although I know I'm probably going to come out of it again, I know that I'm probably going to go back into it again. And when you think of 60 or 70 years doing that – hopefully, I smoke so it won't be that long – but that's a long time to be going through cycles of crap.

There is something very significant about the word *cycles*. It does a lot of narrative work. It provides some kind of plot, a temporal pattern of experience in which highs are followed by lows as if ordained by nature, even by physics. It explains the present in terms of the past and it points to the future also, and it is clear in Becky's account that she see it as something to expect endlessly. Yet unlike many plots which explain personal experience it is particularly limited. Experience is secondary to the pattern, removing the idea that the content of the experience is significant other than as an indication of where on the "cycle" Becky is at that moment. It removes concepts of agency and of recovery, and seems to close off the possibility of the environment significantly impacting on Becky's experience. It seems to perform an "aetiological closure", which is a phrase I have taken from critique of the diagnosis "borderline personality disorder" (Shaw and Proctor, 2005). I feel that this is a *biological* story, although psychologists (and for that matter, historians) speak of *cycles;* my guess is that, as a story used by Becky, the idea probably has its origins in the diagnosis of "bi-polar disorder" which she had used at one stage, although she described it as inadequate. Yet immediately before all this she had said:

... everything in recovery is tiny tiny baby steps...

It may have been that she meant that this was her experience as she commenced the part of the circle which heads away from the lowest ebb, but I rather think this has the ring of Cognitive Behavioural Therapy (or perhaps Solution Focussed Therapy) about it. *Recovery* is also a word with a plot. The word "recovery" also connects this comment to the "Recovery Movement" - and in particular the ways in which it has been interpreted in the NHS in becoming the "Recovery Model", about which, more will follow in John's chapter.

Because everything in recovery is tiny tiny baby steps and sometimes that is the most frustrating thing in the world... Because I've got a job now, and I'm in therapy... no more hurdles for me to get over any more. There is, but they are just tiny little hurdles now... but sometimes it's the little things that make the bigger picture better. So if I focus on like, fixing the tiny hurdles... It has a bigger effect.

Becky presented stories that do not sit easily together. She was able to speak of recovery, progress, therapy and learning, and yet the inevitability of circular experience dictated in some way by faulty genes. For Becky, psychological problems carry a connotation of being long-lasting and having wider impact, and chemical problems as being more temporary and resolvable. That it

should be that way round is very interesting. I wonder if someone would have expressed similar views (were the language to make sense to them) in previous centuries. Although she told a general story of moving from a depressive diagnosis (felt to be too circumstantial) to a more biological (bi-polar) diagnosis (felt to be more validating of the extent of her difficulties) and then becoming dissatisfied with the way in which this did not take trauma into account and thus to a more satisfying "borderline personality disorder", she still uses both kinds of stories to explain the present and predict the future, as further illustrated here:

Yeah. I'd like to get to a point where I no longer have automatic suicidal thinking... That's the goal, that's my only goal, I never want to sit there and think I want to kill myself ever again. But not naive enough to think that I wont go into services again in the future... that I won't need medication to help me... I'm not naive enough to hope for that. I'm not as bad a mental patient I suppose as some people could be, I'm not one of these – what do you call them – revolving door patients where I'm in and out of institution but I probably will need counselling at certain points of my life. And a little bit of a lift with meds, but... to me that's okay... just as long as I don't want to kill myself.

The nurse in me can easily imagine myself on the receiving end of some of her statements:

Before I had the breakdown last year for six months I kept going to my GP and saying, "I want to kill myself you need to do something about this, I'm going to kill myself on this date...

As a community nurse I have had many similar experiences. A colleague visited a service user who had taken an overdose timed carefully to be just before their arrival, another lined up tablets on their table and saying they would take them if I left. This set of stories needs further explanation; several participants had the experience of being rediagnosed either from psychosis to personality disorder or vice versa, and it is necessary to think more about what this shift of stories entails and what contributes to it. One of the reasons it is necessary is that it may be thought that the difference is one which should disqualify people from participating in this research in that it might imply that the voices experienced by Becky and others with "borderline personality disorder" are not *bonafide*, that their voices are merely "pseudo hallucinations". However, I want to defer that discussion until after the first four participants, who all have contributions to make to it. One aspect is that I think they show us that this may not be either/or, but stories that need to considered in combination.

I also felt my nursing opinions about this issue shifting, and now as I look back I see this as a major shift in horizons that Frank speaks of (Frank, 2012, p94). I now saw more clearly an aspect that being with Becky as a researcher rather than a nurse seemed to be unmasking. I could see that the stories used purposefully by Becky were not exactly her own: they were often provided by the professionals and the diagnoses she had been given in her guest for help with her overwhelming experiences. Her switching between stories which connected her to experiences and agency, and then to stories which remove them seemed less some kind of pathological refusal to take responsibility for her life, something I would certainly have felt in the past as a nurse, but rather the contradictions inherent to the stories. Given that the stories made available to her by the experts the state had provided contained genetic, chemical, environmental and personality-based explanations, each with different aetiologies and located in different areas on my political map, is it surprising that Becky's account of her life and attempted understanding contained contradictions? Was it not guite reasonable that Becky should try to understand what of her difficulties were her responsibility and what, for a variety of reasons, might be beyond her responsibility? And to try to understand to what extent her difficulties were wrapped up with life experiences or with her biological make up? With so much at stake in terms of stigma, societal expectation, and the sense that she might be an upsetting person at times (she apologised to me for talking about self harm, for example), was it not also understandable that trying to protect herself motivated Becky to use stories in the ways that she did? Frank suggests that it is important to understand what is driven by fear and what animates desire in stories (2012, p81). I think it is reasonable to say that Becky is

driven, perhaps by experiences of strong emotion, to ask questions about mind and body ("properly psychological" vs "chemical"), freedom and determinism (because questions of responsibility seem to be key to so much of her requests for help), and to ask which of the kinds of stories available from the different points on my map are the most explanatory for her (and in so doing, discovers at least something of the ways in which those stories contradict each other). This might sound rather obvious, but for me it is a profound observation upon stepping from the role of nurse to the role of narrative researcher.

Frank would have me "thank" Becky's narrative for what it reveals. I feel it has begun this thesis in a complex way, revealing some important themes:

- That different diagnoses may be made for the same person over the course of time.
- That different diagnoses and/or psychological approaches have a bearing on notions of responsibility and agency.
- That different diagnoses and/or psychological approaches carry different implications of the primacy or otherwise of experience over biology, or vice-versa.
- That concepts of recovery exist which seem to contain some incompatibility with some biological explanations, such as genes, at least in the way that they are commonly used.
- That a person may be highly "multi-storied", resulting in taking medication for difficulties described elsewhere as genetic or environmental, and yet believing that a recovery is being made through goal setting.
- That these contradictions may be present in the individual but can also be said to express the contradictions of a wider system, and indeed it seems fair to say that this system's contradictions are themselves somehow predicated on straddling some of the oldest and most thorny philosophical questions: mind and body, agency and moral responsibility, issues of self-hood, that have shown themselves not just as present but somehow being key to the questions Becky is asking about herself, and her acceptance or non-acceptance of the different explanations offered to her.
- That there is a need to consider these stories and the dialogue between the stories of "psychosis" and "borderline personality disorder".

However, there were more stories to come. Becky and I had been talking for nearly an hour, during which time she had used three cards to tell me mainly about diagnoses, stories which she clearly felt I should know about. It was only after the cards were used that I asked her to tell me more directly about hearing voices and emotions, which somehow, had hardly come up.

I went to... a new psychiatrist in [place name]. He started asking me questions that I've never been asked before, like, "Do you get a lot of noise in your head sometimes?" "Yeah I do actually. Quite a lot. And it's loud. And it tells me that I need to hurt myself."... "Okay – you probably have borderline personality disorder". "Okay – what's that? Because I spent the last 10 years of my life learning about depression!" [Laughs]. Now they tell me I've got something else – well they didn't say – at the time they called it "emotionally unstable personality disorder", but yeah... And when you start looking at that, and looking at the patterns of behaviour that those people would have I kind of have a lot. And I've been on and off antidepressant medication for about 10 years, and this doctor gave me an antipsychotic at a very very low dose... But it's, I think that that has done wonders for me having that tiny little crutch, that's really helped because it's like... Antidepressants were keeping me up – nothing was there to control when it gets too up, or things aren't right in my head... When I'm very very poorly – I remember saying to [name of friend] in the breakdown, "I don't know what's real any more", and its... the antipsychotics help with that a lot, obviously. That's what they're there for.

...I'm not saying I love my voice. It's a pain in my arse, but there are really good moments and I know why it's there – which I suppose I'm really lucky in because some people just get told "oh you're schizophrenic". It's there because of a chemical imbalance, or it's just there. I know why mine's there... And since learning about myself enough to know why he's there... Has actually really helped my relationship with it.

Me: Why is he there?

He's there because he's my parent. He is the person that I needed to help comfort me and regulate my emotions and that can kind of still be seen a lot now. If somebody is nasty to me I have a tendency to just sort of go, "Okay"... And my voice is going, "No, that's not right. Fucking say" – excuse the language – "fucking say something... Tell them... How you feel". And there are times now in therapy when I might shut down and my voice actually says to me. "you can't expect your fucking therapist to know what you're thinking - she's a therapist, she's not psychic! So tell her how you're feeling". And I think that I've had a better therapeutic relationship with her because of that... So there are moments when it's crap but there are also moments when I feel like I am part of the team. I have always got someone fighting in my corner, it doesn't matter that the rest of the world can't hear it [laughs] I know it's there. I know that's a bit strange, probably, how can you get attached to something that tells you to hurt yourself? But it happens, I suppose, it's all I know and comfort.... And there are moments when I have real problems with my parents, such as, my mum and dad are a bit rubbish, and my mum once said to me, "I don't care any more Becky, you can sit there fucking crying all night, I don't care". And I went away and I just remember thinking, "please don't leave me" – because that's what he's there for. And those are the moments when, like I say, I don't know what I would do without it.

## **Eight months later**

Becky and I are meeting again. She has moved house. The friend who supported her to come to the first interview has become more unwell (a terminal physical illness) and much of Becky's life is orientated around caring for her in what seems a touchingly dedicated manner. Eight months has made quite a difference, and Becky seems more confident and independent. She has a very different focus in this interview which is much more related to voices and emotions, and seems to be linked to the HVM. I think this was partly because of some of my questions, but mostly it was what Becky wanted to talk about. She has been attending an HVM peer-support group for voice-hearers. She was attending this group at the time of the first interview too, but it seems to be a more useful story to her now. There are many parts of her speech today which reflect emplotment from the HVM, and she retells her psychiatric history as one in which no one ever really asked her if she hears a voice but always has done, a factor which she sees as pivotal for her self-understanding. This is the story that Becky is telling today and it seems to open up some very interesting possibilities for her. Here I present the opening of our second conversation.

Me: Okay. Right... Thank you again for your interview last time. I really found it brilliant, to write it up, and reread it, and read it again recently. Very meaningful. So... one of the things that I am trying to understand with people is about whether voices and emotions are connected in any way. And you said a few things that show that you have really thought about that, too. So, for example, at one point you said that the voice has a purpose for you, and that that purpose is to "regulate your emotions". And you also said, that... it, "pushes you to stick up for yourself"... to explain yourself more fully, that kind of thing, to be more assertive. You have said that it also... that the voice is most, "pronounced" when you are low, or panicking. So... to me, that is at least two or three ways that you feel that voices and emotions are linked.

Becky: Yes.

Me: Are there any other ways, or does that cover it?

Becky... I think it works both ways. It can be very distressing and very very loud, and overwhelming, when I am panicked or down. But I am starting to find that there is the other side of it as well, where when I'm very happy, he's my little friend. And different things come out. And sometimes, perhaps, when I am stressed or down, or panicked, the overwhelmingness of what is being said to me is an expression of what is going on inside. So, I am much more understanding of the automatic thinking now – I know why I am being told to kill myself. It is because I don't feel I am coping, I would like to remove myself from the situation and that if I suddenly get this, "you need to jump in front of the bus", it is like, "shit! I need to take a step back and work out what it is that is bothering me so much that this thought has come into my head".

Me: Okay...

Becky: So... This is really bothering me, okay, now I have to deal with that, and rather than keep pushing everything away, and trying to get that voice to stop telling me to kill myself, I now go, "why do you want me to kill myself? What is bothering you?"

There are several aspects here which represent essential plot lines of the HVM. The first is that the voice is *purposeful*. To say that this is contrary to what may be understood in mainstream psychiatry is an understatement, since the term *insight* is used in psychiatry to describe the knowledge that one's *hallucinatory* experiences are not real (with the implication of not meaningful or purposeful) and that one's beliefs that try to rationalise them (apart from a belief that they are secondary to an illness) are *delusional*. This "insight" is absolutely key for risk assessment.

Are voices "vocalisation" or "communication" (McCarthy-Jones et al., 2015, p181)? Is phenomenology causal or merely symptomatic; explanation or description? I know of no phrase which encapsulates the HVM concept more than one they frequently use: *don't shoot the messenger*. As Becky shows by taking the demands of the voice as an indication that she needs to question herself (rather than the voice): "what is bothering you?", the presence of the voice (perhaps especially when it is overwhelming or commanding) is taken as a need to reflect on Becky's own experience. In describing the HVM idea here as *the opposite* of "mainstream" psychiatry, it is possible that some people may object. Is it really true that this is the accepted approach of the HVM? Equally, has there ever been such a thing as "mainstream" psychiatry, and does it always insist that all such experiences are "meaningless hallucinations?". These objections I will consider further with Angela.

The second aspect of Becky's opening statements which use narratives drawn form the HVM is that her voice is described as being positive in some way, or at least that in positive engagement (not "pushing it away") the voice may hold a path to the resolution to distressing emotions. I want to suggest that after the legitimate concerns about creating a "straw man" argument above, this remains a fundamental difference. In 2015 I took part in a six-day training given by the HVM to about twenty people, fifteen of whom were clinical psychologists employed by the NHS. The rest comprised voice-hearers and me. I found it fascinating to gauge the changing atmosphere in the room. At the beginning the psychologists expressed hopes that might be summarised as another string to their bow. During the second day, a voice-hearer with an astonishing trauma story (even by the standards of the psychologists, two of whom worked in a specialist trauma service for refugees) explained how she had come to understand the relationship between her life and her voices. After this, the atmosphere had changed: the psychologists saw that this was more than just another approach: there was a sense that the insights that the voice-hearer had gained were more profound (and more helpful) than the psychologists had come to expect in their practice, and something they very much wanted to be part of. The slight distance they showed at first translated into fascination, and they began to explain what they saw in terms of the other trainer (the nonvoice-hearer) being a very unusually skilled therapist (he had helped this particular voice-hearer). although this was denied strenuously by both trainers. However, a real sticking point came later in the week: the trainers said that in their experience there was no such thing as a negative voice. But what about the tormenting ones that say degrading things or threaten to kill children? No, these turned out to be positive too. Fundamentally, even such difficult voices, we were told, are trying to prevent further harm to the voice-hearer and help them to know themselves, acknowledge their experiences and make sense of the world. Yes, some of the voices were behaving in counter-productive and frightening ways, and this needed to be discussed with them, but the motive of the voice turned out to be a good one *in every case*. This was hard for all of us to accept, as can be imagined, including a voice-hearer who was being being helped to think about his voice-hearing experiences for the benefit of the group (he nevertheless found the training to be of benefit, claiming that his voices had changed for the better as a result of the training and were now less powerful than they had been for over 20 years). This positive valuing of voices is something which will be discussed further, including with Claire who also attended the training.

Becky clearly felt that her voice could be positive, "a friend", or at least that much could be gained from seeing it as a prompt to self-examine and self-care. Becky's phrase "pushing it away" is very reminiscent of the requirement within the HVM to "accept" voices, which was part of the title of one Romme and Escher's most often cited books (Romme et al., 1993). The narrative of the HVM is that in all it does, psychiatry suppresses and avoids voices, the opposite of what the HVM views as essential, hence *don't shoot the messenger*.

Yet, just as in the first interview, where it was evident that Becky uses multiple stories to think with, there are elements here which suggest emplotment from a different source: Cognitive Behavioural Therapy. The phrase *automatic thinking* is straight from the CBT lexicon and probably came from the therapist to whom Becky refers. It is another phrase which seems to imply a particular kind of *mechanical* narrative. As I nurse I hear this most as *automatic negative thinking*. The word *cycle* (above) was shown to be a strange hybrid of explanation and non-explanation, a cause which nevertheless contains *aetiological closure*. The plot of *automatic* seems similar.

I would like to consider this alongside Frank's suggestions of illness narratives: *chaos, restitution* and *quest* (2012, p118). It is important to begin by saying that the argument here is not that Frank has been inadequate in his three categories. Frank is himself keen to stress that such typologies must never be seen as a finalised list and he expects others to add to his list (2012, p121). What *cycles* and *automatic* do is not, I think, found within Frank's three. They are not obviously related to the narratives of *restitution* and *quest*. Both of these evoke images of illness as part of a strong plot in which health is either restored like the prodigal son or is found, possibly through gnostic revelation, trials or at the end of a journey. *Automatic* and *cycle* are certainly not *chaos*, Frank's description of a kind of plotless plot<sup>14</sup> <sup>15</sup>; they are a particular type of strict order and a person evoking them is inviting a heavy emplotment. They contain mechanistic inevitability or determinism, or something which continues indefinitely unless something significant intervenes: a circle must be broken, for example. They seem to exist outside of the personal: patterns to which one might succumb. They reduce hermeneutics, make experience secondary, evoke fate rather than agency, "behaviours" rather than intentional action.

To the chaos plot-that-is-not-a-plot *mechanical* is somehow an explanation-that-is-not-anexplanation. Lucy Johnstone views diagnostic categories in psychiatry as circular arguments (2013; 2014). Perhaps these terms are narrative equivalents and are answers that beg the question first asked. It brings the past under an organising principle in order to explain the present, and alters the understanding of forward motion. It raises the expert, the *mechanic* to know, examine, take apart and reorder the machine. In a few instances perhaps the person could be their own mechanic, but there seems to be an implied need for a new body of knowledge to achieve this. All of these features of *mechanical* plots therefore relate to issues of power, and more than

<sup>&</sup>lt;sup>14</sup> The way in which events become "brute" events in *chaos* narratives seems closely allied to Michael White's description of 'unique outcomes' (White & Epston, 1990, p15), essentially unstoried elements of experience.

<sup>&</sup>lt;sup>15</sup> Facetiously, I notice "automatic" and "cycle" are both found on the front of my washing machine.

anything they seem to support the current status quo of professionals and their "cases". If the psydisciplines were bodies in search of a narrative of professional self-perpetuation then this is precisely the kind of narrative they would want, which is not to say that "being stuck" or "going round and round", or "needing help" are not entirely genuine and reasonable ways for distressed people to feel. It is interesting that although there are versions of bio, psycho and social stories within the HVM (often with clear elements of Frank's "Quest") yet I cannot think that I have ever heard something like a version of what I have described as a *mechanical* narrative there.

I am not of course the first to notice that the body and machines find affinity in the medical mind. Lupton gives a history of *mechanical* as a metaphor in physical medicine. She also finds it raises the mechanic, separates mind and body and has the effect of "valorizing medical techniques which focus upon locating a specific problem in a part of the body and treating only that part, and devaluing healing relationships which rely upon spirituality, personal contact, intimacy and trust". Her *mechanical* has a place on my map: "sickness becomes viewed as the product of biological destiny, located within the individual and therefore requiring the intervention of technology to 'correct' the faulty code, hence drawing attention away from the examination of the social context of illness such as poverty, racism and sexism" (Lupton 2012, p60).

I confess I do not know how to place *mechanical* on Phillip Smith's diagram (p24). Smith might describe them as "low mimesis": language suitable for "efficiency and price, routines and procedures" (Smith, 2010, loc 343), but just as the relationship between it an agency is not that it removes agency but that it transfers it, so it seems that it creates a low mimesis for some and a high apocalyptic imperative for others. The "patient's" actions are to accept, monitor, and manage a localised and de-politicised problem, but the doctor actions are caught up with an urgent global epidemiology and may justify the use of the Mental Health Act (1983).

This suggested illness narrative category, *mechanical*, is uncomfortably close to one of Frank's most moving statements: "a life that is not fully narratable is vulnerable to devaluation" (2012, p75). Frank also notes that a person "becomes claimsworthy by virtue of being narratable" (2012, p75). Thus a mechanical narrative could never be a politically neutral one. Yet this is not simple. Just as there is a sense that although Becky's "shit genes" partially protect her, they allow Becky to *hold her own* against societal expectation. *Mechanical* may allow her to repel an expectation that she should be fully in control of her thoughts, or that linear progress is indispensable.

In this second interview, Becky described aspects of her past in which she found it very difficult to live with or express strong emotions. This led to self harm as a means of coping, and, she now feels, a voice that is trying to help but not doing it well:

Me: ...that sounds like you are having a conversation with the voice -

Becky: Yes

Me: Does it answer you?... Are you asking it, or are you asking yourself?

Becky: I can't say he would give me a very clear answer... Because in a way, I know why he is produced, like, he came into being to be a parent.... But at the end of the day, I have to deal with him like he's a child.

Me: Yes... You said that as well in your [other] interview, that he was like a parent.

Becky: Yes, he is like a parent, he wants to protect me, but at the same time, he is obviously not emotionally developed enough... Say, I feel a bit suicidal because I'm upset about this, it's straight to, "kill yourself!" So, if you go in with right, you're a toddler... I know something is bugging you and you are being very clear about that, but you have to kind of work with it a little bit to work out what it is. It can't suddenly go, "oh, I'm really bothered today because [name of friend with severe illness] fell over and that really upset me, and therefore I think we'd like to kill ourselves.

It seems important to note the use of the word "we". In my experience as a nurse and as someone with a good deal of exposure to the HVM voices are usually described by those who experience them as "it", "s/he" or collectively as "they". Here I will just say that this is clearly a way in which Becky feels her voice and her emotions are linked, that each makes sense of the other. This story about the voice Becky creates a kind of thinking about thoughts, an ability that psychologists often refer to as "metacognition".

In her first interview, the voice, which was less of a personality and more of a noise, was only really an explanation of a latter diagnosis. Now, however, both emotions and voice are part of a much more central story that uses past to view the present:

Becky: I think growing up with it, you learn very quickly that if somebody walks into a room and you are talking to nobody, that is strange! It gets a very adverse reaction! So you learn stupid little techniques... And the worse it got as I was growing up, nobody really asked me the right questions. No psychiatrist turned round and said do you hear a voice in your head? Nobody asked so – don't tell them – because I don't want to be institutionalised. I would rather pretend it's not happening.... Because that's a great way of dealing with things! [sarcastic tone]. But it never occurred to me to turn round and say... It was something I had to get rid of, if that makes sense. When I first went into services, the aim was to make the voice stop. Without letting many people know that I have it. Are you on antipsychotics? Yes – because it might actually get rid of it. It was only when I went into the hearing voices group that this whole other thing occurred... Well, you might not be able to get rid of it, so you've got to learn to deal with it.

I want to carefully suggest that this story belongs more to the HVM than to Becky. This is not to say that Becky is being disingenuous. Perhaps this is a proudly significant story in Becky's life, but the confusion of her earlier years and contact with psychiatry so obscured it that it is now hard to tell in a way which feels her own. Yet, to me, someone who has heard many similar stories, it seems it is something of a type. What I want to notice is that it seems to be replacing the many diagnoses of the first interview, and producing a different past, present and future, creating sense of emotions and experience and also it creates a new way to be responsible. It has also recast the voice as a helper, albeit one who needs Becky to interpret it and negotiate with it. Being a "voice-hearer" is therefore a story with a great organising potential, and Becky admitted that it was something she had found through attending am HVM group, prior to which she had not seen hearing a voice as such a "big deal". The effect of this restorving is a sharp move of inflation on Smith's model (Smith. 2010, loc 340), a much more emotionally loaded "romance" of triumph over adversity (with perhaps the tragedy of a mental health service which did not ask the right questions). However, this is not merely an effect on genre: Becky reported that its effect was also that the voice got louder and clearer. This was initially very worrying, because the content of the voice was generally about suicide, and yet with it came a new personal power:

Becky: I thought if I address this thing it is going to get louder, and I am going to end up just walking along the street and throwing myself in front of the bus. And part of going through the hearing voices group was also learning that the voice does not have the power to throw me in front of a bus. It can't do that. It can talk about it, and it's very distressing, but I am in control of myself.

I kept going to meetings, I kept having therapy, I kept talking about it. I tried different things – I tried – you know some people say there is a method of, "I can't listen to you right now, I will talk to you in half an hour for 10 minutes –

Becky: - that doesn't work for me. If I tell it to go away it's going to get worse. So... Okay, right, you want to kill yourself... well, okay, I'm going to try this: "What is it you want from me?"

Me: So, it is better than you could try to sort it out then and there than to postpone it?

Becky: Yes, yeah. Because that also helps with my anxiety. so, therefore, if I'm helping my anxiety, it is going to quieten the voice. Does that make sense?....It's all about trying to change the way that I feel about it, and then it will feel better.

Finally, Becky reflects on her changed understanding, something of Smith's romantic hero(ine):

I always felt that there would be these cycles of crap. There is always going to be these cycles of crap. But I am is a bit of an odd point in my life, because I pretty much feel that I can do anything after what I've been through. Two years ago I felt like the weakest person ever, and that I couldn't cope, and now I stand up and – I know it sounds a bit strange but I'm a little bit proud of what I've gone through. It has made me the person I am today, I'm obviously not that bad, because I got quite a lot of friends. I'm not naive enough to think that I will never experience emotional difficulties again... But I know I'll get through it. I don't think I knew that for a very long time – I think it was very very hard to learn that I could get through it.

In this genre, there is a narrative pull towards over-coming against adversity (Smith, 2010, loc 363), and that observation feels very like being with Becky, especially in this latter meeting.

# Claire

I met Claire at a lecture given by Ian Hacking in 2013. We were both there because of our interest in hearing voices, but Claire's interest was, as it turned out, personal and academic. From that time onwards, Claire and I met regularly and talked about voices and about narratives. Since I had got to know her separately I somehow felt I should not ask her to be part of my study. Happily, she volunteered.

Beyond our interviews, there were several experiences that we had together which illustrated some important things to me, and I want to begin with one of them that showed me that hearing stories is very poorly thought of as *data collection* (another, some training that we jointly attended, was mentioned in regards to Becky and will be discussed later). I had spent a number of hours with Claire thinking about different ways to help people tell stories for research. At that time, I thought the *Emocards* that I eventually went on to use were a bit basic and open-ended. It was through trying them on each other that I began to see why both of those things were very helpful indeed. As I gained experience I began to see what a powerful tool the cards were, and how positively they were often received. However, in early 2013 I had another idea in mind. I wanted to use the Tree of Life tool (Ncube-Mlilo & Denborough, 2016). I spent a considerable amount of time learning about it, and Claire and I used it on each other. Essentially I rejected the Tree because it is more deliberately trying to write new narrative and alter perspective than seemed suitable for this research and it also needed several hours to complete. If I work as a nurse again it will be one the first things I look to use with new service users. During that session, Claire used the Tree of Life tool to explain, amongst other things, her long and complex personal history with music performance. The next time I saw her was about six weeks later. She told me that she had returned to playing her instrument and having lessons for the first time in many years. As will be seen in her narrative, this is not simply a hobby: it has had an effect on her voices too. It seemed that telling her story had opened a new chapter for her. Rather than being "data", stories make action possible. I therefore tried to learn from my participants whether telling their stories changed them or their understanding in any way, although mostly I just had to speculate. More than this, the importance of hearing and discussing stories in a responsible way seemed to arise, the ethical issue that I described in my opening chapters which the ethics panel did not examine. Yet this guestion cannot be answered without asking what makes one story better than another:

Dialogical narrative analysis prescribes no ethical criteria, yet it also resists moral relativism. The recognitions that there are always more stories and that any story enacts a particular perspective need not lead to the nihilism of believing any story is as good as any other story... Less dangerous stories make the world and actions more complicated.

Dialogical narrative analysis works from within storied lives first to show how people are holding their own, and then to open up the range of stories available to guide their efforts. Life is inherently dangerous, that danger including the companionship of stories. But the enrichment of that companionship outweighs its dangers.

(Frank, 2012, p159/160)

I felt that the above Frank quotations were extremely helpful. It *is* possible to say that certain stories are less good than others, if their result is a simplification which disqualifies a diversity of experience and knowledge. It is better to (sensitively) run the risk that one's interaction with another may leave them with new questions which remain unanswered than to close down such questions, avoid new stories. These ideas will be returned to at the conclusion of this thesis, but at this early stage they led me to hope that my interviews, provided they moved at a pace set by the participant and found ways to positively value their experiences and stories, were unlikely to be more harmful than not having such interactions. I would not have made this judgement had it not already been my conclusion as a mental health nurse.

There are many things that Claire contributed to this research. For the purposes of this thesis I will focus firstly on her use of the story called "dissociation" as a means to understand a relationship between her emotions and her voice-hearing, and secondly on what it was like for Claire's narratives to be placed in dialogue with that of the HVM, which, just as Frank suggests, is an intersection which allowed me to more fully understand each. The theme of dissociation is introduced by Claire but developed further through the narratives of other participants.

Claire: And at that point, having been highly achieving all my life I suddenly found myself on benefits... and I felt I couldn't keep up with my friends who had been at [a prestigious university] because they were all earning lots of money – and there was me on benefits. And I seemed to take on the identity of somebody who was a service-user, a mental health service-user. Somebody who didn't have a job, I was sitting around a day-centre with other service-users, and I thought I would never recover. And now I have a fear of ever becoming like that again.

There is no doubt that this is the *force of fear* which drives some of the stories Claire told me (Frank, 2012, p81). Claire has had many difficulties, including being bullied and abused, life-threatening problems with food and self-harm, traumatic experiences of voices, and considers herself to be a recovering alcoholic, but these rarely seemed to cause fear in the present in the way that day-centre does, with its associations of a loss of future, loss of status, lost identity, being friendless, having no ability to direct herself or create change: a physical space and narrative deadend. I suspect Claire would agree that the day-centre finds some expression within her every day. I came to wonder whether it alters her ability to find solidarity with other voice hearers and people who have struggled with the many difficulties she has had with eating and self-harm. There is a sense that Claire is frightened that one day someone will tap her on the shoulder and tell her that she belongs back there.

I have decided not to include much detail of Claire's undoubtedly traumatic childhood. When reading accounts of trauma, perhaps in some way one asks whether they are "bad enough" to justify the resulting struggles. I sometimes felt that I glimpsed a little of the difficulty Claire has in believing that the stories she told me are going to last and can continue to provide the comfort and strength and self-knowledge she needs to stay away from that day-centre. There is a sense in which Claire has had to fight for this narrative and all that it can do for her. I therefore do not want to present the detail in a way readers might be pulled to judge them as 'enough' or not.

I have always found it very difficult to feel emotion, even as a young child. I either feel overwhelming emotion – you know and I cry a lot and stuff – or I just dissociate from what I feel. So I find it very difficult to – you know – kind of feel emotion.

Me: Can you say that more about "dissociating from emotion"? I mean... Presumably that wasn't the words you used, that you would have used then?

No! Then I would have just probably said that I don't really feel emotion that much.

Claire has one thing in common with Becky. Psychiatric services were dramatically altered for her by the late change of diagnosis from "psychotic" to "personality disordered". As soon as a new consultant diagnosed "borderline personality disorder with complex PTSD" it seems that two things were made possible. Firstly, Claire was able to imagine herself as someone with a history who could be understood and secondly, mental health services were able to recommend a range of psychotherapeutic processes to reach that understanding and Claire undertook over four years of private therapy. However, to say that this means Claire welcomes the diagnosis is wrong. The following transcript seemed to reveal something especially interesting about Claire's relationship to different diagnoses:

...You know – the voices that I hear... link to traumatic things that have happened to me. Now they might sound like people that I might have met at one point or something, but I don't make that association really now, because the voices are the voices that I create, and they come from my inner world, and a link to things which I have not been able to cope with - it's a kind of... What it really is... is a psychic kind of conflict - you know a psychic split issues that I can't – you know – have not been able to process. And sometimes I've medicated it, when it's been particularly bad, I've medicated it – but medication has never had any impact on my voices. And my psychiatrist, former psychiatrist, said that with borderline personality disorder and complex PTSD often medication isn't that affective, unfortunately. And... I used to think I had schizophrenia and kind of schizoaffective disorder and to people who I know less well... I would just say, "oh its schizoaffective disorder", because I don't want to go into the fact that I've had trauma. But actually... in [place name] that diagnosis was originally made, because I turned up in a very very disorientated upset state, and the psychiatrist had not read my medical notes going back many years earlier and when I moved to [place name] my psychiatrist went through all of my medical records, which are very extensive, very carefully and she said that she had made the link between me hearing voices and trauma. And she was sure that it was borderline personality disorder, which was more complex, and she thought that complex PTSD was a diagnosis which should be considered. But, from my own understanding of it, and from the process of psychotherapy, I do not think diagnoses have been very helpful, because I've had so many over the years. You know, I had bipolar at one point, I had schizoaffective disorder, I've had complex PTSD, borderline personality disorder – made when I was a child and again when I was an adult, you know - they're just words, you know? And I'm actually a person, and I have to process my own emotional experience and I don't think that labelling people as a particularly helpful approach. And... I also think that learning to navigate one's way through one's emotional experiences, even if those are emotions which appear on a kind of spectrum where it's overreaction or an under reaction, it is still helpful to actually understand how those emotions are processed, and how they are expressed, because that - you know because gaining self-understanding you can start to be able to function better. I think. That's how I see it. Hmm...

I do not believe that I have ever had a conversation with someone in my role as a nurse quite like this. Yet as a researcher, it seemed that Claire could tell me that she uses the different diagnoses she has been given to different effect, to manage different responses. This, to me, is an example of a person being a conscious narrator and I think it also reveals once again what the stories of different diagnoses do for those caught up in them. In here is Karl Jaspers' *ununderstandability of psychosis* and the "aetiological closure" of "schizophrenia", because once a psychiatrist began to postulate a link between trauma and experience, available stories would no longer allow for them to be "psychosis"<sup>16</sup>. However candid people have been with me in my role as a nurse, I doubt they would admit to this kind of use of diagnoses, perhaps because they saw me as someone for whom they should treat diagnoses as facts only and not as stories.

Several years of psychotherapy and CBT took Claire out of the day centre and into a life with friends, work, and new self-understanding. What she has learned through psychotherapy were the things an outsider might find to be very reasonable but that she did not know: that her extreme emotions reflected the extreme circumstances of her upbringing. One can also see that Claire has learned a narrative explanation for voice-hearing. She heard a voice upon discharge from an eating disorder clinic, at 14. It was the doctor's voice. She heard a voice aged 20 when her grandfather, a man she loved, died after a series of distressingly debilitating strokes. Leaving a boyfriend to live alone at university led to a period of voice-hearing. A period of work with teenagers which she enjoyed was relatively voice-free. The decision to write a novel exploring her anorexia led to a period of hearing two male voices, and then a period working as an au pair in a family with a very critical woman intensified them. Reduced mobility and role after a spine operation was difficult with voices, too. Claire began to use alcohol to try to "blot them out" and to avoid emotions. Claire was able to tell these narratives of voice-hearing linked to stress because of her

<sup>&</sup>lt;sup>16</sup> see Understanding / Explanation, p89, for further discussion

psychotherapy. She still hears voices at times, and especially mentioned that she did once again after meeting her father and her grandmother's death recently. She described this latter instance as being a prime example of the voice replacing a "squashed down" emotion; she visited her grandmother and knew she would die very soon, she wanted to cry about it but could not. The next day, she heard a voice telling her that her grandmother was going to die.

I used to think there was something wrong with me, but now I have just realised that this [voice-hearing] is like a learned behaviour over my whole lifetime, this is how I learned. This is how I coped....I created creative ways to cope – because that's what I had. That is what was available. And I've always done it so... It might seem strange to somebody else but for me that's normal.

By describing voice-hearing as learned behaviour Claire places it with three immensely difficult parts of her life: her teenage anorexia, serious self-harm through cutting and her adult troubles with alcohol addiction. The term "dissociation", used above, is a very important one for other participants too. It is a word she has learned (through psychotherapy) which provides a way to think about her experiences that she previously "had no words for". It became clear in our conversations that Claire views anorexia, self-harm and alcohol as *means to increase dissociation*, they have aided her in processes of "not feeling", "burying emotions" or "being numb" *from which voice-hearing is the result*. Playing musical instruments as a child and teenager was part of this, although it now (after a gap of many years) forms part of the opposite, which itself is a remarkable illustration of the power of stories, and of music too.

Claire feels she has been helped by Cognitive Behavioural Therapy, especially looking at finding new ways to cope with difficult emotions and her voices and, above all, to challenge the negative patterns of coping and the negative things that the voices say to her. She has learned to think of the voices as "internal saboteurs". She has never had a positive experiences of voices, they come on most strongly when she is feeling anxious and she has to find ways to fight to avoid their influence and to prove to herself that they are wrong.

Claire and I did two things together which exposed these stories of psychotherapy and CBT to the stories of the HVM. Firstly, we both attended the annual Intervoice Congress in 2014. Secondly, we both attended some training in HVM approaches, six days spread over three months. Claire was attending the training too. The HVM was not entirely new to Claire. She told me in her first interview that she had been really helped by reading about (and in some cases, meeting) voice-hearers who had found recovery in the HVM. For her, they were proof that the "battle" could be won. However we both experienced the HVM to a new level through these experiences, even though I have some experience in this regard (see *Ten Weeks*). In our second interview, Claire was able to speak candidly about these experiences of the HVM. Given that Claire has come to view her voice-hearing experiences as being a means of coping, linked to life events and emotions and secondary to them, dissociative not psychotic, what exactly was the "dialogue"? What points of difference came into focus?

The group that was doing the training witnessed a member exploring his voices for the first time. Previously his most usual response to them was "F-off!", and it was said that in the HVM it had been found that this was unlikely to be successful and that an accepting approach was better. This is certainly found throughout their publications and, strikingly, voices are often formally welcomed to their meetings. Knowing that Claire had also described saying "F-off!" to her voices, that in some way a lot of her life-choices seemed to be a "F-off!" to her voices, I wondered what she was thinking. The following section is presented at length because it is an example of the way in which I tried to make my Dialogical Narrative Analysis a joint project between myself and my participants. Here, Claire is considering the difference between her own understandings and those of the HVM.

Claire: I found the [HVM] a bit problematic, if I'm honest, because...you know, when we did that training together for six days in [place]? That voice-hearer had constructed her voices as having different personalities, different ages, etc, etc. Personally, that approach would

not work for me.... Because I just see it as like dissociative crap. And sometimes it has some kind of meaning to me, because obviously that voice was coming from me..... I actually think the approach where you see it as being linked to a person could be potentially very disabling.

Me: I felt... a tension in the room. I'm not saying it was a bad thing, but there was this noticeable thing in that one of the voice hearers... said that he had learned over the years to tell his voices to "F-off". And that's what worked. And very quickly there was this counternarrative that opening up to the voices, asking them why they're there, kind of knowing them as people, or as a social network in some way and understanding them and, and not having this... battling relationship with them was the way forward. So we heard one man say, yeah, I'm doing really well at the moment because I've really learned how to tell them how to "F-off".

Claire: I'm aware of people who do use that approach and it's worked for them. But I think if the voice is linked to the persona of someone who has actually very seriously abused you, then to start giving it a personality and an age it seems to me like really weird actually. Really, you know, because if... something's deeply traumatic why would you start giving a voice that sounded like someone who's abused you a character and an age? I think that is, to me, bizarre.

Me: Does it feel like it gives the voice more power somehow?

Claire: Yeah....I think it will give it more kind of, kind of authority in a sense and make it more real. And I was talking to a psychologist who's part of our hearing voices project in [place] and he agrees with me that actually if you start giving voices personalities, for some people that will make them seem more real and that is more disabling.

Me: This is the nub of the issue here, isn't it, that... kind of, what part do the voices play in the therapy? Are they included in – is that the right way I've put it?

Claire: My therapist might occasionally say, what are the voices saying? ...But the thing is that, you know, it's about deconstructing it as a dissociative experience.

Me: So tell me a bit about what that's like then, when, so you hear a voice and now you feel able to deconstruct it as a dissociative experience. What does that phrase mean?...

Claire:... I would just, you know, I'd question it. You know, like kind of, 'why do you think that?' You know. If the voice is saying I'm stupid. 'Why do you think that?'

Me:... When you talked about cognitive strategies, is this the kind of thing you mean?

Claire: Yeah, what's the evidence? Why do you think that? Or if it's being particularly nasty, well, "Fuck off!". And it's about having boundaries with it....It works. Put it this way, when I had no boundaries for the experience I was sitting in a kind of mental health centre, seven years ago, thinking I'd never work again and it didn't help that around me were lots of other very disabled people.... I'd been written off. And actually then the voices in a sense were so negative and critical I wrote myself off, you know.

Me: Is there a sense that, that this is about, like, what is me and what is not me? So like when, what may be the approach that you've been able to take is to be able to quite clearly say, that isn't me....

Claire: I'd see it... as myself, plus three voices. And I mentioned in the previous interview that I'd met my father for the first time in thirty-three years... at Christmas, and, it's emerged

since the meeting why [Claire's mother] divorced him. And, and he was abusive to me when I met him and... and I heard his voice afterwards on about two or three occasions... But it's kind of, I had to talk about it in therapy, the nature of how it felt to be neglected for thirtythree years, then to meet him, then for him to behave in an abusive fashion which is why I severed contact. And he, he'd abused my mother. When she left him he tried to rape her, and she told me that, you know. My mother completely believes what I have said because she knows what he's like. And... you know, to find out that my own father had been done by the police for fraud, you know....

Me: That was a particularly moving part of your interview.

Claire: I mention it because I then heard a voice telling me that, you know, that he did love me really. It was just manipulative, and he had tried to manipulate me when I was with him. And so it was crap. And so I was able to discuss with my therapist what the voice said, and to realise that it was absolute dissociative crap. And it's been very helpful that in a way because....

Me: ....One of the things that seemed to be said in that training was that the voices were somehow, it was possible to see them in a positive light, even the derogatory ones, even the ones with catastrophically difficult messages to hear.

Claire: I wouldn't agree with that because with me it's never ever been a positive experience. It's only ever been negative, and I wish I'd never had it.

Me: Whereas the "hearing voices" approach says that rather than saying they're nonsense, they're not right, they would encourage people to say that this is – don't shoot the messenger... bring the messenger in, let's hear it. Let's make sense of that experience. So there's quite a big difference, isn't there?

Claire: ....But I feel their model, by seeing voices as being characters and personalities... it takes it away from being a kind of internally generated phenomenon. And that is potentially disabling.....But then I have met voice-hearers like [names two prominent voice-hearers in the HVM]....who do have these relationship with voices, and they function at a very high level, so it is horses for courses, I think. People have different approaches.

Me: Do you think that... if you – it's really hard to know this, you know, the people that you've just mentioned, they... they didn't have psychotherapy as you have had... So... you know, one of the ideas of the [HVM] is that the voices are a way for people to actually access the emotions that they have been dissociated from. Do you think that you achieve that through other means?

Claire: Yeah, because... I reconnected with playing [musical instrument] after twenty years of not playing. I started playing again about seven months ago, and actually I notice, when I play a musical instrument I'm actually able to much more emotionally engage with myself, and it can actually make me quite tearful, playing [instrument] sometimes...it's been a very helpful thing. I found that by connecting with emotions, the voices, I hear them less and they're less intrusive. I think by actually connecting with my emotions I hear less voices.

Me: And do you think you've seen that in the last seven months?

Claire: Yeah. It's very clear, yeah.

Me: Has anything else helped?

Claire: ...Socialising with people. So, you know, actually seeing friends, you know, kind of engaging socially with people helps as well. And if I work really obsessively, on my own, in

the library for hours and hours on end that would bring on kind of voice-hearing experience. I do hear voices every day, but not all the time. ... but if I'm sensible about the pressure I put myself under, and I balance it by, you know, doing things I enjoy like playing the [instrument] and seeing friends... it's manageable. And I am actually a very obsessive person so it's been very difficult for me to challenge my obsessionality and to put boundaries around how much work I do because I'd quite happily do about ten hours of work a day ....you know, getting a healthier balance has actually really helped my mental health. And I'm teetotal, I don't drink alcohol. Making various kind of lifestyle choices about, you know, what I eat...not drinking, has helped. And, yeah, in the last eight years I've cleared all my debts so, you know, so as a student I have no debt now and, you know, that's helped and, you know, just doing practical things helped. And that's why I found the [HVM] where the whole focus is on this kind of relationship with voices as characters, you know, voices being messengers – it's not a very practical approach in some ways, you know. It's not very grounded in reality.

...I think that the process of psychotherapy has really enabled me to make connections and to identify emotions, because I found it so difficult to identify any of my emotions. I just went through life kind of not wanting to feel anything. But actually by feeling emotions, I actually hear less voices, or the voices are quieter, so actually I have made the link between a voice... in a sense... articulating an emotion, or a feeling, that I am not able to feel myself. So if I dissociate totally it gets externalised into the voices. If I allow myself to feel my emotions, and work through them, then I hear less voices – or the voices might stop altogether... As I said earlier, I did have an 18 month period in my 30s when I didn't hear any voices and during that time I was able to feel my emotions more. So I think emotional shutdown is linked to voice hearing actually.

Claire's Narrative	HVM Narrative
Sees the voices as being most helpfully claimed as internally generated.	Arguably a little ambivalent about this. A main approach of the HVM externalises voices - as a "social network", even if they may also describe a mechanism of (internal) dissociation.
Views them as "internal saboteurs".	Tries to accept voices and finds explanations which show them to be ultimately helpful, even if they appear to be highly abusive.
Content is likely to be misguided, misleading and might be best dismissed. This can be done by CBT style techniques, such as challenging the accuracy or validity of the voices. Failing this, telling them to "fuck off" can be effective.	The content becomes a guide to new understanding, especially about emotions. Challenging the content is done, but care may be taken to avoid the kind of oppositional relationship that Claire describes.
Voices part of a habit of coping with emotions which Claire describes as "dissociating".	Voices may be linked to emotions through a process of dissociation. This was certainly accepted by the training we attended, although the HVM also contains members who do not find this the most helpful way of thinking.
Voices strongly and directly linked to being stressed and overwhelmed, and the content of the voices tend to relate to the causes of the stress and relationships.	Very similar.

Claire's Narrative	HVM Narrative
Forward direction has been found by exploring and expressing emotions. This has led to a reduction in the frequency and intensity of the voices. The result is a life in which experience, emotions and voices are bound up together.	Forward direction may be by exploring and expressing the voices. This might to a reduction in overwhelming emotions and greater understanding of them. The result is a life in which experience, emotions and voices are bound up together.
Feels that the HVM approach is not really for her, although accepts that others have been able to "function highly" through it.	There is a sense that, because of her continued non-acceptance of voices, the HVM may view Claire as only partially understanding all that she needs to to recover. Her progress partly represents a more successful suppression of her voices.
Does not wish to see herself as a "voice-hearer" in the way that the HVM do, despite acknowledging that it is good to be with people for whom voices are not stigmatised. Claire plans to continue her (peripheral) involvement with the HVM. However, Claire does not especially find the "civil rights" aspect of the HVM to be useful or attractive, and feels that it will continue to mark people as different and therefore stigmatised: " <i>another label</i> ".	Likely views Claire as continuing to pathologise voices. HVM strongly endorses a more positive view of voices and sees the identity of "voice-hearer" as being a means to challenge the stigma and validity of illness models and abnormal psychology.
Claire's dominant narrative about her voices seems to operate from the part of my map of experience which is just to the left of centre; personal psychological account which views biology as reductionist, but views accounts like the HVM as being too systemic and politicised. Perhaps voice- hearers are oppressed but they are best helped through a process of self-learning and personal responsibility.	Perhaps the HVM operates from a position on my map of experience which is just to the right of the centre (although other positions are also present too). It contains a psychology which seeks to show the impact of trauma, abuse and stigmatisation on the voice-hearer. It generally sees psychiatry as a societal tool for the oppression of voice-hearers.

Arguably, there are three key differences in the above table from which the others follow:

#### First key difference

Firstly, in psychiatry voice-hearers may be divided into the categories of "having insight" or "being insightless". For psychiatrists, this describes whether the person knows that the voice is a hallucination, and not real. This carries with it a number of complex connotations, because the word "real" is being used in a way which can be said to hide a lot of other ideas about nature, the self, and meaning (a strong theme of Ian Hacking's work, e.g. 2013). Such insight is a highly contested concept and unsurprisingly it is felt by some to be a deliberate marginalisation and impoverishment of the experience of the diagnosed (Geekie in Read et al., 2004, p149). Claire reported good relationships with mental health professionals, but certainly found biopsychiatry limited. She said that despite taking several kinds of medication, none of them had any effect on her experience of hearing voices. Also, she cited research which suggested that psychosocial approaches to psychosis lead to more people returning to work (referring to Open Dialogue (Seikkula et al., 2011), a model of mental health service provision from Finland which encourages a more systemic and less individually pathologising approach to distress). Nevertheless, Claire seems to share a common view within biopsychiatry that exploring the voices carries the risk that they will become too powerful and that the knowledge of them as an "internally generated phenomenon" would be under threat. This knowledge seems to be a key part of the power that Claire has gained over her voices and is a view that may do some of the same work as "insight". The insight of "not real" in psychiatry activates the illness story, and forms the characters of doctor and patient and all of their attendant powers and moral goods. It also contains an element of belief that the "illness" may return regardless of current health (Blackman, 2015, p26). Claire's "internally generated" does not activate an illness model, but instead defines the sphere in which she must look to gain knowledge, power and skill as being personal, activating stories of self-management and responsibility and overcoming. She sees linking voices and life events as the key to progress in her life, and said so explicitly. Both deliberately locate the voice within the person, both share the same sense that to externalise voices is somehow risky and unhealthy, but the possibilities for action under each is very different. The HVM is perhaps ambivalent about whether voices are best seen as internal or not, focussing simply on the relationship one has with the voices which is to be altered by understanding their context and meaning and through re-negotiating the balance of power (Romme et al., 2009, p26). In my opinion, this makes HVM closer to Michael White and narratology, where Claire is closer to the "true self" of the psyche (if the HVM can be said to have a united position, about which there will be more later).

Claire: ...In the [name of peer support group]... we had a voice hearer... He said that he'd gone up a multi-storey car park and the voices were telling him, you know, it was kind of suicidal. ....I'd be very concerned in that group promoting voices as being messengers.

This does seem to highlight the importance of a particular emplotment within the HVM. They say, "don't shoot the messenger", but does the "message" need to be understood through the right kind of interpretative framework?

Claire: And I think the other difficulty I have with [the HVM] is often voices are inaccurate. So if people are seeing them as messengers of the past, what is the message they're listening to?

#### Second key difference

It does seem that Claire's use of psychotherapy and CBT has encouraged her to see voices as something of a side-effect of her experience of emotion, and that emotions have been the primary focus of therapeutic work. Tackle the emotions, and the voices will be positively influenced:

But you can engage with emotion in a way where you're not necessarily engaging with a voice itself, you know. I've engaged with my emotion through doing practical things like playing [instrument] or just talking about how I feel.... talking about my life. Changing my life. My life is very full now. I've quite a lot of friends, you know... And I don't see myself as being trapped in the trauma of my past because I've talked about it and worked through it and moved on.

Within the framework of the HVM, one starts with the voices, and the emotions which go with them can then be made visible and explored. Claire said that she has had to learn that she is angry and that not being angry (that is, not allowing herself to be) is a driver of her voices. The HVM often engages with a person's angry voice(s) which at first seem to have emotions all of their own, and then, in the process, the person may find they have a right to that anger themselves. The interesting question is whether this is simply a case of "meeting in the middle" or whether the two narratives have important differences. It is probably also important to consider whether a person might experience voices which are so intrusive and intense that they are the only possible starting point.

#### Third key difference

This leads to the third aspect: the valuing of the voices. Claire was repeatedly welcomed at the HVM training, and it was also said a number of times that it was important to uphold voice hearers efforts to live with their voices as "good enough" and as resourceful ways of coping. But had Claire only gone part of the way on her journey, missing a breakthrough, perhaps storing up future problems? I had a chance to talk with the trainers at a later stage to ask about this. They were very concerned to ensure that this was not what they wanted to communicate, and that voice-hearers own sense-making was not compared to an approved model but held up as valid. They insisted that there did not need to be one view only. I felt they were very genuine in this desire and that the more hidden message that Claire (and I) perceived at the training (about whether her engagement

with voices was incomplete or failing to accept them) was therefore a good indication of the dialogue between stories rather than a set approach; an unintended consequence or even unavoidable part of stories in dialogue.

To what extent is it a necessary interpretation to view voices, even the negative ones, as ultimately being positive? For Claire it seemed a little over-stretched (and it did at least initially for the psychologists on the training too). An example that was given was moving from the terror of a voice shouting "kill yourself" to asking, "what would be better if I was dead?" and then on to view the voice as a helpful part of understanding the untenable nature of an existing life that the voicehearer needs to address in order to be happy, thus re-framing this negative voice into a selfprotecting and helpful one. In this kind of process voice-hearers report a kind of liberation and changed relationship that they may not find elsewhere, and Becky reported something similar. So, as above, there is a question about whether the "messenger" requires a skilled translator, a careful emplotment. Claire prefers to see voices as misleading and untrustworthy and something to be overcome. Their existence may tell her something about her emotions which needs to be addressed, but the actual content of the voices is to be rebutted, something to shut down through projects which prove them to be wrong. In this sense, her voices are as unacceptable as ever before, and within the HVM there is a belief that this may itself make the experience of them more intense. Under a model of dissociation, this makes a certain sense: if voices are part of the way that a person experiences emotions they cannot tolerate, then being intolerant could feed into a cycle.

However, Claire pointed out that accepting the voices as a messenger does have other complications, too.

# ...actually, if you were to kind of give that credence, and actually see it as being a messenger, it would be a very self-destructive relationship you would have with yourself.

What Claire is alluding to here is something which is also discussed within the HVM, although I am not sure if Claire has heard it there. A leader within the HVM in the UK and beyond is Rachel Waddingham. She has struck a chord with voice-hearers with training on this subject, which she describes under the title of "taboo and violent voices" (Waddingham, 2016). She suggests that the problem with viewing all voices as dissociated parts of the self is that when they say appalling things it seems that the person needs to accept that they, somewhere, think or desire those things. That may seem impossible to accept and unhelpful. Perhaps it would even be oppressive to suggest that voices must originate from one's own emotions in this context. Rachel has voices which she thinks of as dissociative parts of herself to accept and learn from, and voices, "not yets", she does not engage with in the same manner. Rachel is not one of my participants and I can only speculate about this based on the times I have spent with her and a conference presentation she gave in 2014, but I wonder if this division allows her to value voices in general but continue to value herself too by leaving the most difficult voices unstoried.

Part of the concept of a narrative self is that we are bound up in a system of stories by which we can say that something is "me" or "not me". Anyone can have a sudden thought where they imagine pushing their friend from a cliff without needing to worry that deep down they must be a murderer - they would simply view it as an uncharacteristic "not me" thought, unstoried, remaining outside of plot (this kind of scenario is so beloved of philosophers I have no idea where I first read it, but very similar terms, that of deciding if thoughts are internal or external based on preference, are discussed in Stephens & Graham, 2000, loc 1543-59). Should a voice-hearer be denied this possibility about their voices? Claire seems to make a difference between *message* and *messenger* with her understanding; the voice is more of a "something" than a "someone", as accepting it as a "someone" could increase anxiety and negative self-image when that someone is part of herself.

So if they'd been taught more a model where it's dissociative crap and not just to pay any, you know, much attention and just, you know, just see it as kind of crap that might be a more helpful approach.

There are a number of ways in which this idea of *internal or external* to the self has been approached so far. The first is to do with "hallucinations" vs "pseudo" voices, opened with Becky (and deferred until after Lisa). That theme touches upon Claire's narrative and now in this comparison of Claire stories and the stories of the training we attended; a question is raised about whether there is something about Waddingham's "taboo voices" story which does the same narrative work, albeit described in very different terms with different valuing. Becky used the word "we", Angela will introduce us to other ways in which internal vs external may appear, including "parts" and "alters". I somehow think that this "in or out of the self" concern is found on McCandless' chart (p26). There is something Left-leaning about the voices-as-social-network idea, and something Right-leaning about voices as "internal saboteurs"; my map also forms the same binary. In the former one could renegotiate dynamics of power to gain a fulfilling role, in the latter one overcomes impediment to achieve independence.

One of the effects of a narrative of positive valuing is that people who are part of the HVM can have an experience of belonging which Claire, by her own admission, cannot share. At the HVM annual Congress there is frequent talk of people finally being with others with whom they can belong; "my tribe", as one speaker said. This is in some way the defining achievement of the HVM, as noted by Woods (2013). Claire does not say, "I am a voice-hearer", feeling good about it. It seems to me that this is a result of the ways in which the narratives oppositely value the voices. Perhaps at best Claire could experience the HVM as something like Alcoholics Anonymous - there is a sense of shared experience, perhaps, even a feeling of the same affliction, but not "my tribe"? Claire said it quite clearly: *I don't see it as something that I want or as positive.* Being with other people who hear voices probably also makes the day centre feel uncomfortably close for Claire.

In conclusion I offer one of the final effects of this difference in narrative. While the HVM might express reservations about the progress Claire has made, Claire was highly skeptical about the progress made by the voice-hearer who was one of the trainers. In fact, she doubted that such an immersive relationship with over 10 voices could be helpful, and expressed doubts about the trainer's account. Could the events and memories revealed by voices be reliably said to have taken place? Yet the trainer told me afterwards that she found Claire's emphasis on "high functioning" judgemental. Claire traced her emphasis on functioning to her psychotherapist's origins as an Occupational Therapist, although it probably would not be too speculative to suggest that a childhood in which achievement was the only acceptable part of her may also be significant. Both women seemed to feel liberated by that which the other felt was skewed, incomplete, unwise. I find it difficult to write about this without seeming to somehow betray each of them slightly, who have overcome so much and been generous to me. I see this as being related to an attempt to be an insider to both narratives. To me, this is part of the personal risk of DNA: I may be seen as duplicitous. There is something in this which speaks to the ways that stories help people to "hold their own", and about being caught between.

# Ten Weeks

Joachim said I had to try *working with voices* (Romme et al., 2000; Corstens et al., 2008; Sapey and Bullimore, 2013). In 2005, I did. My team were mostly supportive, actually. Well, everything else had been tried. The man was in his early 40s and he had been detained in hospital over 20 times over more than 20 years. I carried on giving him his injections throughout the work. He'd been on everything, every combination, every dose. I kept all my injection paraphernalia in a small plastic lunchbox, and used to draw up the thick oil from glass ampules, the up-turned sterilised lid on my knees. By this time the whole procedure was as natural to me as rolling a cigarette was for some of those who received it, for the post-injection fag.

Eight years before this I had been a student nurse on a ward at a time when he was admitted. After a restraint incident in which he had lain there on his bed, trousers around his ankles while being injected, he had turned his head and whispered to me that he would like to fuck me up the ass until it bled. I hoped he had forgotten that.

I got out the Maastricht Interview (Escher et al., 2012) and, nervously, we started.

I worried that he was waiting for something clever. The questions were, well, pretty basic. What voices? How many? What did they say? How did they say it? When did they say it, and how often? Did they sound like anyone he knew? What was the tone of the voices? When did they start? What was going on at the time?

We discovered that he heard eight different voices. I sat on his sofa, writing all over the interview sheet in blue biro. I say, "we discovered" because he didn't really seem to know, exactly. And over the next two or three weeks he contradicted himself about some of them, which at first made me think I must have written it down wrong. He was excited, leaning forward in his chair. I was excited too. There was no clever bit. Finishing the questions and going back through them took weeks, because we kept talking about his experiences in hospital, what different consultants had told him, about religion, about his parents, about being gay. He felt sure there was a God but felt scared to tell me. But now we were working together. Did I think that being gay was wrong? Sinful? I felt we were moving in the same direction for the first time. I felt like the nurse I wanted to be, instead of the one I so often had been. I was working very hard, listening, reflecting, writing - but in another sense, it was all so easy. He said he had always wanted to talk about it all. Did I know the consultant who once had whispered to him in a hospital corridor that Jesus loved him?

The team joked about us walking off into the sunset together.

Then there was a significant realisation. The first voice never told him to push the woman, back in his early twenties, on the train platform. It didn't say that at all. It said, "thou shalt not kill". It was an angel.

And he decided that three of the voices somehow weren't voices: they were just the kinds of things those people would say, anyway. Somewhere in all of those ward-rounds of repeated questions he felt they had become "voices", but they had never felt the same, really.

Ten weeks later, he had a two-week period of silence. It was the first time he had experienced such a silence since he was a young man. I thought we were going to have a party or something. But he wanted to tell me more about the loss in his life. I was left with an odd feeling that as it turned out, it wasn't really all about the voices at all.

That was when I knew it. Of course, I have read all kinds of things since: no one needs to tell me now that "schizophrenia" is a contested category. But that was when I knew it for myself. *If the primary symptom of this "degenerative genetic disorder" can disappear after ten weeks of talking, not even very clever talking, then schizophrenia cannot be the illness it is made out to be.* Other people will say these recovered voice-hearers can't have been properly ill. I've heard it all and I can't even be bothered to be respectful anymore. First you say they weren't ill and next you tell me they aren't recovered. But this man had been detained under the Mental Health Act *twenty times*. If he wasn't "properly ill", no one is. No one.

After that, I left the team. Someone had threatened me with a knife. Apoplectic, he held it towards my face in a B&B with no lightbulbs on the stairs. The police said we should have contacted them much sooner. I found I couldn't go past that house easily, after that. So I swapped to another team in a different part of the city and I never found out how this story continued. I think about him, this first one, a lot.

# Angela

Angela: ... For me, personally... voices I hear are very much interwoven with past experiences, emotions that I'm feeling, they reflect the ways in which I relate to other people... And over time the way that I have related to other people has changed, as I've matured I suppose. You know – a lot happens between 19 and 28. And so... So the way I relate to my voices has also very much changed. It would be impossible - I cannot - to separate out any aspect, really. Yeah... Any experience I have, even when it gets really overwhelming, which does sometimes happen... I do know... this is happening in my life, that is happening in my life, I'm feeling this, I'm feeling that, and this is what is going on in my head, and the voices are reflecting that. But now, it sort of feels like it's gone back to more to how it was in the first place which was the voices really aren't the issue at all, not even slightly, even when they are really angry and shouting horrible things at me, they are never really the issue... The issue is how I feel about what they are saying, and what they are shouting. And that's almost a... a side-effect of what's going on, you know. It was... the mental health system that singled out the voice-hearing experience, and talked about it in a way that made it very very very separate, and very very very significant – and the reality was it was never really significant. Voice hearing is just an experience, it is just the way I experience myself, and the world around me – it has always been like that – I cannot remember a time when I didn't hear voices, didn't see things, didn't feel things – there has never been a time when that has not been the case. You know it's kind of like - I don't know, I'm trying to think of another experience – I don't know... For example if you had a really tense neck because you really stressed and your neck really hurts, it's not the tense neck that is the issue – it's the stress.

It is the same sort of thing really. And the way it was talked about, the language that was used, really profoundly affected the way I experienced that voice-hearing. And I feel like it has gone... I wouldn't... For a while, there was a period when I sort of extricated myself from the mental health system, I came off the drugs, and I would identify – you know – as someone who hears voices. I wouldn't identify as someone who hears voices any more, not because I don't hear voices, but because it is not significant enough [laughs]. Do you know what I mean?

Me: So there's a kind of irony here. You agreed to participate, and I have invited you to do so because of this idea that you are "a voice-hearer". But from what you are saying... and I liked the way that you described the way that the emphasis that mental health services placed on it changed it... It raised it to a different significance –

#### Angela: Completely.

There were several times when speaking with Angela when I felt she was more qualified to write this than I. As with all the participants, her presence is a gift. Angela has explored her inner world and the world outside with as much rigour as any DNA could bring to it, she is very well-read and strikingly clever. She is cynical about research, about nurses and about PhD's and I was certainly intimidated. She was also generous, warm, talented and funny and I came to admire her very much.

There is no doubt that Angela had been a "serious case" in the terms of the mental health system. She explained that she had spent five years in and out of acute wards, had an eating disorder, compulsive rituals, self-harm and Class A drug addiction, been diagnosed with depression, then borderline personality disorder, schizo-affective disorder and then schizophrenia. She was prescribed clozapine, licensed for "treatment-resistant schizophrenia" (BNF, 2016). She never managed to fully shake the personality disorder diagnosis, however. She ended up with a higher

than average dose and had severe side-effects. In fact she ended up on six medications simultaneously. It was amazing to hear her describe it all in the past tense.

...I was always saying when my medication was changed I was saying, "what is this this medication doing, in my brain? What is going on?" ...they used to say things – gloss over the fact that they didn't really know what was happening and try to blind me as if to say, "you wouldn't understand". But really they didn't know. But I wanted to know. And by the time I got clozapine, I'd tried so many that – that I was really pushing – you know... I remember sitting down in front of my psychiatrist and saying, you know, because he called it the "gold standard". I remember saying, "what does this drug do that is different to all the others? Why does it work so much better?" And he couldn't give me an answer. I started getting really very annoyed and angry because I felt like everyone was just fumbling around and it was all... it was horrible. Really horrible. Very dark. ...You know, clozapine comes with a lot of baggage... be a schizophrenic on clozapine... there is a certain way you are seen by everyone, by mental health staff around you. You are at the end of the line. You are buggered.

...[A]II expectations of having any kind of quality of life sort of go out the window, and no one seemed to care whether clozapine made me incontinent, gave me heart palpitations and things like that..... and it completely stripped me of my dignity. I would wet myself out in public.... I was a size 22. And I was supposed to be okay with this.

We sat in cafes at first, and conversation was theoretical and tentative. Then we booked a sideroom in a town hall and talked. There were occasions when I felt I wanted to pace up and down. Over different conversations over about 10 months, two of which we recorded<sup>17</sup>, Angela revealed mental health services mostly as an astonishing and traumatic waste of time in her life. She first approached a doctor at the end of her teens feeling clear what she needed, which was to talk with someone about her difficult emotions connected to past trauma. Years later she left mental health services still searching for that help. In between, she said, mental health services had *raped her brain*.

It was almost like where I started again, where I should've started at 19. I was sort of doing it again at 24. This time I didn't use services.

I wish I could simply present all of Angela's transcripts verbatim but it would be over a quarter of this thesis. The following sections cover the major themes, and often the analysis is Angela's own. Several themes have already come to light in the previous interviews and I will focus in particular on three new themes; others I leave out. The first is an opportunity to view the mental health system through Angela's stories, which, above all, brings out themes of *pervasive violence* in several forms, and violence will be the lens through which much of Angela's story will be discussed. Becky and Claire have already introduced us to the HVM. However, in a final section, Angela takes us much further into thinking about what the HVM is and indeed, more than any other person she challenged my own relationship with the HVM in ways which helped me to articulate some uncomfortable ideas about stories in general, and my story in particular.

<sup>&</sup>lt;sup>17</sup> A number of times I noticed the difference that having a recording device made. I also wondered if the thought, "now we are doing the interview" was emplotting too. With some participants I had separate conversations which I then referred to in order to bring those issues into the recorded interview. On one occasion, with Lisa, we had an interview in which we seemed to finish several times, only to restart each time after a few minutes: as the recording device was switched off, much more free conversation began. I was delighted that Dialogical Narrative Analysis allowed me this degree of flexibility.

# A timeline

Of all of the interviewees, Angela had the strongest sense of past, present and future. At one stage I wrote a timeline based on her interviews, something that would have been impossible for most other participants. I do not for a moment forget that all of this information was provided by Angela; it is a story told for a purpose. However, it is an implication of Frank's position that there are no stories about the mental health system which are not told for a purpose, *perhaps none more so than the ones found in the official notes*. Angela never disclosed to me anything about the trauma that she had alluded to in her childhood and early teenage years and I never felt I should ask. I chose not to present the timeline because of a sense that it may be seen as a finalised or authoritative account.

# Violence

Angela's stories introduce themes of violence. There seem to be three aspects to this.

- 1. The term "schizophrenic" is bound up with physical violence, and this was a driver of fear and had consequences for the way that Angela related to her own experiences, her future, and a choice to conceal her voice-hearing from psychiatry for a long time. This physical violence is seen to be a part of the stories surrounding "schizophrenia", which leads to:
- 2. Further kinds of *narrative violence*. It becomes clear from Angela's account that this violence is found in the way that stories are used and what those stories do, especially as they come into conflict with each other. Angela hints at the the idea that the winners of this conflict are often the ones who can call upon the most numbers. This violence is not less potent than the first and the imagery that she uses about them could not be more violent: rape, for example.
- 3. Treatments given by psychiatry were violent too directing and altering Angela's body in ways which were highly undesirable to her, invalidating and frightening. This will open a theme which will be continued by Lisa and must be treated with care. It is not for this work to assess the validity or efficacy of such "treatments", but I will include a section which details some of the stories which surround them in 2016. However, it is very much part of this project to view "medications" as *storied*, and as such, subject to new forms of assessment. This will be discussed further.

# First violent story

Angela says she has always heard voices. However, from reading about "schizophrenia" in a psychology textbook at aged 17 and feeling that it described her, Angela felt a previously unknown terror that she would, within a few years, have become a risk to others' lives.

And then I started getting really frightened because I thought, "God! What if I start killing people?"

This is clear emplotment, and it is interesting that for Angela "the media", the most common target of criticism about the proliferation of conflations of "mental illness" and violence, was not directly involved. In fact, it was a psychology textbook, a teacher and a class video that reinforced the view. The textbook described "schizophrenia" as something which lay totally outside of the the realm of psychological explanation, in effect disqualified from the chapter. To hear Angela describe going to the school library at age 17 to try to discover if her voice-hearing really did mean that she had just a few short years left as a safe person was extremely moving. Her account raises questions about the authoritative emplotment of textbooks.

I was this ticking timebomb and I was very frightened which is why I ended up going into the library and trying to find something that could make me feel better about the situation that I was in.

It was really terrifying. I think – I think – I had this kind of seed planted... It almost set me up to know that when I did go and see the psychiatrist... I had that in the back of my mind. You

know it was almost reawakened, you know this idea that maybe the book at school was right.... And I'm now 19 and I'm having a breakdown. So I was almost... "primed" is probably the wrong word... But to take on board this idea that – you know – I'm mentally ill, my brain is going wrong... Even though I was very defiant about for quite a while... I was so outnumbered, that I began believing it.

The textbook accused Angela of being someone who was pre-determined to be violent in the future. Panic and a determination to hide her experiences followed. Angela's retelling of the story about her psychology textbook reminds me of Philip K. Dick's "pre-crime" unit in *Minority Report* (1956). It raises the idea that what is at stake is an issue which relates to "freedom of the will", which is not to say that this thesis considers that freedom/determinism is a valid binary, but that the stories here evoke it.

...There was a symptom list, and I remember in this symptom list – I was about 17, 16 or 17 – and thinking, "Jesus! Shit!" You know that's – I have a lot of those – and that was the first moment that I thought I could be mad.

Following the pattern I have already established, I will not discuss here whether it is correct that "schizophrenics" are violent, apart from to note that (a) again, we cannot have confidence in the category "schizophrenic", and (b) Angela's account and others like it suggest an emplotment, invalidation, a social alienation, institutionalisation, the use of compulsion, the law and treatments under which violence seems positively encouraged, *regardless of whether a disease with an increased risk of violence is in process.* Angela said that because she found the mental health system to be farcical, she could not respect its rules, and treated efforts to help her with contempt. She felt clear at the time (and clearer now) that she would not have received the diagnosis of borderline personality disorder if she had been a man, although she acknowledges that her angry behaviour (which included throwing chairs) was problematic. It is therefore simply impossible to know what violence could have been inherent to Angela or inherent to the "natural course" of an illness called "schizophrenia". Even from this early stage it seems to me that this DNA suggests that statistics surrounding "schizophrenics" and violence are worthless.

### Second violent story

It follows that Angela's second set of stories concerning violence are not confined to stories *about* violence, but are stories which for Angela *are* violent. With this Angela moves us straight into the very essence of Frank's ideas of stories "holding their own". Angela is aware of this kind of philosophy, and understanding it is undoubtedly one way in which she has survived (which is not to imply that she is "merely" surviving). For Angela, much of this story of violence is the story of mental illness in general:

*Me: I've asked you to pick three cards… Have you decided which one you're going to start with?* 

Angela: I'll start with this because it's the most obvious to me really.

Me: So why have you picked that card?

Angela: Oh, well I thought it was quite appropriate... Considering [laughs] what we're doing today, really. And sort of the mindset I'm in – a picture of a brain just reminds me of the whole medical model thing. Yeah. The whole five years I had.... I just thought... You know it's very weird... When I was younger I loved science. I – you know – loved the anatomy... of anything really. The brain, I liked the straightforwardness of it all and... it was quite a contrast when that was almost used... to harm me. So yeah – I'm not a big fan of pictures of brains any more [laughs]. So I think that's probably why I chose that. Very obvious.

Me: ... The picture represents something being used to harm you?

Angela: Yeah. Reducing me to that [points at card]. Just that... which is, quite violent. Yeah – it feels quite violent. Like I'm just walking brain...

Me: So – hang on a minute – you said that you felt you were "reduced to" a brain?

Angela: Yes.

Me: When did that first happen? And did you know at the time that it was happening?

Angela: It pretty much happened immediately when I went to see a doctor.

Angela explained the effect of this violence:

When I first got completely overwhelmed and... I needed some help... And I had this very wrong idea of what kind of help I was going to get. And I didn't think I was this sort of walking brain. I knew that all my experiences were meaningful and I needed to talk about it - but I was immediately reduced to a chemical imbalance. And medication was thrown at me and I was – I did – I did notice at the time – and in a sense that was quite comforting. because I kind of thought – oh well I thought that there was this really complicated problem and that I would have to have years of therapy for it, and but actually [affects bright happy voice] it looks like it's all going to be sorted within a few months. [Normal voice] so at first it was quite reassuring. As time went on when they couldn't sort of fix me... I got more and more reduced to a brain – you know – in the beginning it seemed that... I had depression, and borderline personality disorder, and eating disorder and all of that kind of thing... it kind of seemed to go more and more and more towards the medical as I was becoming more and more hopeless I suppose and entrenched in this madness I was going through. And eventually it was just ended at schizophrenia – you know and it really was just your brain. And that was it... and there wasn't any therapy or anything like that. There was no consideration of me as a person it was just... What is going on in your brain. And what pills can we give...

In Angela's account is the *application of a story* by others from whom she was seeking help. This story contained elements which she feels removed the meaning of experiences, the requirement to talk, contained a false promise of a quick and comfortable resolution, and that the less it seemed to be a helpful story the more it seemed to reinforce itself. This reinforcement was partly in that it was, as Angela said, a story about degeneration, which meant that somehow it contained both *stories of treatment and a return to health* and simultaneously stories of *expected deterioration*. For those caught up in this story, it produced (from Angela's perspective) "no consideration" to Angela "as a person". Angela felt that the narratives carried extra weight because she was "alone and outnumbered"; distressed, removed to hospital and surrounded by many people all recruited into similar stories, it became very difficult to resist. She ironically remarked that her mother had bought a book about how to understand someone with "personality disorder", but that no such book had been bought when she was rediagnosed with "schizophrenia".

From the statement above, and from other things Angela said, she felt "tricked" by psychiatry. Firstly, quite simply, she was told that she would be admitted first for a couple of weeks, but it turned out to be four months (and many subsequent admissions and the use of the Mental Health Act in the community too). Secondly, the promise that she had a fixable problem simply was not borne out.

Whatever the merits of the diagnoses given at the time, not only did they fail to help Angela understand herself or resolve her difficulties, they also failed to predict the future, prognosis being a significantly important part of diagnosis. The stories which became helpful to Angela will be discussed below, but here it is enough to say that while Angela still experiences difficulties, she is not recognisable as the person in the description above. She is a warm and caring person, and works with children. It is therefore particularly easy to examine the stories for what they tell us about the services which evoked them rather than the person who was their target (which is to say that when someone is so changed it makes it clearer that we are asking questions about Hacking's interactive kinds not natural kinds). Becky and Claire have already helped to open the narrative of borderline personality disorder, and for them both it constituted something of a relief. The relief was found in now being thought of as someone whose experiences were causal in their difficulties, and whereas there may have been a sense in Becky's account that a "chemical" problem would have been more easily fixed, in the end both Becky and Claire found diagnoses which viewed their experiences as psychotic to be invalidating. The same is certainly true with Angela in regards to the invalidation of brain-chemistry/psychotic stories. She saw it as a dehumanising reduction, and not only that, it made her frightened that she would start to "kill people". However, unlike Becky and Claire, Angela did not welcome the personality disorder diagnosis. She described it as misogynist. Whereas Claire in particular found therapeutic value in the diagnosis, Angela, who experienced Dialectical Behaviour Therapy, a form of therapy designed for people with that diagnosis, found that she was infantilised by a "boot camp" approach involving older women in maternal roles, and that she began to act to meet the expectations of the diagnosers: it was easier.

Angela described the diagnosis of borderline personality disorder as like being backed into a corner. I think it is interesting to consider it with the second story of "psychosis". In some ways they are opposites, but in Angela's case (and Becky, Lisa, Amber, and Mel too) they have been held simultaneously. What are the effects of the two together? I think that question is worthy of its own piece of research, but I suspect that it leaves no part of a person which cannot be pathologised and no part of a person to resist. They are both no reasons and the worst of reasons together. A possibly important question in this consideration of what the stories do is to notice that they were not applied in the same order. Becky, Claire and Lisa were all given psychotic stories first and personality disorder stories second (which in my experience as a nurse is more usual). It seems that the mental health teams in charge of Angela's care gave them the other way around, that is, if they were able to ever apply one in preference to the other very successfully. To be described as psychotic and then personality disordered might be a relief (I only say it might be), but when it is the other way round does it have the same appeal? I also think that Angela has done more reading about borderline personality disorder than Becky, Claire or Lisa and therefore she is more likely know its controversial status. Angela feels there are two very clear reasons for the new diagnosis one was being defiant, another was still withholding that she was hearing voices.

I was always quite defiant, and I think that's why I got the BPD diagnosis... Towards the end of my second admission, because I was a pain in the backside, really, because I... I wasn't happy with what was happening, and I wasn't communicating that very well, and I think I didn't need to communicate that very well, you know I was in a mental hospital they were sort of almost asking you to be crazy - you know - what is expected of you in a mental hospital? Yeah? You say crazy things because that's what people are expecting you to say, so you know - you do sort of live up to the expectations that are placed upon you. in a funny kind of way.... But I was very angry, I was always very angry so that's why they were always so quick to medicate me. I threw things a lot. I was banned from quite a few groups and things... and I'm not proud of the way I behaved at all but I was very angry that... I was very angry that it all just seemed so absurd to me. I remember sitting in these CBT group sessions, or maybe a psychotherapy group session... And the first sort of week that I was in, I didn't say a word - I was completely mute - possibly for longer than a week... And I knew, I knew that... what I was experiencing, what I was bottling up, was so explosive that there was no way that I was going to be able to even begin to explore that in a group. And I was angry that they hadn't read my mind and knew this! You know... And I was trying to communicate that very very badly...

I think the reason that I had so many diagnoses is because – well, human experience is really complicated right? And individual. It would be difficult for most people to go through the DSM and not be able to pick out quite a few that they fit into. And it also had a lot to do with my honesty over time about a lot of what was happening. Keeping quiet about the

voices – I kept quiet about the voices for I think it was probably a good year. So... Psychosis wasn't really something they thought about until I said about voices... And then we just went into the whole psychosis spectrum.

As I nurse I vividly recall being taught to say "they have become upset", not "I have upset them". I passed this "wisdom" on to others. In this, and in Angela's account there seem to be key aspects which push stories from the right of my "location of experience" map towards the left or the extreme left. And, as this occurred Angela both noticed it and felt that her humanity was eroded by it. The text book did this, the diagnoses and "treatments" did this, and ways in which her relationship with psychiatry and what she saw as her resulting anger was reframed as her own personalised anger and flawed personality. She occasionally had moments of strong energy and emotion, both frightening and exhilarating, during which she would run about the town screaming and warning people of impending disaster. She always wanted to reduce medication and did so many times without the support of the team. She was lonely, distressed and had poor self-esteem. On the one hand, she was difficult, angry, uncooperative, and by her own admission behaved "like a teenager". On the other she was overwhelmed with disturbing and powerful unusual mental states that services must have felt were genuinely psychotic (this is clear because she was prescribed clozapine which may only be prescribed for "treatment resistant schizophrenia"). For Angela, however, it was not really the case that once described as having "schizophrenia", the other labels were dropped. In fact, she feels she was always felt to have borderline personality disorder too, and, actually a consultant psychiatrist said to Angela's mother at the end of the six years that he still did not know, which was one of the catalysts for seeking other kinds of help.

For Angela, the "narrative violence" did not simply end here with the difficult nuances of diagnosis stories. Angela said that low self-esteem of being diagnosed had contributed to her acceptance of other kinds of abusive intimate relationships also. The psychiatric narratives that Angela was required to accept seem likely to have contributed to ideas that being able to control her own social circumstances was beyond her.

## Third violent story

The third violent story is about "treatment". It has to be in inverted commas because calling it such may also be emplotment (Moncrieff and Cohen, 2009 for example). The stories of the psychiatric team not only enabled/legalised but also valorised the force and the forced use of substances that seem to have been destroying Angela's health:

You know I was about 16 1/2 stone or 17 stone, I had heart palpitations I was always at the doctor's being hooked up to all these bloody machines all the time because – you know – my heart was under so much strain, my joints were under so much strain because I was so big. I couldn't breathe properly – I was smoking so much – because I had nothing else really to do, and it kept me awake really, that was the main reason I was sort of smoking about 60 a day... I mean – I left uni, I had all these ideas – you know I was... I literally went from sort of being 19, partying, taking drugs at uni, doing young things, being interested in fashion – clothes you know... Now I was... You know 23, 24, huge, didn't want to walk in any shops and buy any clothes because there were no sizes big enough – you know I had to go into the sort of plus sizes, and they didn't care about looking good. I was in an abusive relationship, because I didn't think anything of myself and...

Bonnie Burstow attempts to understand what stories psychiatrists (and nurses) perform which allow them to be part of this kind of violence. As a nurse I was trained in "control and restraint", and have given people injected medication under restraint, into buttocks, while they may have been screaming that they did not want it. I do not pretend I did that every day; I was able to find roles in which coercion was less gross. I also know some of the care that was taken by nurses to ensure that this was not simply thuggish behaviour. Through research described as "Institutional Ethnography" (2015, p17) Burstow argues that there are a number of stories which make such action possible, indeed having the possibility of virtue. Firstly, the essential nature of medical

intervention is reinforced simply by the twin facts that the psychiatrist has the longest training of anyone in the team and their training is medical, spending years learning anatomy and physiology. It is therefore natural to everyone that the teams in which they work are to provide interventions of a medical nature, reinforced by all of the language of diagnoses and treatments, doctors, nurses, patients, hospitals etc. Burstow finds a prevailing story among psychiatrists and spread throughout its literature:

Since the 18th century, the standard depiction of the "state of psychiatry" is precisely that a new day is dawning, that psychiatry is breaking from the error of bygone days and revolution is happening, characterised by sound science, more humanity, and openness (2015, p150).

Burstow claims that it is stories such as this which allow eager trainees to be blind to the violence that is staring them in the face (and indeed to abuses of science and self-serving anecdotes). Regardless of questions about the science-validity of psychiatric medications one may marvel at the power of these narratives. From my experiences as a nurse I would add that there may also have been a mythologised *Well Angela;* a parallel story that somewhere was an Angela who would want this were she not the Angela currently present. Nurses receive comfort from stories like *Well Angela,* by telling each other that *Well Angela* will thank them (for that which she may currently detest them). I believe it would be interesting to ask whether the attraction of this story is felt by service-users too, as it becomes the condition by which one is accepted by the nurses (and certainly a condition upon which discharge may be predicated). One can find service-users who are later recruited into the story (much to the delight and relief of the nurses who frequently tell their stories).

For Angela, there is a further narrative about "medication" and emotions. While a university student, she became addicted to heroin. Believing that she would return to being a "model student" by tackling this addiction, she successfully stopped using it completely. However, she found that her memories and emotions became unmanageable. Angela feels that what psychiatry offered was a state-sanctioned heroin. At no time did it stop her from hearing voices or experiencing distress, but when she did stop taking it, which she did on several occasions and never with the support of the team, the experience was as it had been upon ceasing heroin: intolerable emotions and paranoia.

And there was some comfort in the idea that I was mentally ill, and there was a pill, and I wouldn't have to deal with... You know – because I'd already been taking drugs, street drugs – so it was already going down the same path that I was operating into already but I tried to get out of which makes me quite angry... You know I had kind of stopped trying to deny it all, and I had been through that – you know – withdrawal, that trouble of coming off drugs by myself at 19... Only to be put back on drugs were serving pretty much the same purpose. I feel quite furious about that, to be honest.

... They knocked me for six and, I know now why the clozapine works so well – because it knocks you out like no other drug I've ever taken. I mean in the first week I was on it I basically spent the entire time asleep. And that was on 12.5 mg, which they start you off on. They titrated up to 100 over the course of the week and I spent the week knocked out. And I ended up on 600mg of that stuff... I can't really remember a great deal about anything when I was on that, emotion wise, I remember being – I just wanted to sleep all the time, I didn't really care. I did still hear voices, I did still have these beliefs of – you know – being persecuted and things and I hope these moments where I would sort of explode with this... this panic. And I would go completely crazy and I would feel like... and I would have to – and I would be very mad. I would go into the town, I would start shouting and screaming... warning everyone of this imminent danger – whatever I felt it was at the time.

It has already been seen, in Becky's chapter, that this thesis may be attempting to add *Mechanical* to Frank's *Chaos, Restitution* and *Quest.* The degeneration of "schizophrenia" seems to contain

something of this kind of mechanical narrative, being another plot of inevitability which removes personal experience as meaningful or influential, and the possibility of agency, although the mechanism here is not so much cyclic as that of a "ticking bomb". However, this time it becomes yet more clear that mechanical plots do not simply reduce agency. It described Angela as unable to take intentional action; her "illness" played the role of agent. Although Angela was recruited into a story which appeared to diminish her agency, the other members of the cast gained enormous agency, as I noted with Becky. Here, the "mechanics" in the story gained the power to do almost anything to Angela. She could be detained, her body could be held immobile, injected, inflated to a size 22, made incontinent, subject to other side-effects seen and unseen, directed to individual and group "therapy", to housing, and could be monitored, measured, surveilled, arrested by the police and handcuffed, all without consent.

In reading Deborah Lupton on Foucault, I came across a simple sentence which seems to illustrate something further about the experience of "control and restraint": "in mental illness the body is the apparatus by which the brain is kept restrained, often against the owner's will" (Lupton, 2012, p23). Much of this is through the use of buildings, doors and locks, but in actual restraint of the body, the "mental patient" undergoes a further violence, Angela's *reduction*, between the person and brain; not only is the restraint a kind of violence, but *the fact* that the whole person may be restrained through the application of force *to the arms only* is another kind of violence, that reduces a person into parts and their arms to "apparatus". Lupton's description reminds me vividly of my training in "control and restraint" techniques in 2000. It is all about arm rotation.

### The war on drugs

In May of 2015 the 52nd Maudsley Debate was held at The Institute of Psychiatry, Kings College London. The motion: This house believes that the long term use of psychiatric medications is causing more harm than good. The fact that the motion was carried does not of course constitute proof, and indeed the pre-debate vote showed a majority in favour. However, the existence of the debate at this time is very telling. A number of factors have led to this time when it seems psychiatric medications are under a profound re-examination. Lupton charts a growing disillusionment with scientific medicine extending back into the late 20th Century, "on the part of both intellectuals and some consumers", whereby "[t]he effectiveness and benevolence of medicine began to be challenged, and so too was its claim to inaccessible and arcane knowledge based on objectivity and political neutrality" (Lupton, 2012, loc 128). This has accelerated in the post 2008 economic climate with a much greater general interest in the role of corporations and the economic models which best sustain them. My personal observation is the economics has increasingly become the field of interest for people to view and understand relationships from those between them and their neighbours to those between countries; we are all amateur economists now. Wars are frequently described as being about economics, in 2015 political parties are now described in terms of their relationship to "austerity" which has become a new way to interpret what people may previously have been content to describe as "left" or "right" and "anti-austerity" is a banner under which people will march. The Transatlantic Trade and Investment Partnership, seen as a dramatic extension of corporate power over democratic government (Lee, 2015) was the cause of a recent demonstration involving 250,000 people in Germany (Johnston, 2016), and yet many in Europe feel that economic power over democracy is exactly what Germany has exercised over Greece over successive Eurozone crises. David Graebber and the "Occupy Movement" he helped found has been successful in forging the category "the 99%" (2014), and one of World's best selling books in that year was written by Thomas Pikketty (2014), a radical economist, now an advisor to the UK Labour shadow cabinet (James, 2015).

Within this climate, Peter Gøtzche (2013; 2014) of the Cochrane Institute described the pharmaceutical industry as "organised crime" and many were ready for it; Robert Whitaker (2011) had already re-opened profound questions about the role of psychiatric medication in the U.S., conducting an extensive European tour schedule and opening something of a floodgate of similar criticism on his *Mad in America* website. In the UK, psychiatrist Joanna Moncrieff has published

extensively and damningly about the research practices of "big pharma" (2009a; 2009b; 2015), and the idea that "big pharma" and the DSM work together to form new illnesses for financial gain has a name: *disease mongering* (lhara, 2014). Moncrieff's work followed two popular books by Dr Ben Goldacre (2009; 2012) and the "All Trials Campaign": greatly raising public awareness of serious malpractice in medical research. In the space of about eight years, concerns about the corporate power of drug companies and their role in shaping "mental illness" have gone from the fringe of critique to its very heart. On 11th May, 2016, Whitaker joined members of the *Council for Evidence Based Psychiatry* to present the evidence against "anti-depressants" at the House of Commons (see Whitaker, 2016, for his presentation).

A further factor in this "perfect storm" must surely be the travails the *chemical imbalance theory*. In 2013, at the time of the release of the DSM-5, a member of that task force (Burstow, 2015, describes the members' personal financial interests in pharmaceuticals) admitted that the chemical imbalance theory was "only ever a metaphor". Or at least, that is how it seemed to be reported. In fact, this phrase appeared in the *Psychiatric Times* at least as early as 2006, but perhaps most notably by Dr Ronald Pies in 2011. He opened with a denial:

...[T]he "chemical imbalance" trope has been tossed around a great deal by opponents of psychiatry, who mendaciously attribute the phrase to psychiatrists themselves. And, yes the "chemical imbalance" image has been vigorously promoted by some pharmaceutical companies, often to the detriment of our patients' understanding. In truth, the "chemical imbalance" notion was always a kind of urban legend — never a theory seriously propounded by well-informed psychiatrists (Pies, 2011).

Pies, US Professor of Psychiatry and Editor in Chief of the Psychiatric Times, has repeated this argument vociferously since. I could say that I have heard scores of psychiatrists (GPs also) in the UK use the phrase "chemical imbalance" on an almost daily basis. I could point to many publications in peer journals reviewed which focus on chemical mechanisms as causal factors in "mental illness", however, nothing better illustrates the absurdity of this denial better than the stunned and bewildered response one gets from mental health professionals and final-year student nurses upon informing them that the chemical imbalance theory is only an "urban legend". They more usually believe it to be the foundation fact of their practice. Just what kind of an institution is psychiatry that it allows such tropes to exist so commonly without being decried? Is it a scientific or a cultural community? Pies is undoubtedly right that the pharmaceutical industry has encouraged the theory. He may possibly be right that many psychiatrists understand "mental illness" as being multi-factorial (including genetic and neurological explanations which may be equally fraught, and autoimmune theories as well as psychosocial ones), but he in no way answers the many questions which arise: when one is detained in the UK under the Mental Health Act one is detained for "treatment" and that "treatment" is primarily a chemical one and adherence to it is a primary condition of discharge from that detention. It is does not automatically follow that one should medically "treat" an urban legend, and one cannot use that language with impunity from the charge of spreading the idea that "mental illness" is biochemical.

What would it mean to provide a DNA of "medications"? It would seem that stories about medications must be very secondary to their actual action on the body. Even without interviewing any professionals it is clear that Claire and Angela (and certainly Lisa) have all had experiences and thoughts about medications which have been quite independent of the intentions and understandings of those prescribing them, but surely there is a way to cut through beliefs about medication with test results which provide some kind of greater objectivity about their effects? In physical health care this could include a fruitful diversion into the literature surrounding placebo and nocebo effects before looking at *the data*. Yet it has already been seen that the very act of prescribing medication *for distress* is wrapped up with narratives on the left of my political map and cannot be considered to be narrative-neutral. As one begins to read further about psychiatric medications one quickly learns that they are not prescribed in conjunction with test results: there are none, and neither are there any to measure their effectiveness. The very notions the body and distress are surrounded with narrative mist; add in the controversial status of the DSM and it

becomes clear that the mist surrounds prescribers, the substances and their recipients. And there is *still* the issue of placebo and nocebo.

One could argue that the *only* way to understand psychiatric medication, and what it does for those taking it, those prescribing it, those funding it and those producing it, from the glossy marketing right down to the widely established reduced life expectancy (something that surely adds urgency) and including the legal framework which supports its forced use, is via the means of a DNA. However, such a work is a book on its own. I merely intend to establish here that it is possible to view medication in psychiatry as more part of narrative than natural science, and that medication is not in a separate category to everything else which is being opened up in a DNA of voice-hearers and emotions.

I do, however, wish to make one further comment about medication, and that is to suggest that if such a book were to be written, it would not be entirely one-sided: writers who propose that medication causes the very problems it seeks to address are often guilty of firstly arguing against the idea that experience can be biologically determined *and then* claiming a determining role for psycho-active substances, forgetting the points they have just worked so hard to establish. On my map, they counter one fully internalised story with another. To me, this tendency seems most prevalent in North American publications and websites in which there are strong Libertarian narratives (further exploration of which could be a fascinating chapter in the book). The arguments that it can produce (such as the most common: that SSRi antidepressants are a major cause of suicide) seem to get in the way of a critique of psychiatry rather than create it, even if there are wholly valid concerns about the restorying of pharmaceutical side-effects as aspects of illness.

### **Revisiting the HVM with Angela**

Other views are as valuable, but more than any other participant Angela had a coherence to her voices-and-emotions story which, although very personal, was built upon reflections about the assumptions and strengths of many ways of thinking.

This chapter began with Angela's disclosure that she no longer considers herself "a voice-hearer", despite continuing to hear voices. There is no doubt that Angela feels that the HVM were crucial in her escape from mental health services yet she has left them behind. Angela pushed me to question my own relationship with the HVM, and what indeed the HVM actually is, and after our final transcribed interview I began to write the two vignettes called *Something made me tell a lie*. It contains the kind of details that Smith shows us are able create a "deflationary attack" on tragic/ romantic/apocalyptic narratives (2010, loc 368), and the HVM contains many powerful stories I have had an interest in performing for a long time. Yet, with Frank and with Angela, I want to notice that *all* stories are dangerous. Certainly Angela would want me to begin with all that is good about the HVM, and no words put it better than her own. I want to add that I do not think it is correct to imagine that all people within the HVM would disagree with Angela, and some might even share her current views, something like the next stage of a journey. There are many people in the HVM who are concerned that as they become more established they should not become more monological.

...I think the important thing that [HVM] does... until I knew about them no one, not a single person, had ever mentioned to me that it would be anything other than a chemical imbalance in my brain. It just wasn't on the cards at all. And of course the minute that you put another option there in the mix, it changes everything. Immediately. And even if I had chosen not to go with that, it still would have given me a choice. And I think it's the choice bit that is the important part. I think that's the empowering part. So, I'm not even sure that it's the ideas of the [HVM] I think it is that it provides another option. And I think that is the powerful part.

Angela also felt that the fact that the HVM is not part of services is important. There was a strong sense that for her, the importance of discovering the HVM is that in joining with them one "extricates" themselves from the system. You have to find out about them as if they are an underground movement. Somehow this makes what one finds there to be special and empowering:

And because it's not part of mainstream services, and you have to sort of extricate – well you don't have to extricate yourself from them – you have to go and seek out a hearing voices group for yourself, or hopefully someone in the services knows about one, but you still have to take yourself there. It is not prescribed... So I think what it is is that you are choosing off your own back... To explore this way. If you are a patient that is stuck in a system, and you are doing things in a certain way, you are expecting pills or whatever to help you, if you just don't have any other information, it's like... You are stuck in a certain way of thinking and it just gets you into the habit of guestioning stuff in ways that I haven't honestly done before in life. I was never really taught at school or anywhere to think for myself. So I think that the [HVM] really fostered that... And it's very an anarchistic and that's very appealing when you've been squashed down. I think that's the empowering part about it. I think when I started to get into some murky waters with it all really, was when - it was all sort of going really well, and I was understanding my voices, and there's this recovery story, I think Eleanor Longden at the time had just done the TED talk... I was feeling a lot better because I had a lot of people around me. Life in general was going quite well, I had new friends... at the time, I wasn't really acknowledging those, I was more along the lines of, "it's because of the [HVM], it's because I'm understanding my voices"...

Perhaps the need for the HVM to feel like an anarchist movement has significant effects on the stories that are perpetuated there, especially ones of moral polarisation. More than this, it poses questions about how to position the HVM on the political map. In fact, I believe it is very difficult to know how to do that, for two sets of reasons. Firstly, anarchism is not a left-right political position, but a political position regarding individuals and the state. At the conclusion of this chapter I suggest (with a citation from Foucault) that this anarchy element seems very suitable to Angela. Secondly, the HVM contains many other political positions too, in addition to different kinds of knowledge. For example, the *Thessaloniki Declaration* (Appendix 5) is not an anarchist statement but a call for collectivity in ways that are probably more Marxist than anarchist. However, in the UK part of the HVM I do not see much take-up of that declaration, and instead psychological or psychodynamic approaches are stronger, and this arguably reflects our more neoliberal mainstream, showing that the HVM are not outside of the influence of national politics. As I will discuss later, within the HVM are elements of knowledge found across my 'map of experience', with their own versions of the interface problems between them.

I am therefore uncertain whether one can say that the HVM is an anarchist organisation, and perhaps it does not know itself (see the section *Something made me tell a lie (part 2)* for some more reflections about uncertainty about the stories of the HVM). There is much about it that holds true with Foucault's views expressed in *Beyond Structuralism and Hermeneutics* (1983, particularly p211). The HVM is *transversal*, it is not anti-science but rather anti entrain techniques of power, especially those which create and define the persons as subjects, the privileges of power, against mystification and secrecy. However, these are clearly Angela's views too, and she eventually felt he had to leave to continue to express them.

As well as being surrounded by supportive people, there are other parts to the culture of the HVM that Angela sees as essential. There is something about the story which is "seductive":

Angela: ... The good thing about the [HVM] is that everyone is an expert. Everybody knows about themselves and it's good because there is this feeling that you don't need to have all these doctors and mental health professionals to make sense of things. And that is fantastic.

If you give any person a network of people and a sense of belonging, they are going to feel great.... I do feel wary... because, it's a very seductive movement. It's a very emotional one. It's a human rights movement – and people love human rights movements – because of course they do. Because everybody feels oppressed and rubbish, and they want to feel part of something that is empowering. And that's fantastic, but I think it's really easy to get swept up in something... And I think that's good, and I think there are drawbacks to that. And I certainly think that – I mean I said it before – there is certainly a particular narrative there gets pushed a lot in [HVM], the recovery, 'I'm all fantastic now" and... I think that's got quite a lot to do with... I think they want to, of course they want to appeal to the masses, and that's really important, you need to do that, you need to be... seductive.

But it's also not so great – I mean.... There's a lot of people... who are really fucking angry – excuse my French – with that, and don't feel they fit into that, and that is really sad. I think they have important things to say.

I have used it, it was fantastic, at a time in my life and it did help. I can't say it didn't. But I think I've used it as much as I can, now.... I do reject the idea that I am a "voice hearer"... for the same reasons that people say that they reject any other psychiatric label – it's more complicated than that. Say I was to try to stand up and say 'I am a voice hearer', I think that would bring an awful lot of assumptions about me, which is exactly the same as if I stood up and said "I am a schizophrenic". Having said that, it is a much more empowering label I think, in terms all that it is referring to a particular experience, so I can definitely see why people would like that and want to identify as that. Also, the [HVM] have done a fantastic job of making hearing voices cool. I think that's a great thing that they have done that, and hats off to them for that. When I was involved, and considered myself as involved very much with the [HVM]... I suppose I need to point out that I feel that I went on a kind of journey with it all. I do feel like I have almost drawn a line in the sand.

Angela recalls a few specific incidents at HVM events when she began to feel uncomfortable. For example:

I do remember a couple of people sort of standing up and giving their stories, and it really did go very much like this: my life was awful, I was in hospital, I was dosed up to the eyeballs, I was condemned to a life of misery and schizophrenia, hospitalisations, then I found the [HVM], and they saved me. It wasn't even subtle. It really was very much that story. I got quite angry at that conference I thought, "no! no no no! Hang on a second – you, as a person – as a person have got to this point. please please, give yourself some credit! For getting to where you are." And I just suddenly thought God – there are these people, these "mental health champions" at Time to Change<sup>18</sup> and it was very much... I mean when people believe in the medical model, they say "I took these meds and they saved my life! Without these meds I'd be dead!" And I hate that, because it is like, "no! No – you are deciding not to end your life!" And so you've got people saying, "if it wasn't for the [HVM], if it wasn't their ideas I would be 6 foot under". And I said it myself. There was a point where I very much believed that story, I genuinely believed it. But at some point, I started to give myself a little bit more credit.

Throughout Angela's thinking about the HVM it is a clear theme that she feels that there may be something about a story which can make ones own actions less visible. Illness stories reduced her and connected her to determinist fears that she might "go on a killing spree". The Charity Rethink's national *Time For Change* campaign Angela found to have this feature too. In becoming connected to the HVM Angela was certainly helped in ways which were just not possible for her in the mental health system, which was arguably catastrophically disabling. Yet the "salvation" story itself began

<sup>&</sup>lt;sup>18</sup> This is a charity-organised campaign ("Rethink Mental Illness") in the UK to "destigmatise" "mental illness". Some survivor groups feel it is unacceptably medical, as Angela does.

to be only possible if she discounted the role of her own intentions, and the possibility that she might have made any choices herself. And, it seems from what she has already said, that Angela found that the HVM story was, after a while, rather too simple and she needed to use it as part of a number of ways of thinking, rather than a monologue. However, to do that seemed to necessitate promoting herself as an agent in a way that did not seem to sit quite right with the HVM dominant narrative.

*Me: I am really interested in this "salvation" story.... okay... Here's a thing. So, you said you heard me on the radio –* 

Angela: yes

*Me:* do you think I told a "salvation" story? Of myself, as a nurse? I talked about how I found this new [HVM] approach, I worked with this person –

Angela: you did a bit, yeah!

*Me:* he helped me to see the light, everything changed, I finished the interview by saying, "there's no going back for me, it's grabbed me..."

Angela: Oh, when I heard that I genuinely believed you, it's not like I think you don't believe what you're saying –

*Me:* Okay, well listen to this – Lucy Johnstone<sup>19</sup> was my psychology tutor at university. She was paid for by the university, I didn't meet her at some kind of smoky underground club, where we talked anarchist thoughts – that was my nurse training. So when I say that my nurse training did not equip me in any way –

Angela: [laughs]

Me: is that fair?

Angela: well!

Angela had much to say about the idea of dissociation. Broadly, it is the most helpful concept to her in understanding her experiences and her voices. She experiences voices heard as if outside of her head, and also times when they seem to take over and she does not recall what happens. The latter experience she tends to describe in terms of "other me's" or "parts". These two kinds of experience are not clearly distinct but a "sliding scale". She suggests that a psychiatrist would refer to them as "dissociative identity disorder". They have a strong feeling of being in a different space, a garden, a rainbow, bedrooms - places where these "me's" "hang out". She does not generally refer to her three main voices as dissociation (although she feels that is a good explanation for their presence) because although they can distract her they do not "take over" the way that other parts of her can (Angela was reluctant to use the phrase "take over", because she felt it implied that these "others" were not her, which they are). Yet this description makes it sound more ordered than it seemed to be for Angela, or perhaps more than I was able to understand: she tried to precisely describe a very alien landscape. However, *what was key was that the voices and other experiences carried twin themes of emotions and personal experiences somehow personified*.

Angela felt that she had heard the word *dissociation* first in the HVM. She felt that it was another story, a metaphor more than a mechanism, but that it was more helpful than harmful. Nevertheless, despite its explanatory power Angela was concerned that it did also not become a monologue:

<sup>&</sup>lt;sup>19</sup> Key critical UK clinical psychologist, author of *Users and Abusers of Psychiatry* (Johnstone, 2000) published a year after she was my tutor.

This is a "voice hearer" – and a voice hearer fits into this dissociation model... now that is bollocks because there's loads of people that hear voices that have a very spiritual explanation for their voices. So we're back in the same territory aren't we? So we don't like the word schizophrenia because – oh you know it doesn't describe our experiences, and that is not okay... and you can have spiritual people, who hear spirits who are going to turn around and say, "how dare you call me a voice hearer!" It's just as violent! I suppose in the end that is why I ended up rejecting it – there was the same kinds of themes running through the HVM as there was through psychiatry – a strong desire to make everything very predictable. To fit in boxes, and powerful people, with agendas, and people being carefully recruited to support that agenda. It's all right – this is life isn't it? This is what life is. It's the nature of humans in a group. And language. You can't really get away from it. Find another group of people to attach myself to [laughs] – as we do, don't we? I'll do it all over again.

It's a cohesive thing, isn't it? The need to belong, and that's okay. I suppose it becomes not okay when people are being very coerced. I think that's when I would start really kicking and screaming.

At the end of her last interview, Angela was even slightly generous towards the medical model, saying that it had allowed her to be a child for a while, although this did not amount to a retraction of her criticisms of it. She also said that were she to have come across the HVM before her contact with psychiatry it would neither have attracted her nor made sense. This begs the question of whether the HVM is a narrative which makes sense on its own, or only as a counter-narrative to psychiatry, a theme I return to in two vignettes titled "Something made me tell a lie" parts 1 and 2.

There is a paragraph from a postscript to an essay, both by Foucault, that seems to me to resonate with Angela's struggles, especially in regards to stories which make one's own actions and experiences less visible. It manages to account for what appears to be something contrary about Angela's path; her initial attraction to psychiatry; her revulsion of psychiatry; her initial ambivalence to the HVM; her subsequent attraction to the HVM; her departure from the HVM.

They are struggles which question the status of the individual: on the one hand, they assert the right to be different, and they underline everything which makes individuals truly individual. On the other hand, they attack everything which separates the individual, breaks his links with others, splits up community life, forces the individual back on himself, and ties him to his own identity in a constraining way. These struggles are not exactly for or against the "individual" but rather they are struggles against the "government of individualization".

Foucault, 1983, p211

*Whatever people say I am, that's what I'm not* (as the Sheffield band *The Arctic Monkeys* debut album title has it). This struggle against the "government of individualization" will be explored further within the discussion of John. Frank is also helpful here: Angela has experienced *institutional emplotment* (Frank, 2012, 134). Indeed, it is hard to imagine many stories that could be a more profound example. The institutions are clearly psychiatry *and* the HVM (with appropriate caveats about the gains that Angela attributes to belonging to the HVM). The loss of one's own intentionality may be the *price of admission* (Frank, 2012, p136). I also cannot help but wonder if there is a relationship between the above quote and the experience that psychiatrists call "borderline personality disorder", although it understands the location of pathology very differently. Gail Hornstein describes allowing others to define one's experience as "narrative surrender" (cited Sayce, 2016, p21). In my opinion, Angela had to resist surrender many times in order to rise as her current self, and I sincerely hope she will find this chapter a tribute to her courage and brilliance.

# Something made me tell a lie

The room had about 10 nurses in, and perhaps 25 voice-hearers, and perhaps the same number again of assorted on-lookers. The workshop was led by two nurses who wanted to open a discussion about their experiences as mental health nurses also connected with the HVM. They asked me to describe my *nursing journey*. I talked about my time on wards, the bucketfuls of medication, the ECT. I explained about the man with whom I first did *making sense of voices* work<sup>20</sup>, him again, what he taught me, what he discovered, what changed, that I felt that for the first time we were moving together. As I said *"moving together"* I put my hands together and moved them from left to right, across my body - and then I could say no more. The Scandinavian voice-hearer next to me kindly put her arm around my shoulders and I sobbed. Foucault was very interested in confession: he said it was central to production of truth and power (1990, p56).

I am not sure why it happened exactly. Frank tells us that stories are performed for a purpose. This was the story I had told myself for years, on Marius Romme and Sandra Escher's sofa I had sat and told it, and I reproduced it now, in the room. Then an expert-by-experience told a story about how she had once betrayed a nurse's trust. As I finally composed myself I said in a shaking voice that I had learned to play psychiatrists like a piano. I regret saying it.

Later I found myself thinking about this moment repeatedly. There was something about the situation and about the people there that encouraged me to tell this story in this way, and something about the HVM which had been encouraging me to think that way for several years. It was Frank's *price of admission* (2012, p136). *In fact, this story is nonsense*. I lied, somehow. I cast myself as unaware to begin with. I cast my first experience of using the Maastricht Interview as a moment of epiphany. In fact, none of this was new. I had Lucy Johnstone, author of Users and Abusers of Psychiatry, as a third-year tutor on my nursing course in 1999, and she was not even the only tutor on the course with critical views. We had a rigorous sociology tutor who worked very hard to ensure that we spent a lot of effort writing essays about the social factors of distress. A tutor on a biology module openly expressed doubts about the relevance of physical and biochemical aspects of the brain in understanding distress. Another tutor pushed us very hard to reflect on ourselves and spot our prejudices and become useful to people therapeutically; I can remember them all vividly.

In fact my initial compliance with psychiatry was not driven by ignorance. One significant purpose of my story was to protect me from this knowledge. It hides the period of five years when I worked as a mental health nurse without helping people to make sense of "psychosis", a period in which it might also be fair to say that my need to be a "team player" played a role in a choice not to pursue some of the questions that my training posed to me. It casts my training and the teams I worked in as the villains - leading me astray, indoctrinating me with a bio-medical view from which I was "saved" by the HVM.

Just as Angela felt, this also hides my own efforts. And actually, the "initial compliance with psychiatry" is not simple, either. Although I did feel a need to be a "team player", I began telling work colleagues almost immediately that I had strong reservations about the validity of the phrase "mental illness" and the role of medication. I dispensed lots of medication, of course, but I had argued for moderation, I had been a difficult nurse to get PRN ("as required") medication from, much preferring to sit with people and discuss their distress or pointing out that there was something very strange about drinking coffee and smoking all evening, and then asking for sleeping tablets and benzodiazepines<sup>21</sup>. I had placed a high degree of importance on one-to-one

<sup>&</sup>lt;sup>20</sup> See 10 Weeks

<sup>&</sup>lt;sup>21</sup> In so doing, I was going after the easy target - the service user. Towards the more significant target of the prescriber I was less confrontative.

talking, inexperienced as I was, right from the beginning. I left ward nursing as soon as I could because I found the bio-medical aspects of it to be so at odds with my own beliefs, and I had worked in a day therapy unit from less than three years after qualifying. At this day therapy unit I worked with an Occupational Therapist who had a masters in "adventure therapy". We took service users, sometimes from the ward, to do things like rock climbing, abseiling, kayaking, orienteering. We did not call them patients, we called them "students" on a "personal development course"<sup>22</sup>. As I moved into community work, my desire to promote ways of making sense of experiences and demedicalising experience continued. I started to find ways of reducing dependancy on long-term medications on my caseload. I talked with my caseload - I did not simply monitor their "illness". We set goals, I learned how to treat them as people with the potential to recover. It was in this context that I first did Making Sense of Voices Work. This was no *Damascus Road*. It was not the first time I had experienced "moving together". It *was* wonderful and it gave me something hugely important - confidence that there did not need to be a divide between "psychosis" and the rest. It gave me a hunger to do more work with voices, which I did, and it did allow me to step further towards treating people with equality more than I think anything else could have.

Although the saved-by-the-HVM story makes my own efforts invisible, in an odd way it also promotes them. It casts me, through association to the HVM, as uniquely able to see through the mental health system's evils. In this story of moral polarisation, I became one of the good guys, a *hero* in Smith's romantic genre. And, as Smith says, romantic genres are particularly vulnerable to attack from realist positions (2010, loc 368); this story, like other stories, is deflated to a lower mimesis by detail. The mental health system was not wholly bad and neither was my nurse training, and many nurses I have worked with also have strong reservations about the medicalisation of distress. Were I to try to paint myself as the romantic hero in front of former nursing colleagues, I expect that they would be able to bring up embarrassing examples of times when I was nothing of the sort. Why is this difficult to admit? Because, as Smith says, when one is at war only an apocalyptic narrative will do - and if either side start to behave in ways against their moral stereotypes, if the gap starts to close between good and evil, then negotiation is possible (2010, loc 380).

But what would have happened if I had told this "lower mimesis" version of events in the workshop? Would it have paid an adequate "price of admission"?

### Update: Emmaus not Damascus

I have just spoken to an Anglican theologian. It was not the Damascus road (Acts, ch 9 vs 3-9), it was the Emmaus Road (Luke, ch 24 vs 13 - 35)! On the Damascus road, Saul/Paul was confronted with the blinding light and ever since we have "seen the light" at such moments. On the Emmaus road, the downcast and confused disciples met a man they did not at first recognise but he helped them to reinterpret the scriptures to reach a new understanding. This man was an expert narratologist and stories he told have endured for millennia. He connected up the familiar events into a different plot: a different past, present and future. The travellers became recruited into a new story. Their mourning evaporated. So perhaps I was not "lying": the events of *Ten Weeks* were an Emmaus Road experience. Both roads are dangerous. A Jew and a Christian would view the Road to Emmaus rather differently.

<sup>&</sup>lt;sup>22</sup> Something which may be seen as controversial in the light of the chapter with John.

# Lisa

July 2015: I have just had a text message from Lisa. She cannot make our second interview because she has only just been discharged from a short admission to an acute psychiatric ward. It was a stipulation of the Research Ethics Committee that I did not recruit anyone who had either been under the Mental Health Act or admitted in the past six months. This possibility, an admission after commencing the research, was not discussed.

My supervisor and I agreed that we had a moral obligation to see Lisa again, should she be willing. When we meet for a second time in September, Lisa tells me the whole story: since we last met ten months ago a lot has happened and she has been admitted to hospitals for physical health reasons and mental health reasons. She has been hearing a new voice, different to any she has experienced before, yet she now says she is the happiest she has been for years and she looks it. She has decided, she tells me, that her emotions and her voices are related. As long as she is taking care of her emotions, she says, the voices will be alright. It is possible to see something of this in her first interview, but not stated as firmly as this. She attributes this change to noticing what has happened to her voices as her relationships with her partner and with alcohol have improved dramatically. So far, Lisa is the third person I have interviewed who seems to have had an improved experience of voices during the research period.

We first met in late 2014 in a cheerful room with comfortable sofas, part of a mental health support project. Lisa spoke carefully, quietly and at times with long gaps. I found I was trading-off asking too many questions with leaving silences which were a little uncomfortable so early on. I was to discover later that this conversation was really the first time anyone had asked her directly about her experience of hearing voices in a 1:1 setting. The second recorded interview, nearly a year later, was the second time. Thomas & Longden (2013) suggest that the narrative work of biomedical stories is to privilege the *form* of experience over *content*. Whatever else Lisa's stories reveal about hearing voices, over ten years of contact with psychiatry without being asked directly and in detail about her voices may remain as the most striking aspect of her story. In the year prior to meeting me Lisa had experienced some of the ideas of the HVM, and in some ways her participation in this research is another opportunity to see a person at the point that they are becoming exposed to new stories.

## Emplotment

After the first interview, I felt I understood something about Lisa which was very important, and I present this first because I want to show that it was a way in which my stories tried to emplot this interview: I felt that she must have been abused as a child. She described a loneliness which some would regard as neglect. I felt she had probably been abused in other ways too, perhaps sexually, and I felt that it was possible that I knew things about her that she might not, since all she could present were gaps in her memory with an inexplicable (to her) "terror" of her extended family that resulted in her being mute around them. She also could not remember her half-brother until after he left home, when she was eight. She said that she had been her father's "favourite", but that this had changed for reasons she did not know at about 12 or 13 years old, also the time that she seemed to stop having easy friendships at school and her voices started to become abusive. As a teenager she was tormented by accusing and blaming voices, had problems making friends, selfharmed and abused alcohol, and also said that she "slept around a lot". Without any particular researched idea about trauma in mind, I felt that all the signs were there. And, it is not so odd that I should think this: not only did I have a "trauma and dissociation" model in my mind, but the work of some heavy-weight researchers about the prevalence of childhood abuse in people later diagnosed with psychosis (Read et al., 2005).

Lisa's story makes visible issues of memory, emotions, voices, narrative and truth and as will be seen, questions about abuse and its implications. There are two stories, quite apart from the

*medical story* that has dominated Lisa's understanding of herself, that could be evoked to emplot Lisa's experiences: they are quite different stories that lead to a different valuing of voices, a different understanding of her past, different actions in the present, and a different set of priorities for the future. However, Lisa flickering in the space between the *trauma and dissociation* story and that of the voice-hearer as a *common human variation* was mostly in my head, not hers. I think Lisa experienced the same kind of feeling, but probably between the *medical story*, the *common human variation story*, and a story from a radically critical conference that suggested to her a causal role for medication in her difficulties, something touched upon in the last chapter. All of these stories make a tension in this chapter between letting Lisa speak and bringing in the views of others.

I want to begin with an uncomfortable moment during the first interview. She had been saying that she had decided (following attendance of a conference with alternative views about psychosis) that taking medication was responsible for these significant gaps in her memory and then, during the following interaction realised that her memory problems probably pre-dated taking the medication. She looked horrified:

Me: I'm just trying to understand... Because that's quite massive... You were saying that you can't really remember your brother before he went to university. Even though you would have been about – how old when he left?

Lisa: Eight.

Me: ...At eight, you know children can remember quite a lot.

Lisa: Yeah, I remember from when I was two! [laughs]

Me: Yeah.

Lisa: But I can't remember my brother.

*Me:* Do you think that you used to be able to remember your brother? But since taking medication you can't? Or –

Lisa: No – I think I couldn't remember him anyway. I think...

Me: So... memory has always been... ...maybe

Lisa: Yeah... I'm not sure.....I had not thought of that before... [short silence, seems confused/unhappy].

I had already been speaking with Claire and Angela about voice-hearing, dissociation and trauma, and that is what I was trying to establish with these (leading) questions. That operating or evoking a certain narrative could lead me to believe I knew more about her than she knew of herself shows it is a powerful narrative, making it possible to interpret hidden parts of other people, a narrative which even imparts power to the user to override the statements of others; the dissociation narrative includes the power to make Lisa's later denial of abuse into a confirmation of it. *It has the hallmarks of a dangerous "Freeden" ideology, able to decontest itself.* Not only that, but it has the power to bring all aspects of Lisa's difficulties together as one object of struggle, creating a story with a tragic theme and moral polarisation: one of Phillip Smith's inflated genres (2010, loc 290). It might be thought that if I spent more time with Lisa, if I interviewed her family, her medical professionals and read her medical notes, then this question about trauma would be resolved. All I can say is it *might* be, but those resources and their accounts would also be subject to the work of decontesting; I might simply not believe them, and with a narrative firmly planted in the systemic section of my political map I would likely find myself explaining that the family have a vested interest in individualising the abuse by claiming Lisa to have always been different, mad. Lisa's part

in this research is something which reveals more of the way that narratives work to recruit us, to alter what we see, to change the truth and to alter the future. At the centre of them is a person (and unseen others) who may be exonerated or abused by my account, and of course, me: researcher and health professional, connected to conflicting narratives.

Lisa also contributes to other stories within this research too. As someone who has not spoken about her voices very much, it seems even more possible to ask whether the very fact of being interviewed by someone about voices and emotions has been emplotting, perhaps valuably (although I am not particularly proud of the above interaction). She also contributes to the evolving discussion about hallucinations/psuedo-hallucinations because I suspect she has, within the narrative of psychiatry, both, and it will be after this chapter that I take up some of the postponed questions about this. Finally, she continues to connect this research to questions about iatrogenic harm, in particular medications.

# **Common Human Variation**

Me: I have asked you to pick three cards. Which one do you want to talk about first?

Lisa:... Probably... The budgie.... It looks rather lonely. And... It is caged in....

Me: Okay....what was it that made you feel you relate to that card?

Lisa: I think probably more the loneliness.... Because I do quite often feel... lonely. Although... my voices... kind of make me feel not lonely as well as lonely. It is a bit of a two-way thing.... Well... I think... sometimes I feel lonely and my voices are... positive – they make me feel like I've got friends but... sometimes they gang up on me. And if I'm already feeling quite alone, they make me feel even more on my own...

Me: Has that been always the way?

Lisa: No. When I was little they were like friends. I think. Yeah....

Me: ... You heard voices as child?

Lisa: Yes... because I used to... I used to play a lot on my own and... and they used to sort of play with me. If you know what I mean.... like you have a friend. And you were maybe playing shops or something. They would... sort of be another person....

Me: So they were friends to you at that time?

Lisa: Yes

Me: But that hasn't always been the way?

Lisa: No. At some point they kind of turned – some of them turned against me... and blamed me for not... forming relationships with other people. And... sometimes they were quite annoyed at the fact that I couldn't do that...[but] I had someone to play with. And also, I've got a massive extended family and, like when I used to be round my extended family, I was pretty much mute. I never said a word... So at that time my voices were sort of friends I guess. I don't think they were imaginary friends, in the sense that some people have an imaginary friend. They were actually speaking to me, rather than I think me making up what they were doing, they were actually there [laughs].

This section, and others like it, seems to fit with a story of voices being a *common human variation*. Lisa is a voice-hearer and seems to have always been one; she told me that she had thought it

was normal. In 2012 Marius Romme and Sandra Escher told me that they had come from a recent meeting in which Intervoice endorsed the phrase *common human variation*. In 2014 it appeared in this way:

The HVM understands voice-hearing as a common experience, not inevitably pathological in itself but rather part of the diversity of the human condition (Corstens et al., 2014, p291).

However, Romme didn't actually say that. He first said *natural human variation,* and then corrected himself. We spoke about the word *natural*, and he said that it had been a version of the phrase they had considered. There is no doubt in my mind from hearing the way that members of the HVM often evoke the phrase *common human variation* that many do see the phrases as interchangeable, and in a sense, the word *common* has no particular explanatory weight unless it is linked to other concepts.

HV is a common human variation therefore it is part of our nature therefore it is not morally wrong nor (biologically) pathological therefore it should not be viewed negatively and makes voice-hearers into a valid minority group with a case against discrimination and gives them a valid claim upon the state for inclusion

Part of my justification for viewing the story as having all of these components is the way that I hear it used. The phrase is often coupled with left-handedness (which the HVM claims has a similar prevalence), homosexuality (which they imply is a biological minority with a history of stigma and pathologisation) and the Civil Rights movement. It is often said within the HVM that they are part of the "last great civil rights movement" (Longden et al., in Coles et al., 2013, p161 - 180). In other words, whether they would be happy to have it said in this way or not, this is the HVM's version of a biogenetic aetiology of voice-hearing. This seems to mirror the neurotypical/atypical movement within diagnoses of autism, a parallel I first found in Ian Hacking (2013). Arguably, several of these steps conceal significant assumptions. Most important here is that nature is used as a moral argument, with all of the attendant problems. "Schizophrenia" is, among other things, also a biological argument about the valuing of voices. If psychiatry is a practice of normalisation dressed up as medicine, then common human variation cannot be above criticism either. One does not generally hear people within the HVM say that voices are biological, but instead use words such as "human"; given the ways in which many members have found psychiatry to invalidate or stigmatise through biological arguments, this is understandable. Some might say that the word "human" implies a higher-level of organisation to biology. I agree: it could mean that, and there must have been a reason that the Intervoice committee decided to replace the word "natural" with "common". However, my experience is that it is not used in that way, because it is often used to contrast psychological accounts.

## Interfaces within the HVM

It would be wrong to imply that the HVM are unaware that there is a conceptual conflict between this story and the story of *voices as dissociated emotions*. The writer from the HVM possibly most associated with the literature of dissociation is Eleanor Longden, and she told me in 2013 that this is in many ways *the* question. One story depathologises voices but the best the other can say is only that they are the product of a means of self-protection which might have been the best available at the time (but needs addressing now), and it is difficult to claim a *right* to that. Perhaps

the HVM use the *common human variation* story in order to talk about rights and solidarity and *dissociation* stories in order to portray themselves as a body with expertise to offer personal help. Just like the biomedical *illness like any other* story seeks to use biological argument to directly alter social status, so the *common human variation* story is an important part of efforts to forge the HVM as a political body. The HVM therefore have their own versions of bio, psycho (and social) explanations. It would hardly be fair to expect that the HVM could have resolved the associated interface difficulties: psychiatry certainly has not, indeed, the philosopher Wendell Berry would say that psychiatry is part of the creation of such interface problems (Goodman, 2015, p1011). Perhaps living with this conflict is the best that can be done with the stories currently available.

Yet the interface between *common human experience* and *voices as dissociated experience* stories within the HVM is different to the interface between biomedical psychiatry and clinical psychology stories. Within psychiatry, the interface is typically understood through the lens of Zubin and Spring (1977); there is a dormant biological pathology which becomes active as a stress threshold is passed.<sup>23</sup> However, within the HVM it is perfectly possible to imagine Lisa as having always heard voices, that they are biological (the positively-valued *common human* kind), but the key factor in the experience of voices is their benevolence or malevolence, which is not ascribed any biological causation. Instead, malevolence might be driven by trauma, or fears driven by the prejudice of society, or the mental health system, or the attitude a voice-hearer has towards voices. This seems to be echoed in Lisa's account:

I do think that over my life I have probably had little traumas – not like major, like being abused or anything – but just little things that happened along the way which made my voices not very nice to me.

This interaction with Lisa questions what constitutes "enough" trauma, or the "right kind". Judith Herman, author of a much-cited 1992 work on trauma (Herman, 2015), claims "filt was recognised that the most common post-traumatic disorders are those not of men in war but of women in civilian life" (cited McCarthy-Jones et al., 2015, p4). Is it therefore adequate to categorise trauma in terms of particular events? Burstow presents a "layers of trauma" model (2015, p239), which contains at its bottom layer the idea that life itself may be traumatic in that we are born to die. It would not be right to be dismissive of the power of that trauma in shaping us either, but it does beg the question of whether trauma stories may decontest themselves: if trauma may be used as an explanation which is so fundamental, then is there any experience which could escape trauma models? This is part of what is witnessed in my interactions with Lisa; how could anyone defend themselves against such a model? If trauma is that ubiquitous, does that not suggest that it is not the experience itself which is significant, making trauma models more about interpretation and coping, or resources (or, dare I say it, biology?), or does it even separate trauma and dissociation. making dissociation into the key part? I think these are real difficulties if one feels the need to make a model or monologue. Personally, I would be willing to believe that dissociation is far more ubiquitous than serious abuse trauma. But then I also consider life to be dramatic enough to often be considered traumatic. And I also suspect serious abuse is not uncommon either.

During her second interview, while discussing different ideas about voices, Lisa specifically said that she had not been abused in any way and, although she felt that her difficulties in teenage years with relationships and her physical health amounted to being traumatic, she pointed out that she had been hearing voices since her early years, as long as she can remember. They were friends, filling in the other parts of her childhood play. She was lonely, with both parents working long hours downstairs in the family shop. She recognises that during periods of isolation the voices

<sup>&</sup>lt;sup>23</sup> That is not to say that this accurately summarises Zubin and Spring's original intentions. They saw "vulnerability" as being psychosocial as much as biological. However, in recent years mental health services have seized on their model to help solve the interface problem between the growing psychology and the established psychiatry, something described by a number of critical authors (e.g. Johnstone in Romme & Escher, 2011, loc 822).

have always "taken over". After falling out with a friendship group at age 12 or 13, voices became more mixed, and often blamed her for the difficulties she experienced. As a teenager, she developed two physical health problems and was very unwell, often missing school. She became increasingly alone and the voices became increasingly negative. My earlier assumptions about abuse started to feel less clear.

Me: Did the hospital help you to understand things?...

Lisa: No. I was just in hospital and they put on medication till they found one that worked.

Me: And when you say "worked", what did it do?

Lisa:... Stopped me from trying to kill myself. I think that was basically their aim.

Me: So this medication that worked, did it make you feel differently about life?

Lisa:... I don't know. I cannot remember a lot of the last 10 years.... I don't know. I honestly can't remember.... I've been taking medication – well since 2005 – there have been various different cocktails of medication.

...It was depression, then it was psychotic depression... And then it was borderline personality disorder. That is what has stuck [laughs]. [Short silence]. But I can't remember much of the last 10 years, really. Which is not good [laughs].

Me: Do you think your emotions are different to other people's?

Lisa: No, no I think they're the same.

Me: Because, I'm just thinking about borderline personality disorder -

Lisa: Someone thinks that my way of behaving, and being is... dysfunctional. That's what I see borderline personality disorder as. I think it used to be. But then... I think a lot of people... go through a phase of taking drugs and... stuff... What I find confusing is that I can't remember a lot. And I don't know if that is down to me drinking... And stuff, or if it's down to... my medication. I don't really – I'm not really sure. It's a bit scary though, not remembering lots of stuff. Because I've lost a chunk of my life, in a way. I think it is more to do with medication and it is anything else, really. And sort of suppressing emotions, really, I think that's what medication does.

*Me: It suppresses them?* 

Lisa: It kind of makes you a bit numb.... So I think... I have reduced my medication, and my voice is there are a lot more than they were when I was on high doses. So... But now I'm all right with them being there, even the not nice ones –

Me: How come?

Lisa: Because I think that they... just... just trying to help me, rather than... rather than seeing them as – even the not very nice ones – rather than seeing them as being a bit bullying, I think maybe they are just a different way of thinking of things, maybe. Or just amplify how I actually feel. I think the medication – I think that that... that kind of suppresses them...

*Me: …But it also suppresses your emotions?* 

Lisa: Yeah

Me: Yeah... And you feel it has done something to your memory?

Lisa: Yeah... Majorly! [Laughs]

### Re-storying and a new voice

When we had first met, Lisa spoke of her resolve to cut down or stop medication. This was particularly driven by attending the aforementioned conference just two weeks before. She had heard a lot of people talking about medication being problematic and preventing recovery. I felt it likely that the phrase "suppressed emotions" was something quoted directly from the conference, but it may also have come from some training that Lisa attended previously by the HVM, or from the HVM group she started to attend the past few months. In the above section she puts forward the idea that Claire found so controversial, that even negative voices are important and informative in some way. I am not sure to what extent this too was a new idea that Lisa was trying out, having heard it at the conference. In fact, it was only at this conference, during an exercise on paper that she began to think that she had two voices rather than one, or perhaps two kinds of voices, and that voices and past trauma might be linked in some way. Her relationship with her voices was clearly not an easy one.

Lisa: And also it's about maybe making links to your past... With what your voices are actually saying. And I knew that I do have... I do have sort of recurring things that my voices say, and that's when a lot of people have said to me things in the past... and that's usually negative stuff... That people have said to me... and also the fact about medication, I think that's what I got as well. That actually I have pretty much – not lost the last 10 years of my life but I've been sort of just wandering through, and not really thinking about things too much, or trying not to think about things too much... When really I need to move on. Yeah. And I think really the only way I'm going to be able to do that is without medication, because like we were saying my memory is pretty shite....

Me: So it seems from what you're saying... attending things... with the [HVM]... Have encouraged you to think a bit about voices... Not as something that's better not to think about too much – distract is the word you used – but actually something that could be meaningful both in terms of your past, and in terms of telling you something about your present... So that's been relatively new?

Lisa: Yes.... Sometimes... If my voices tell me to do things I will do them – but that is when I feel like, I'm a bit weak.... and I think that some people take things out on other people, where as I take things out on myself, and my voices tell me to take things out on myself. And sometimes they tell me to take things out on other people, but, just to shut them up a bit, I just do it to myself. Self harm I think has been a big problem for me. Sometimes it just snaps me out of a mindset.... but... I used to cut and burn, but my partner doesn't... like me self harming. So... I self harm where no one – like head-banging and that kind of thing. But I have done – I have tried to kill myself quite a few times, obviously not successfully but, I think the worst was I ended up in a coma for like four days, I took an overdose. So, yeah... If I feel weak, then my voices... I tend to be more prone to doing what my voices tell me to do I think.

Lisa was also able to say that being exposed to these new ways of thinking about voices was making her feel that she need to make plans for the future to be different. When we met again, things *were* different. Owing to the acute physical health problems she had been hospitalised and had two courses of steroids. She reported that these gave her great difficulties with her mood. In the middle of this period she began to hear a new voice, and a brief admission in acute psychiatry. Lisa told me about the new voice:

Lisa: I have never had voices with religious content... But I had... almost my "maker". I don't really believe in God... I sort of saw it as my maker telling me – he gave me a specific date of when I was going to die, and... I was fine, I was preparing things... preparing to die, and... I was all right with it. I was quite calm about it, and then as it got closer to the date I started panicking and then ended up on the psychiatric ward.... But my psychiatrist thinks it's to do with the steroids I was on, and the change in my medication – downing it – and my body not quite knowing... Because also I was on other tablets, which made my liver inflamed, and so I was having... My body was kind of just... It didn't know what was going on.

*Me:* The way that your psychiatrist explains what happened was that your body was in such a state that... that caused this voice?

Lisa: I think, yeah. He saw it as having a connection to my mood being so erratic. Being on steroids.

Me: Why do you think you got this new voice? Does that make sense to you?

Lisa: It makes bit of sense to me, in the way that it might have triggered that voice. But I don't know if that voice was kind of waiting to come out anyway. I'm not sure. I can still – although I have not heard the voice for a while I can feel it... here [gestures]....About 6 inches above my head.

Me: ...Did you sort of know it was there before it started speaking?

Lisa: I knew it was there, but... I don't know, it was more of a feeling that it was there... But like I say, I've never had any voices with a religious content before, I don't believe in God as such, even though I think all through my – when I was little I always wanted to. So maybe it's been there for a long time, anyway. That kind of feeling.

Me: When you were in hospital, with this... awful [physical illness]... Did you fear you were going to die?

Lisa: No, it wasn't then, that was last November. This voice came... I think it was May or June. It had given me a date that I was going to die. About six weeks.

*Me: so...* Where you physically better, before the voice came, or was it in the midst of all of that?

Lisa: It was in the midst of all of that.

Me: ...it sounds like that when you say you felt calm about it, that it kind of makes sense to you in some way...

Lisa: Yes. It did make sense to me. Because at that point I knew that I didn't have any reason to be on this planet. For various reasons really. So, I was calm. I was preparing things, you know. Like sorting the house out, and I had met up with a lot of people that I care about, and I knew that it would be the last time that I would see them. so I was trying to put things in place, everything to be right for when this day came that I knew I was going to die.... It was very calm, almost sort of a loving kind of voice. I did keep it to myself quite a while, but when I did tell my CPN and my psychiatrist... They all thought that I was... really unwell. But I didn't feel unwell. Mentally, I felt really quite happy, and my head was feeling really quite sorted out.

*Me: Did they think that this was some kind of evidence that you were planning to kill yourself?* 

Lisa: Well, they were asking if I was. And, to be honest with you, I think what started to panic me was the closer to the date was... I might be told that I would have to do something. Do something to die. But I didn't know. I didn't know if I would just have an accident, or if I would get told to do something. I wasn't sure. So I think that is what started to panic me. More than the actual dying. It was how it was going to happen.

#### [Short silence]

In this second interview, Lisa continued to see medication as "suppressing emotions". The following shows some of her decisions and why she has a growing sense that voices and emotions are linked. It also shows someone now making new and significant health choices in her life.

Lisa: I am on a lot more medication than I was. They have added a new...antidepressant.... I did increase my antipsychotic a few months ago, but then decreased it again. But then, I am on a lot of medication for my physical health problems as well.... At the moment I am not thinking about coming off things. So I don't feel like it did last year, when I wanted to come off all my meds. But I am actually a lot happier. Even though I am on more medication. Because I think I have done other things – I have stopped drinking – it will be a year in a couple of months, it is about 10 months that I have stopped drinking... And I think that has made a bigger impact on me than if I had stopped my medication. I stopped drinking the day I came out of hospital.

We discussed the achievement of giving up alcohol, although Lisa feels that it is her partner's cessation which has made the most difference because with him sober she is less lonely and the house is a lot calmer.

Lisa: .... The voice that normally bullies me, doesn't bully me as much... now. It isn't that he is not there anymore, he's a lot quieter. He doesn't bully me, basically. He doesn't really have anything to say to me.... When I was drinking, I was very impulsive. So if my voices were bad, And they told me to do stuff, I was more likely to. So that, that isn't so much of a risk any more. I feel safer - yes - that is what it is, I feel safer.

Me: I'm really glad about that.... So, you feel that [alcohol] choice is actually more significant than a medication choice would have been for you.

Lisa: Definitely, yes.... And I have got a good support network with my workers. My psychiatrist is really good, so is my CPN, and my support worker as well. Plus I don't see them after having two or three drinks anymore. Whenever I do see them, it is a lot more productive, you know, what we talk about. Yeah. I'm in a better place.

Me: [a question about what she is trying to "produce" with her mental health team]

Lisa: I don't know, because I still don't actually know what I want to do with my life. And I never have really, but I am busy, I try to do stuff every day, something every day, so I'm doing a lot of volunteer things... which I enjoy, and I see my family... and sorting the house out, getting rid of stuff that I don't want or need, which is quite good. And cleaning. I hate cleaning, but I am doing it – so I'm doing stuff... I don't actually know what I want to do, but I am managing to do it and I'm feeling quite happy.

### [Short silence]

Me: Do you think that you being happier has changed the voices? Or do you think they have changed and as a result you are happier? Which way round you think it is?

Lisa: I think me being happy has changed them.

Me: Do you get to talk about how things have changed... in the [Hearing Voices] group?

Lisa: Well, I have been not coming regularly. I think, with the group, we talk about if someone is having problems with their voices, and because I haven't been having problems with my voices as much, I don't really speak much in the group. It's more about supporting other people. But what I do find good is the week that we don't meet – because we only meet every other week – a couple of us meet at the pub just for a coffee. I find that more useful. because we're not actually talking all the time about the voices, which is what the group is for, it is more of a social thing. I'm actually getting to make friends.

Me: from what you are saying, your closeness with your partner, and friendships seem to change the voices as much as perhaps talking about them does?

Lisa: Yes. I think that I was – not under an illusion – but I thought, the same with the medication. If I come off medication, then everything will be all right. I think it is that similar kind of thinking but actually it is something else that has made things better.

The above text poses many questions. One of them is about medication. Lisa has been taking psychiatric medications for over a decade. She has also been "alcohol dependant". Just like Claire and Angela, she does not feel that medications have been helpful with her voices, and it is clear that she has continued to hear them throughout. She has a consistent belief that they have "suppressed her emotions" and damaged her memory, although alcohol will certainly have done this also. She feels that she has separate problems with her memory, which in the first interview was described in the context of worrying "blank spots", and in the second as being difficulty with short-term memory. Despite having a diagnosis of borderline personality disorder, she has had a recent diagnosis of psychosis, and has in any case been prescribed "anti-psychotic" medication for many years.

In the last chapter it was suggested that a DNA of medications would be a worthwhile project. Lisa's medication story can be used for a more humble purpose: it illustrates the way that narrative genres are raised or lowered, in the manner of Smith. The way Lisa described her new thoughts following the conference was like someone awoken from ten years of sleep-walking. She had been trying to "avoid thinking", but now saw the need to "move on". Indeed, the only previous example she could give where she felt she had any kind of revelation about herself was when a CBT therapist helped her to see that everything about her life was somehow going in circles (one can imagine what s/he was trying to achieve but it did not seem to be a description under which much action could be found). There were two strands to this awakening; firstly, she had identified that she heard two different voices, a new realisation. Secondly, she came away with a resolve to reduce or stop her medication. It was clear that she had come to see medication as the lynch-pin of a certain narrative. It was the cause of her memory problems and her stagnated life. Removal would therefore lead to improved recall (including memories of childhood which she found to be worryingly missing) and forward movement with the ability to feel emotions. Suddenly, she found a high "tragedy/romance" genre. The mundane habit of "carrying on taking the tablets" was now changed to a plan of action with extraordinary power to alter her past, present and future. The previously insignificant characters were now morally polarised, she could be part of the reclaiming of her self and of other people from under the shadow of medication, against the wrong caused by psychiatry and pharmacy: the problem was now not just local but global.

Therefore, I met Lisa as a woman with new powers of action. However, as with all strong narratives, it was detail which proved problematic. When Lisa realised that her memory problems predated her use of medication (to the extent that we can be certain that she could know this) it is possible that her visible horror was because, really, her memory is to do with dissociated trauma and she was at that moment aware of it in some way. However, it is just as plausible to say that it was horror caused by the threat to the bubble of her new-found narrative which had provided medication as the explanation to her difficulties. A year later, medication had more or less dropped

out of the narrative and was now mostly mundane, local, not particularly part of moral concerns and not part of a plot with powers of action. It had been replaced with alcohol-cessation and social factors, and efforts to keep emotions positive. Perhaps it would have been very difficult to maintain the original narrative without feelings of overwhelming failure in the face of the difficulties she has faced this year. However, it does seem that the new narrative had been found as explanation for positive changes in voice-hearing following positive changes in social circumstances and alcohol use, and not merely to accommodate a possibly disappointing inability to stop taking medication.

Therefore, for Lisa the role of medication may be central or peripheral, carrying different explanatory loads, and that it may shift up and down Smith's diagram (p27) as the various narratives coalesce around it, and that this is quite separate from any other understandings of what the medication does. The same is true for the voices themselves. Lisa told me that for the majority of her adult life her "whole aim was to get rid of the voices". She "would have just been drinking away, trying to get rid of them". However, now she feels that firstly, her voices "aren't so bad", and secondly, that she now knows that that "they'll never disappear".

Me: Would you say that you have accepted that you hear voices now?

Lisa: Yes... and... I think I will probably, depending on how, how my life... what happens, I'll continue to gain voices, certain voices, and lose voices. I guess it's much like friends, we have them for a certain time, they're there for as long as you need them, and then you – that's it. You don't see them any more.... They have been wrapped up with illness, but I think now I have come to terms with the fact that I will have voices for the rest of my life. But I think they are very much connected with my emotions. Definitely. So if I'm feeling better within myself, anyway, my voices aren't the – the horrible voices aren't going to be as horrible to me.

*Me:* So in a way, you have come to the idea – tell me if I'm wrong here – that your voices are not really the illness?

Lisa: No

Me: Your mood, and struggling, and your life circumstances, those are the things that go up and down – the voices respond to that. It isn't that the voices themselves are illness... Is that right?

Lisa: Yeah... Definitely. I think that's right. Like said, I think I always will hear voices...

Me: So... Actually you have come to a way of thinking that is quite different from mainstream psychiatry in a way... Because what they.... would generally say is that voices are the symptoms of a very serious illness.

Lisa: Well, to be honest with you there has not been very many professionals that I have met that have actually asked me about my voices [laughs].

This shift in role for voices seems very significant. With Claire, hearing voices is a sign of something going wrong, an emotional crisis. However, in Lisa's narrative, voices (that is, the presence of voices) are no longer a sign that something has gone wrong. Voices are an accepted constant, but it is the content of the voice which would suggest something has gone wrong. So not only has medication cessation moved up and then down Smith's diagram (from *apocalyptic/romantic* to relatively unimportant *low mimesis*), the *presence* of voices has gone from being an unexplored feature of illness to an accepted normality, also from high genre to a mundane one, in what seems like a short period of time. It appears that these changes are altering Lisa's experience of herself and her sense of agency to shape the present and the future in very positive ways. Perhaps she is moving towards Angela's position, and there are some similar elements with Becky,

too. I feel that this is now mostly using the *common human experience* story to think about voices, and that issues of memory are for the moment placed to one side.

In the next chapter I want to explore notions of "hallucinations" and "pseudo hallucinations", and this last section further seeds some of that discussion. It has already been seen that Lisa experiences her voices as commands; now she is reporting a new voice which has a place external to her, and is something which goes a little beyond just sound and is also a presence. Despite a sense that it is related to her thoughts about God she was also quite clear that there was a period at the beginning when she did not recognise it as a voice at all and felt certain it was real, a different agent, which was different to her other experiences of voices, and to an extent continues. She was not entirely comfortable calling it a voice:

Lisa: I think the only thing that worries me slightly is that sometimes...Like with the new voice, which I know I can rationalise is a voice, but at the time I knew... It felt so real – it wasn't a voice, it was my actual maker. It worries me that my mind can get tricked into thinking a certain way. I sometimes don't have control over that. I don't know if that means that you are psychotic? ...I don't know. Even after trying to be very rational about things, there is still something that – something that underpins everything and says this is all very real, it is not a voice, it is real. And I know it's real at the time. I don't know what to do with that.

and a little later:

... think a bit differently now, but when my maker was speaking to me, and I can feel him, and I can still feel him now, I knew that I was going to die. I believed him. I knew. And that's why I started making preparations. I tried to explain to my psychiatrist, and she said "it's the voice", and I was saying, "no it's not, it doesn't feel like – this one's different". It didn't feel like any other voice I have had. Which is why know it's not a voice.

She said that her psychiatrist described it as psychosis. One possible explanation for the difference was that this was somehow induced by steroids, although she had stopped taking them some months prior. I asked her whether she feared that she was going to die because once again I wondered if there might be a more dissociative way of understanding this voice. An interpretive narrative like that would not be difficult to imagine: perhaps it could be that she feared that her life was unending suffering and the voice provided her with a belief that the future would be different and perhaps something was in control, a bit like someone I once worked with who could face the day knowing there was a noose hanging from a beam in the attic. Once again the dissociation story can be reinforced either way, decontesting itself: if she *did* feel she was going to die then the voice could be seen as a dissociated defence against that frightening loss of control, if she *did not* feel she was going to die then perhaps she was dissociated from those fears and the voice took their place.

I think it seems fair to say that her mental health team are struggling to categorise Lisa's difficulties:

Lisa: Well, that is what I am diagnosed with, borderline personality disorder. I don't know if I've still got that. I don't know. My CPN said that I might have depression and anxiety, but that it is good for me to have the borderline personality disorder diagnosis because it means that I get a lot more help.

So, Lisa has "borderline personality disorder", "depression", "anxiety" and experiences "psychosis". I too have been guilty of trying to categorise her voice-hearing in ways which seem to attempt some kind of mastery over her experience. I think (ironically) it was because she at first seemed so vulnerable. In our second recorded meeting I took care to reveal to Lisa that I had allowed myself to be recruited to a narrative in a way that I feel had made it more difficult to hear her actual account, and it was following that admission that we had some of our best conversation about the

relationship between her experiences and voices. I find it a constant struggle to treat people as equals, but I feel Lisa showed me yet again why it is always better to do so. I bumped into her some months later at another critical mental health conference and she greeted me warmly, and introduced me to her partner.

# Pseudo-hallucinations / Hallucinations; Understanding / Explanation

The first four participants have brought this work to an essential question: the opening chapters are designed to open up categories, but is there a central category error throughout this work? Might there be two separate categories of voices which ought not to be conflated?

There exist stories about voice-hearing which, when followed to their conclusions, create two categories of voice-hearing. Within psychiatry one form is described as a genuine medical symptom, the other more usually as a "personality" issue. *Leaving aside all of the questions about the validity of those terms* (my ongoing attempt to avoid devoting words to the validity of the DSM, tackled by so many authors already, e.g. Read et al., 2004, p47), this separation is important because it allows people to argue (as below) that there may be voice-hearers whose experiences are of no relevance to other voice-hearers. This in turn is important because those people may believe that in my choice to recruit to this research *any* self-described "voice-hearer", my participants may not all be experiencing the same phenomenon and that differences between them that either they or I may attribute to *stories* are actually something else.

In one sense, this does not especially matter as this research does not claim to be about all voicehearers. I do not have to suggest that this research shows that hearing voices is a homogenous experience, I am just introducing 12 people and the responsibility of transferability lies with the reader. In another sense, however, it is important, because this story which makes a divide between two kinds of voice-hearers (a) is fascinating and relevant as a potential interaction between stories, (b) forms part of the relationship that all four participants so far have had with mental health services, (c) is going to be part of the reason that some will reject this work.

# The Inman Defence

A typical piece of writing which exploits the idea of two categories of voices is Susan Inman's 2015 Huffington Post article, entitled *What you're not hearing about the Hearing Voices Movement*. In this article she claims that the very fact that voice-hearers have understood their experiences shows that they do not have a mental illness and did not have one. For Inman, use of "non-patient populations" of voice-hearers sheds no light on "the mentally ill", and merely illustrates that there are two kinds of voices; illness ones, and non-illness ones, and not that the same phenomenon can be part of wellness. As such, the HVM is dangerously misguided. She claims:

International research demonstrates that many people experiencing psychosis have anosognosia, a brain-based inability to understand that they are ill.

As such, the message of the HVM is false hope to the genuinely ill and their families, and collusion with their delusions. It is not that the HVM's claim that voice-hearers may understand their experiences is special; *any* phenomenological account of voice-hearing is a problem for a view which says that *psychosis*, by definition, is that which can only be explained (with recourse to sub-personal causes) and not understood (as one human to another, with empathy) which is generally described to be psychiatry's position following the translation of Karl Jasper's opus in 1963, although it has origins in the work of Wilhelm Dilthey (Radden, 2007, pp180 -181). If this notion of psychosis is to be maintained as a viable category, then something must be done about

descriptions of apparently *unpsychotic* psychosis. Two further points Inman makes is that the HVM is blinded by overgeneralisation from personal experience, and that it relies on a "poor standard of research". Neither of these accusations are easy to take from Inman, author of *After her Brain Broke, Helping my Daughter Recover her Sanity* (2010) and someone using the DSM categories two years after their rejection by the NIMH (Insel, 2013).

For me to make a choice to be diagnosis-blind in my research was to court a particular problem: if I found that voice-hearers connected their voices with emotions and found ways of understanding them, then in the eyes of others might I not simply be interviewing those with "borderline personality disorder", or other categories for whom voices are "not psychotic", who had gained a little bit of self-awareness? The Inman Defence? They might, under the logic of that diagnosis, be more likely to volunteer for research than people with other diagnoses, because of a supposed greater/pathological need to be understood, to communicate distress and to be validated through such attention. Perhaps the HVM contains a lot of people with "borderline personality disorder" getting together to describe themselves as victims in new and exhilarating ways? The Inman Defence is probably not finally refutable. However, for it to be valid, (and perhaps this is the argument that may carry most weight) an astonishing number of people might have to be described as having been misdiagnosed with psychosis, so many that it might be difficult for psychiatry to gain any credence through using it. Yet I do not wish to imply that only psychiatrists might stand to gain through the Inman Defence. As explored in the last chapter, voice-hearers themselves may have reasons to uphold separate categories of the experience too, and it is not up to me to disagree. Nevertheless, whenever I hear anyone say that hearing voices is probably not one experience but several kinds (I do, frequently, and I anticipate that some will conclude that this is "the message" of my research) I wonder what narrative work they are about to try to achieve.

With unclear and contested categories it is hard to imagine the research that could inform this debate well. Some might instead argue that "pseudo hallucination" is not the first time that the need for psychosis to remain "ununderstandable" (in Jaspers' sense) has led to the hiving off of a new category; I have heard it suggested that the term PTSD arose from the inability to describe U.S. military veterans as having somehow contracted schizophrenia in Vietnam: understandable apparently non-genetic schizophrenia needed a new name despite the many similarities of "symptoms" (and other fascinating genealogies of current categories which began life in the military exist too, e.g. Kirkland, 2010, p107). I would also like to point to my own experience of working with voice-hearers in mental health services (that is, working in a way which encourages storving of voices), and the moments at which I witnessed psychiatrists reclassifying hallucinations as "pseudo" (or once, "psychogenic") in response to my reports of changes. These are people for whom the category "psychosis" was previously just obvious. Yet targeting the word "pseudo" for critique is also made very difficult by psychiatry itself, which acknowledges that it is an ambiguous category (Berrios and Denning, 1996). I feel that it is a story that psychiatry needs and about which it is simultaneously uncomfortable. I am by no means the first to suggest that the distinction breaks down (Honig et al., 1998a; 1998b, for example).

## Whom does it suit?

The key DNA task might be to ask whom the distinction suits, especially when that distinction is difficult to be precise about. Does it suit voice hearers? Angela described her personality disorder diagnosis as like "being backed against a wall", but at the time she was hiding her voices. Claire found it in some ways validating, for a while at least, although she does not find the distinction "pseudo" to be meaningful. It was unclear how Lisa's experiences should be classified, and yet my feeling was that deciding was not especially important. I do not think the interviews I had shed much light on this. What I think can be said is that we currently have a system which appears to assume that all voice-hearers require "anti-psychotic medication" unless proven otherwise, something my participants certainly experienced in abundance. Is this really less risky than the possibility that some voice-hearers may be damaged through approaches which attempt to discover if new ways of thinking may help? Might current practice be driven more by the need to maintain the narrative *ununderstandable psychosis* than by other kinds of sense? If psychiatrists

cannot claim a continuing expertise for an ununderstandable voice-hearing, then is the need for psychiatrists diminished? If that is so, *who exactly is the medication for*? The ununderstandable view also suits those with something to gain from the idea that society and family relationships cannot explain "genuine" voice-hearing, and that is almost everyone: families and society, biological psychiatry and pharmaceutical industries (Read et al., p79), plus some voice-hearers. Also, as even a brief glance at the critical literature surrounding women, voice-hearing and the diagnosis of borderline personality disorder will testify (Shaw and Proctor (2005) provide a helpful summary of a specific critique of borderline personality disorder, but arguably Lisa Blackman (e.g. 2015) does the most to bring voices into feminist scholarship), forming two categories of voice-hearing might suit men/powerful groups for several reasons, including that downgrading to "pseudo" is a way of making the lack of efficacy of psychiatric treatments the result of *the wrong kind of person rather than the wrong kind of treatment,* and the effectiveness of other approaches, more storied ones, unable to shake the foundations of "standard care": another use of the Inman Defence.

The story of ununderstandability has another aspect, that which Angela Woods describes as something which makes "schizophrenia" a "sublime object"; something which is forever out of reach, just outside the frame (Woods, 2011). This is more than the (very real) concern that a story has been used that allows current practice to be justified by future evidence. It intriguingly describes a something which is presented as a quest for an answer, with the tacit understanding that there can never be an answer. Hearing voices has at some times been seen as almost completely diagnostic of "schizophrenia" but "schizophrenia" is once again *a target on the move* (Hacking, 2013). If this is correct Woods seems to be right and then what *is* psychiatry and its "sublime object"? Another expression of humanity's sense of our own mystery? Or is it less innocent than that? Is it more as Blackman describes: we make a very male and self-serving error; using a variety of stories about the self we de-situate (*dissociate?*) emotions and then (irony of ironies) we describe individuals as having deficits which cause them to be unable to tell the difference between supposedly internally and externally created phenomena (Blackman, 2015, p34)? This debate will return with John.

# Matthew

How do I begin to write about Matthew? So far, I had met people I hoped would be apart from mental health services, either now or in the past, but none of them were. As already mentioned, the results of my efforts to find voice-hearers in the "non-patient population" had been almost farcical. How could I find this promised percentage, apparently as common as left-handers? I decided to go looking in spiritualist churches. After a number of dead-ends, I spoke to the regional secretary for a national spiritualist organisation. Not a spirit-medium herself, she nevertheless made some suggestions and had some phone numbers. Eventually, I met Matthew, in the meeting hall booked each week for a meeting that he holds. There was a circle of chairs and a small CD player. I felt that Matthew was genuine and very likeable, and believed what he was saying. He clearly had a strong desire to help others and did so apparently for its own reward. He has been a spirit-medium for forty years. It was unusual for me to meet someone with his views, although I have known many people with strong religious beliefs.

# Inclusion/exclusion

In a new way Matthew raises again the question of what is *bonafide* voice-hearing, seen in the last chapter. In choosing not to imagine that voice-hearing is necessarily pathological, or leads to a loss of "function", or contact with services, there is no reason to exclude Matthew. He does not primarily self-identify as a "voice-hearer", but then neither does Angela, and there were moments of similarity in their descriptions of voices and altered consciousness. Matthew stretches definitions even further, since it is clear that, although one can certainly quote him in ways that would push a psychiatrist to view his experiences as psychotic and his beliefs about them a "fixed delusional system", he actually sought the experiences out, he deliberately developed them, he views them as an ability. He speaks of them in very different ways to those who identify as "voice-hearers" suggesting questions of whether this is an example of language and narrative re-authoring experience, or just a different experience. Did he develop the ability or was his achievement in finding (or being found by) a narrative to explain it? I tried to ask guestions which might help me to make these differences. I wanted to know whether his experiences were ever unbidden, but realised that this was also inadequate (Angela and Ross also describe an ability to choose to attend to and intensify the voice-hearing experience or not), and he views his experiences so differently that his answer was inconclusive. I wanted to know if his experiences were primarily aural, but voice hearers have already taught me to suspect that this in not a particularly reliable means of knowing the experience (it was also a significant finding of a survey conducted by Woods et al., 2015); Angela made it quite clear that she sometimes saw her experiences in terms akin to possession and Lisa felt the presence of a voice prior, during and after a period when it spoke. Some might object that Matthew's beliefs and experiences are somehow different because they are part of a religious framework. To me this is only to say that they are wrapped up in a different narrative, perhaps one which is shared within a subculture, as are other narratives in this research. That in itself is very interesting, but cannot ultimately make it possible to know whether the experience itself is the same or different.

Therefore, my suggestion is that Matthew presents something exciting: one cannot decide whether he should be included or excluded without allowing oneself to make categorisations which are contestable; in order to know whether Matthew is experiencing something relevant to this study one has to become storied. In a strange way there is also parallels with the willingness to think about "mental phenomena" in terms of stories in the first instance: unless one rejects the idea that "mental illness" is unproblematically a natural science, there is very limited value in DNA and, also, unless one rejects Matthew's version of events (i.e. that he actually is in contact with spirits), there is also little point in asking if it speaks to this research.

My feeling is that his experiences *are* different, but as I question myself I conclude that this rests upon this: for it to be "voice-hearing" it needs to be more rooted in distress in some way. However,

the obvious point is that I should beware the influence of the highly emplotting worlds I am most familiar with; mental health nursing and the HVM, although there are people within the HVM who feel their voices are not at all distressing (at least not now). Also, Matthew suffered childhood anxiety which he says that he tended to perceive as physical ailments, and that becoming a spiritualist and then a medium was in some way part of a healing from this, so that he does make a link of sorts between distress and his experiences. This last detail is one which might be of interest to psychodynamic stories of voice-hearing. If voices can be seen as "transmuted historical trauma" (Blackman, 2016), then perhaps a story might be told that Matthew had a history of "transmuting trauma" prior to acquiring his "gifts", and these "gifts" continue to do the same psychic work. However, I feel uncomfortable about making a mechanism out of Matthew. I ran into trouble in that way with Lisa.

Some of Matthew's stories articulated a growing sense as a young man of other "dimensions", and he told me in detail his experience of watching the 1969 Luna landings. While not disbelieving the importance of these accounts, they are perhaps not directly relevant. I have already mentioned what he told me of his continual childhood nervousness, which he described as causing "psychosomatic pain" although he had "loving parents, a loving family, a settled home life and a good school life". There were certainly moments in which I could imagine that he was using a rehearsed story to explain the truth of this spiritual dimension, but I felt they were not rehearsed primarily for my benefit but for his own. I am no stranger to the logic of miracles and messages from nature<sup>24</sup>. There was also a section of the interview in which Matthew used the argument that is usually labeled the "intelligent design" argument, but it is important for me to remember that none of this is about assessing whether Matthew's beliefs are credible, but rather to try to understand the achievements of the stories with which he is involved.

He then described in detail the circumstances under which he saw a spiritualist healer in his late teens, which was something of a conversion experience. He described it as a moment in which he was able to make sense of his life. He mentioned some of the spiritualist books that he read that became important, meditation and a weekly meeting that he began to attend, and some experiences of very warm feelings running through his body. He described all of this as a kind of message, he also described a period when he would attend spiritualist churches and the visiting medium would have "messages" for him, but my sense was that none of this had much to do with hearing voices. What is perhaps significant about those experiences is that they provide a framework into which unusual mental experiences have an established place.

# Gifts

However, things progressed and Matthew put effort into trying to develop what some might think of as unusual mental states or even "psychosis":

Matthew: ...And I started to develop the gifts I have had. Which had lain dormant, if you like, all my 17 or 18 years until this point. And that's when I started getting what you might call "voices", but what I would call, "contact"... with discarnate minds. And I started to give off messages to other people, to give evidence as it was given to me. It was given to me in the form of words, in the form of pictures, images and feelings.... which appear in the mind... just like the thought appears in your mind – these thoughts – which are very sharp, very real... appear in the mind when you are linking with somebody... and then you give that off afterwards. And they either reject it, or accept it. But also, because I work as a trance medium, there was a guide that I know – well I didn't know at the time – wanted to speak through me. They wanted to speak directly through me. And so that started to develop.... And after about 18 months... They started, this man started to speak through me.

<sup>&</sup>lt;sup>24</sup> See *The time when I heard a voice*, p117

Me:... how is it different from you having... a thought, or remembering a scene... Or something like that? You said it was very sharp?

Matthew: Yeah, very distinct. Very... It's difficult to put into words. It's very distinct, very alive, very... Often very specific.... I'm linking, I'm linking up to the spirit world, the afterlife, another dimension – call it what you will – I'm also linking my mind or my consciousness to him [a person requesting a "reading"]. And I'm asking what - what have you got for him, is there any message... So I don't know who is there or what is there... And I will get something given to me. It could be a name... It could be something that is going on around him in his life, could be some worry, could be that he has just lost someone and they could be back to give evidence, in which case I'll give a description – something that means something only to him and that I wouldn't know about... And that is usually very very strong. I don't have to think about too much it just comes. Now... The difficulty for all mediums is... Having the courage to give it off. Particularly if it is something very very specific. Like, you know, "I've got uncle George here, he lived in Blackpool, or he was a tram driver". That is very specific. And only with experience would a medium have the courage to give that off. Which is why mediums will very often skirt around things, and give information that isn't evidential. You know - "your grandmother loves you very much" - that's not evidence. It has got to be specific. And that comes with development.... So it is - when I do a one-toone reading with somebody, immediately I am trying to... See what is with them, who is with them, who am I picking up here? It's like tuning in a... radio. And sometimes the frequency is very very sharp, it's spot-on, other times it's fuzzy. You can't always guarantee how it is going to be which is why sometimes readings work really well and everything is spot on all the time and other times it's not so good. You know – it's an imperfect science.

*Me:* So... you have that experience – and developing at the same time – from what you were saying is a different experience, of being like a conduit, or spoken through. Can you say what that is like to experience?

Matthew: Yes. As a trance medium... I surrender my consciousness, if you like. It's a little bit like going to sleep. But it's not going to sleep, I'm not asleep. My consciousness is sort of moved aside, if you like... and... the consciousness of... of a mind that works through me – a discarnate mind – I allow that to operate through me.... His consciousness takes over, I – this is very difficult to describe – I want to say I'm aware of it, there is an awareness of this consciousness, of this other consciousness and... I've got to use the word, "I" because I can't describe it, I can hear the words that are spoken through me, and also answers questions that our put to him, and there's an awareness of hearing all of that. So I'm not unconscious. And are not totally... that far removed... but I am removed from myself, if you like.

Me: And is it always the same person?

Matthew: There has been one or two, but it's normally the same person, and he's a teacher, like a spiritual – I won't say a religious teacher because he doesn't say anything religious – he's a spiritual teacher... and he's been with me for... I don't know – how long have I been doing this? 40 years. And the reason that it's always the same one, or so he tells me, is that it takes such a lot of effort and training and work on his behalf to get the... intimate link that is necessary for it to work through me in the way he wants to at that level... and that is necessary for him to maintain that sort of contact. He only works through me when I invite him to. He is not speaking to me like now, he's not there when I am doing the shopping or driving... It's only when he knows that I've got work to do, and he will draw close to me. And I will let him come through.

There were two further parts of this conversation that seem significant. The first is that it was important to Matthew to explain that he had a different sense of the individual to the majority of people. He used the phrase *the interconnectedness of all things*, a cliché perhaps but I thought

that he was quite genuinely trying to explain that he feels there is something damagingly misleading with contemporary conceptions of individuality, that a self can only be understood when seen as situated, and that his experiences have shed light on this for him. The second was that he seemed to protect himself from the accusation that he might be insane by understanding that the way that power works in society is to normalise, to prevent dissenting thought, and that as such being in a minority should never be taken as confirmation of being wrong. Yes, this is certainly Freeden territory for him, but I felt that both of these ideas, about selfhood and about power and normalisation are respected ideas that I myself find important. I cannot feel that Matthew is more in the thrall of a particular narrative than anyone else.

One final thought about Matthew is that he did not talk to me very much about emotions, apart from the insecurities and anxieties he overcame through spiritual healing. Perhaps this is simply because within the spiritualist narrative that he uses to understand his "contact" he is not distressed by his experiences but views them as gifts or achievements. Perhaps Matthew's stories connects to work such as T.M Luhrmann's about different cultures contributing to a different valuing of voices and therefore a different experience (Luhrman et al., 2014)<sup>25</sup>.

I contacted Matthew again six months later, but it seemed unclear to both of us what the purpose of meeting for a second time might be. He told me that we could no longer use the hall. I am very happy to let this short chapter stand as it is and feel extremely grateful for Matthew's involvement.

<sup>&</sup>lt;sup>25</sup> I cannot just mention Luhrmann's work so casually. It was published two years after I began my project and is, in many ways, a cross-cultural anthropological version, seeking to ask some of the same kinds of questions. The research concludes, among other things, that North Americans tend to perceive "psychotic" phenomena as a violation of their mind, whereas other cultures may not have such a strong sense of violation and may understand voices as a kind of gift. Lurhmann's work contributed to Larøi et al. (2014), a multi-authored literature review which makes a similarly strong case for the role of culture in shaping the experience, distress and outcome of "psychosis". It is precisely the kind of work that makes Matthew so difficult to include or exclude. Not long ago I spoke to a man from Gambia (someone with no particular connection to mental health services or knowledge) who said, strikingly, "We have voice-hearing in Gambia. If you don't learn what to do with them they can make you ill".

# Steve

I met Steve in October 2014 at the city-centre offices of a non-statutory mental health service provider. Steve did not respond to requests to meet again and has changed his phone number, so I saw him just one time. I had every indication that he valued our meeting, but it is clear that his life is full of complicated and difficult thoughts that affect his ability to make and keep plans. I also think that there is a sense that he began a narrative with the first interview which seemed powerful at the time but may not have been possible to hold on to.

In thinking about this transcript as stories I will inevitably imbue it with an order which will be misleading. Much of what follows is my summary and I am not certain that Steve would fully recognise this as his own story, although it is all taken from his transcript. The reason for this is to do with selection. Steve is articulate and thoughtful and yet seems very confused, and I was struck that he finds it hard to make the selections that a plot requires. He is suffering horribly. He suffers a stultifying daily crisis of inaction.

It would have been good to have met again, excepting only that as it stands, Steve's contribution to this research is to remind us that so many attempts to view the distress of others is limited by partial information, relationships not yet trusting enough for more and circumstances intervening. Perhaps Steve also reminds me that it is not fair to accuse mental health services as never trying anything beyond constant medication; he has had counselling, psychotherapy, art therapy, hospital admissions *and* constant medications, often at high doses. He has also found his way to a "hearing voices" group outside of the NHS (although seemed to be disengaging from this). Steve told me that talking about the voices with me had made them seem lighter and less problematic and he presented this as a new experience. It does seem a lot to imagine that it can have been a new experience, although others (Claire, Angela, Lisa, Mel and Ross) report years in psychiatry without ever being directly asked about voices (or feeling able to talk about them), so it must be a possibility.

# **People and places**

Steve feels that his voices are linked with his mother, who was emotionally unavailable and highly critical. He especially links the voices to feelings of powerlessness and shame at times when his mother spoke critically of him to other adults, over his head. This link is a little complex in that at first he seems to have heard a comforting and caring voice, helpful and even humorous. It may have been this voice or another that he heard "just inside his ear" encouraging him to "abandon" his mother and her way of viewing him. Somehow (and this was not something he described with any detail) this voice became his mother's critical voice. After psychotherapy, it was no longer his mother's voice and yet the same critical themes were taken up by voices of neighbours and have remained.

Steve: [My mother was] lacking in a kind of empathy and emotional warmth, really. That initially was sort of the basis for my.... Internal dialogue, it was her voice, it was what she used to say which I had kind of internalised. I ended up having... I had some psychotherapy for a while and that did help with that experience of hearing my mum's voice... Telling me what to do, or what I shouldn't do or criticising the - condemning me. That did help with that. I had a bad experience four or five years ago. I had a neighbour who lived in that bit of the house where the voices were coming. And he would shout... sounded like abuse through the walls. He used to knock on the walls. Throw a ball at the walls. There was a room, like here – there was a parting wall on the house, it was a terraced house, and... he'd knock on the floorboards at three in the morning. And he'd slam doors... and was really more or less – it kind of triggered off, well I did go to hospital. I felt like I was being brainwashed and just gradually kind of ground down by – he was not a nice person. And then I was hearing voices about guns and... Jihad and all that kind of stuff. He moved out. And I think that – and have had neighbours moved in since, and I have to say

they've probably been... okay really. I'd like to live in a house where I can't hear the neighbours. That's it. You know, if I'm sitting in peace and quiet – I don't want to experience – like here, you know I can hear people talking outside. I want to be able to sit at home and have no intrusions from people being horrible. And it feels like, I've been in the house for 27 years, and it feels like as time's gone on my sensitivity to my neighbours and my environment has got worse. I moved in when I was about 21, 22. There was a very quiet neighbour who lived next door, an elderly chap, and it was me – I was the bad neighbour! I used to get very kind of upset, I was emotionally distraught, because I was not in a good place really. And I used to throw crockery at the walls. Not against him – just a release of that sort of frustration and anger about my relationship with my parents and friends, relationships that I'd had with people. I used to play music really loud. It just feels like the shoe's on the other foot. My neighbours play – although the music tastes of the current neighbour is kind of all right – it's soothing music, but it is loud. But, you know I generally don't play very much music any more.

The voices of his own "internal voices", his mother, voices he attributes to neighbours but seem to be "voices" (the focus of this thesis), and the actual relationships with neighbours (some of whom have probably been rather anti-social) are not exactly described by Steve as four separate types of experience: they blur into each other. Experience leads me to speculate that this would resolve with more opportunities to discuss his voices, which might suggest that he is right in saying that he has not had much opportunity to talk about them. After a short break near the end of our meeting he said:

Steve: But it feels that they have diminished, being here and talking with you. The voices have diminished in sort of... power.

Me: Right.

Steve: And... Usually when I go out for a cigarette I have sort of... I hear voices out there as well. But it just kind of felt okay today, looking at the sunshine looking at the weeds growing around, you know it's all there really. Not too bad. I just hope that when I go home tonight, I don't have a similar experience to last night.

Steve and his flat are also confusingly and distressingly inter-permeated in his transcript. Bookshelves with books he cannot concentrate upon seem to contain the progress and understanding that is always eluding him, as the clock on the wall marks his 27 years in the same flat, curtains drawn, he creeps around to try to keep the voices quiet, staring at walls. He has no visitors except for mental health professionals. *He said several times that he cannot control his environment and it judges him.* The neighbours' voices "mirror" his internal dialogues. One of the picture-cards he chose was of an ostrich with its head in the sand, which seemed at different times to be him within his flat and then the approach of psychiatry towards him. Despite his feelings of extreme isolation, and despite acknowledging that his voices are much less problematic when in company, the one thing he would really like to do is move to a house on its own in the country, where there was no sound, "no intrusions from people being horrible".

Quite often they mirror. All my internal voices mirrors, or is very similar to the experience of voice hearing – I mean I can't hear what the neighbours are saying, and even when they're not in sometimes it's a voice in the distance that I'll hear. It's just going on and on repetitively... Just being judgemental, being critical, and just sort of repeating the same old kind of thing, in a simple way... It's just sort of grinding me down. It's that – I have that experience when the neighbours are in and I can hear their voices, they start laughing and I can hear the sound of somebody having a kind of grievance and someone laughing about it, and it's the intonation or the feeling that I get about that kind of animosity or anger. Not feeling safe really. It's just like bad feeling. My mum was... my mum would get very critical and judgemental, and not really see much good. I've not really seen my mum for a long time....

... It doesn't feel positive or safe.... and it doesn't feel private....

... My neighbours used to stand in their backyard but... I was hearing voices that were saying that if I didn't kill myself they would murder me. They talked about how they were going to do that, put me in a suitcase, dump me in the canal or take me to a quarry... These kind of archetypal things you see in films really, but it got me frightened.

...I mean I'm 47 now and I think when I first came into contact with... in fact I went to my GP when I was about 14 and complained of sort of... not really having a bit of an identity problem, not really knowing who I was... and sort of depressed... and not really knowing, just sort of feeling quite confused and... but I think that... he said come back when you're a bit older, which I did do, and he sort of referred me to the [place name] counselling centre. At that point I started doing a foundation course, for university... but I became quite ill, although they didn't kind of realise, and looking back I was kind of psychotic. My behaviour was a bit odd... That's when I came into contact with psychiatric services, around then. I had a breakdown. I just couldn't cope any more. And in my experience... I have taken – I took LSD in my sort of late teenage years, and the experience of psychosis was far worse than anything I had experienced on LSD. It was horrible. It was really frightening... I just needed help [laughs].

# Storying

There are a number of contributions that Steve makes to this DNA. Firstly, however difficult it was to understand, and with a feeling that it is very difficult to say much about him without risking too much "tidying" of his transcript, Steve said that the interview seemed beneficial, that it led to a reduction in the power of the voices. Since we only had one interaction I do not know how long this lasted.

Steve was full of existential questions, images and details, but very few narratives. If intentional action becomes possible "under a description" (Anscombe, 1979) then Steve's many descriptions are not providing him with much agency. He is very stuck. He really enjoyed the use of picture cards (and asked me if I knew how he could get hold of a set) and commented that *he could have told a story about every card* (I set out about fifty to choose from). To me, he was an intelligent and creative man who cannot find a unifying set of themes; he had many fragments of stories, memories and ideas, but few organising narratives. Prior to beginning the research I had wondered if some people with less narrative would find it difficult to relate to the cards (I had some thought about people being more or less "visual", too). In fact, everyone liked the cards, but I did not expect a kind of opposite difficulty: that being connected to fewer narratives could lead a person to choose too many cards. I think Steve had this difficulty, and John and Rosie too, as will be seen. I think Steve was right in his phrase "identity crisis". It seems to me that if you can tell a story about every card but perhaps find it hard to say which are the most important, then you may have trouble with a sense of self. Michael White says that we need a "frame of intelligibility" that "makes the attribution of meaning possible" (White, 1995, p13).

There is an interesting question about the psychotherapy that Steve undertook. It was able, perhaps indirectly, to alter Steve's experience of his main critical voice, the voice of his mother, so that it went away. However, the same content was then taken up by new voices, and has remained. It would be very interesting to understand this more. Does this mean that Steve was able to alter his understandings about his relationship with his mother, but not alter the way in which he feels towards himself? Or does that question presuppose too much? One of the interesting parts of Claire's story is that she was helped through psychotherapy, during which she made efforts to accept and understand her emotions and then could mount a resistance to her voices. So far, Becky, Claire, Angela, Lisa, and Steve have given this research clear indications that emotions and voices can be linked, with Becky, Claire, Angela, and Lisa all containing thoughts which range from strong ideas to very coherent personal models about this. With Steve

things are unclear, but as this thesis moves from the first six relationships to the second six, it seems that we have already had some tantalising glimpses of stories which link emotions and voices. More than that, there is a very strong sense of agreement with the notion that stories alter the experiences of those performing them, even when the story seems to be restricted to just one conversation. The clear point is that telling stories is never "data collection". As we tell stories we become differently recruited into them, some may increase in genre while others may decrease: movements on Smith's chart.

However, it would be doing Steve an injustice to turn his account into something so hopeful. There is the concern that there is simply nothing going on which suggests anything more positive for the next 27 years. If we add to this the questions about medication and iatrogenic harm which have already been raised, and given that two of the medications Steve takes he has been taking now for 20 years, it really seems uncertain that anyone, least of all Steve, can be imagining a very different future.

Steve: and, there was another – a different type of voice – but it was... I have a noise that goes on in my head. It's coming from sort of inside my ear. It was... saying, "kill her, cherish me, we love our children, we live for our children". It wasn't about me, emotionally – not kill someone – it was my mum, it was about my mum... and it was this female, it was the female voice that was sort of saying, you know, 'abandon your mum'.

### Me: Right.

Steve... "And listen to me". You know, "we are caring people, we're not going to...". Which I guess was... I discussed that at my sort of first appointments with the psychiatrist.... It just seems that a lot of my career in the mental health services has been about – initially for the first sort of 10 years – was about taking tablets, and kind of ignoring the messages that I was sort of having.... It was now just sort of... I don't really know... I've got a bit lost.

# John

My thought about this began with a beautiful idea of the geographer David Harvey. Harvey writes fabulously polemical books about how globalization affects people's visceral lives. In Spaces of Hope, Harvey writes that under capitalism sickness is defined as the inability to work. When I first read that thought, I could not breathe in the face of its profound truth. Anna Kirkland, 2010, p28

*Me: Okay. I'm going to start the recording.... I'm just going to put away these other cards. Thank you so much for agreeing to do this.* 

John: I've picked seven, in the end.

CARD 1	A fishing rod	He sees himself as hanging on the end of a line, dangling over a cliff, and abbyss. At the end of his tether.
CARD 2	Stone pillars	He is a ruin, like the Roman Coliseum. No future. "heading downwards all decaying and worse". Except for other people, people with money, they would look at the card at say, "that's my next holiday destination".
CARD 3	A row of doors	"Endless doors, all slamming in my face You're born into the poverty tribes, you ain't got money, and looks. That's all you ever experience. Doors slamming in your face Bye bye, not today. "
CARD 4	A canoe	"I'm up the creek. Without a paddle. The bloke who was on the boat, he's disappeared as well. That's why I picked that one. That also described my life. Fate is forced on you."
CARD 5	Barbed wire	"It reminds me of workfare, warfare. It reminds me of just how the government these days, this jack-booted Nazi bunch of scum that's got into power, they are forcing us all into like Well it's just like industrial conscription, really, init? Just forcing everybody into the nearest crappest job".
CARD 6	Test tubes	John feels his life is a medical experiment
CARD 7	-	John seemed to have lost the remaining card.

I have so far mentioned two things about John. The first that there is something that links Angela's account to this, something to do with a "government of individualization". The second was my speculation that fewer narratives might make it more difficult to choose between cards. John picked 7 cards, and would have picked more had I not discouraged him, but they were all utilised to tell the essentially same story. Not only was the story mostly repeated with successive cards, but John repeated phrases many times within each explanation. John activated a story within me which required constant and irritating effort to suppress during the interview. There are many names for this story, but I will use one that is important to nurses and I have used the most in the past: *externalised locus of control*<sup>26</sup>. John's story significantly altered who and what could be viewed as responsible for his difficulties, in particular it removed himself. As a researcher I could simply listen, but as a nurse I would have been deliberately asking questions attempting to lead to a plan of personal action and increased personal responsibility. I would have used "Socratic

<sup>&</sup>lt;sup>26</sup> *Loci of control* is a concept I understand comes from Julian Rotter in 1954, but I have never read the original, just absorbed it as part of nursing culture.

questions", "Motivational Interviewing" (Miller and Rollnick, 2002), scaling questions from Solution Focussed Therapy (the text I used was Quick, 2007) and other skills to do so. Between 2008 and 2010 I used *The Recovery Star* (Triangle Consulting, 2016, first published 2008). I saw myself as a change-agent, in fact, that was precisely the language I used.

In presenting John mostly by way of a table and just a few selected quotes, I do not wish to suggest that he himself is summarised in that way, but only the stories he told me. He spoke intensively about class, money and betrayal. I do not know what other experiences he may have had. I do not know what other traumas he may have experienced or witnessed. I do not know what effect meeting me, a well-spoken younger man with a sense of purpose, had for him. This one interview was all he gave to the project, absenting himself from further contact. I am, however, hugely grateful to John for the controversy he makes so visible. I wish this chapter contained more of him. Perhaps I will get to ask him what he thinks of it one day.

# Self Reliance?

In October 2015 I wrote an essay for the Critical Mental Health Nurses' Network website about whether mental health and self-reliance were synonymous (Gadsby, 2015). Ten hours later over a thousand people had read it. John brings to this thesis one of the most important discussions taking place within the field of mental health. If we are to understand the place of John in this work, I believe that this is the analysis that is required. These stories I now want to explore could raise John as uniquely insightful, so it seems very important to focus on how stories could have that much power. I also admit that it is the dialogue between these stories which causes me the most trouble. Yet at the heart of this is perhaps the single biggest driving fear of all stories about mental health: fear of blame.

My role as a mental health nurse has undoubtedly emplotted me towards equating mental health with personal responsibility, self-reliance and personal agency; seeing *health* as synonymous with an "internal locus of control". Looking back at my map of experience, and seeing mental health services as dominated by views which suggest experience is driven from inside to outside, this is unsurprising. I think it is important to notice that this idea of responsibility and self-reliance cuts across both medicalised and less medicalised ways of working in nursing culture. If you are "ill" you need to be trained to "manage your symptoms" (after accepting an illness model) and if you are not "ill" then you need to be shown "boundaries" designed to encourage you to take responsibility for yourself. Either way, mental health nurses find promoting self-responsibility to be essential. An idea to understand the spread of narratives which are acceptable is the Overton Window. This is a metaphorical window that frames the cluster of ideas in politics which are considered sensible or "beyond the pale" (McCarthy-Jones, 2015, p45). I recently told a fellow nurse that I was against the reintroduction of uniforms in mental health settings, because I felt it would bolster the "an illness like any other" viewpoint. The nurse stared and me and said she would not even dignify that comment with a response. I realised that what I had said was, for her, immoral. I was, as she put it, denying the reality of "mental illness"; I was outside of her Overton Window. With John, it is my own response which I feel helps me see the Overton Window. I have been indoctrinated to believe that externalising problem narratives is unhealthy. When I first read it in Michael White's work (White & Epston, 1990, p16) I honestly thought I had read the sentence wrong: he meant internalise the problem narrative, surely?

However, in fact it is probably John who can call upon the most persuasive arguments to support his views. On my map of experience, John is on the extreme right-hand side. He may not know it, but he is joined there by a growing number of critical health professionals and academics. Many of those make three frequent citations for their views. The first is *The Spirit Level* (Wilkinson & Pickett, 2010). In this and subsequent work, the authors use metadata to argue that poor (physical and mental) health is strongly linked to inequality. The second is Peter Sedgwick's *Psycho-politics* (1982), which is seeing something of a resurgence at present, and speaks directly to questions of individualism and collectivism, internal vs external perspectives (see Thomas, 2016, p5, for example). Thirdly is the psychologist David Smail. In the multi-authored volume, Madness Contested: Power and Practice (Coles et al., 2013) Smail is cited in almost every chapter. In November 2015 the British Psychological Society devoted an entire conference to his legacy.

John: 54 years... 54 years, and nothing but troubles, problems, failures.... There's one... endless disaster after another. And then a year ago there... ended with the workfare thing, and then that just sent me AWOL – over the edge kind of thing.... Chucking me off into like a... I've suffered... Seriously bad depressions in my 20s – but the workfare of about a year ago, that triggered me off into like a fatal level of depression. I'd never known that level of depression ever before. And that's why I see myself at the end of that fishing rod, that dangling over the edge... at risk of falling off, plummeting down. That's why I picked that card.

John will not have read Wilkinson and Pickett and it is not fair to say that John is *performing Smail*. Yet he is thinking with the same kind of story, that distal power (class, money, government policy, birth-lottery) plays the defining role in his experience, as will be seen.

### Smail

That Smail is of interest to a DNA (asking whom stories suit) can be seen through quotations such as this:

"A person is thus located in a field of power which s/he both absorbs and transmits, and from which s/he cannot be abstracted as an individual able somehow to choose or decide how to relate to the field of power independently of it's influence. Our experience of being permeated by social power necessarily imparts the illusion that we originate action, but, in fact, we would more accurately be characterised as loci in social space through which power flows" (Smail, 2001, p228).

The "illusion" to which Smail refers he describes as "the most difficult and profound paradox of human existence" (2001, p229): we live as if we are able to originate action, and as if the actions and events close to us are the most shaping of us, when in fact it is what occurs most distally, *over the power horizon* which is most defining. This seems very much at ease with Frank's socionarratology and here too is Dennett, saying that "mostly the stories spin us, not the other way around" (1993, loc 7777). Smail finds a person to be "an interaction of a body with the world" (228). Dennett (with a wonderful metaphor) adds that the self is "the centre of narrative gravity".

Hence Smail rejects sub-personal accounts of experience (accepting that it is in the body that distal power is mediated) and many accounts I label as "personal". His views take him past "systemic" (which he would still consider to be rather proximal) into "super-systemic". In doing so he undoubtedly moves towards the radical left of politics; he specifically criticises Thatcherism and I would say *he counters Thatcher's non-existent society with a non-existent individual*. Frank may be more material than this, saying that "...stories compel because they express in narrative form what begins in bodies" (2012, p81), although he undoubtedly sees narratives as something which also originate far beyond us too. Smail places the body as the site in which power is felt, saying in his "Social Materialist Manifesto" that "distress arises from the outside inwards" (Midlands Psychology Group, 2012).

John:...If you are born into... the poverty tribes... a big part of it is money. Success has got many fathers, failure is an orphan. If you have clearly got money and looks... Looks plays a part in it as well, but they are very closely linked, money and looks, they are almost the same thing. Laugh and the world laughs with you. If you're a winner, everybody wants to know you. If you're a loser nobody wants to know you. Won't touch it with a barge pole. Money is the new god in countries like this nowadays. So, if you ain't got money, you're history. Won't touch you with a barge pole. About the only places that will have you... Places for the mentally ill, or places like this. If you ain't got money or success. You're history. Nobody wants to know you, you will end up like me. In the last few years, especially the last year or two, I've seen... This crisis has descended on me. I've joined not only this one, but a dozen other mental illness clubs. And as I joined them, the weirdest thing has happened. At long last, I have actually come across kids I went to school with.

They will have a second rate, face, body everything. The wallet – they tend to inherit second-rate everything.

The nurse in me kept wondering: is this a story which helps John much? It might be illusory to imagine ourselves as agents but, with his focus on distal power, it seems hard to know what John can do about anything. What could be written on a care-plan? However, Smail gives us reason to re-examine narratives in which proximal power becomes the focus through pragmatism: it is a key driver for the growth of "therapy" (both psychiatric and psychological) and it suits those in power very well indeed. My instinct, to push John leftwards on my map, is therefore suspect, for all that it may contain phrases like "person-centred" and "solution focussed" and "practical".

# Wilde and Rowntree

It is not as if these are new arguments. In 1891 Oscar Wilde wrote that the idea that the poor should be grateful for charity ("a ridiculously inadequate mode of partial restitution") was grotesque, and in his typical style argued that this included exhibiting virtues (hard work, thriftiness) because this would imply an acceptance and collusion with the economic and social ideologies which made them poor (Wilde, 2011, p3). Earlier still, in 1865, Joseph Rowntree wrote, "Charity as ordinarily practised, the charity of endowment, the charity of emotion, the charity which takes the place of justice, creates much of the misery which it relieves, but does not relieve all the misery it creates". In this view he was nothing but consistent: some forty years later he wrote:

Much of current philanthropical effort is directed to remedying the more superficial manifestations of weakness and evil, while little thought or effort is directed to search out their underlying causes. The soup kitchen in York never has difficulty in obtaining financial aid, but an enquiry into the extent and causes of poverty would enlist little support. Joseph Rowntree, 1904, cited Quaker Faith and Practice (2009, ch23)

One suspects that Wilde and Rowntree would have said precisely the same about the distress in society now known as "mental illness" (and indeed, the second Rowntree quotation brings us tantalisingly close, and the trust he founded produces data today which is of great interest to mental health activists in the UK): that requiring people to feel better, to work towards improving their own distress, to take responsibility for it, is tantamount to making them collude with the oppressive systems of power causing it. Later in his essay, Wilde remarks that the word *unhealthy* is "such an interesting word that those who use it do not know what it means" (2011, p12): not a bad summary of Kirkland's book, cited above, and words which now echo in my head every single time I hear either "healthy" or "unhealthy". Feminist literature also adds greatly to this, or perhaps it would be better to say it is not so much an addition as an alternative. Lisa Blackman has produced a number of important documents about hearing voices, but one of her most recent she describes as "within feminist and queer debates that have re-posed so-called negative states of being as offering productive possibilities for political practice and social transformation". Such a point of view can transpose "how do I feel?" into "how does capitalism feel?" (Blackman, 2015, p25).

Ultimately, for Smail, power is not found by "abstracting" a body from the world, because power is a part of the social world. All psychotherapies are suspect because they rely on the idea of personal "will". Yet that instinct is not wholly wrong either:

The idea that we have "free will" thus derives from the experience most of us have had of being able to exercise a certain amount of power. Because we are especially intimately acquainted with the sensations of our own bodies (and may well be ignorant of the source and nature of the powers we sometimes transmit), we mistakenly identify the feelings which accompany the exercise of power as its origination, and we call this "will". Since we cannot choose not to have such feelings, it seems reasonable to suggest that "will" is a necessary illusion. (Smail, 2001, p229)

### Illusory and necessary

What we find in proximal stories may be both illusory *and* necessary: necessary for identity and for action. For me, this is a horrifying realisation (I remember the very moment and location of it, after reading Frank's *Letting Stories Breathe*). John's powerfully monological narrative brings everything under one banner, making personal agency seem impossible, evoking the thought that if on the left of the continuum one is a victim of one's biology, on the right one is a victim of society. John may be right to use a story which casts himself mostly as a bystander since personal agency is a very contested concept, *but he is a person and persons seem to need at least the illusion of it to be able to be and to act.* Is keeping "mentally healthy" (Wilde again) somehow about keeping up this illusion? But how far can we allow this illusion to grow, to dictate, even? There must be a growing suspicion that if there does seem to be a lure towards this "distraction" then it is something which suits the powerful (not simply powerful people, but the most powerful narratives) very well indeed. Mental health is then subject to the same arguments against achievement under "meritocracy": it appears to be a personal attribute only with the most cursory of examinations.

Such Foucauldian suspicions about whether mental health services are a machinery to maintain a status quo leads to thoughts about what we might expect to see if this were the case: we would expect "illness" and "wellness" (to locate the problems of power structures within the bodies of persons), "resilience" and "coping" (to create the virtues to prevent genuine resistance and understanding of the origins of our experiences). We would expect a message that it is not embarrassing to talk about our "mental illness" ("destigmatisation", a means of propaganda), that mental health services can offer you "individualised care" (how ironic that seems now), that you may need drugs, that you may need therapy, but that you can learn to stand on your own feet once more. We would expect everything that individualises experience and keeps our focus on Smail's proximal. Here is Wilde's revulsion of the "virtuous poor", required to collude with their own oppression, in the "unresilient" worker *investing in themselves* by taking an anger *management* course. Beyond this low-mimesis business language (Smith, 2010), we would expect the whole institution to be called something that sounded positive and kind but was really a rebranding, an Orwellian doublespeak: how about mental health? Two words which mean nothing at all precise and yet sound uncontroversially positive; so interesting that those who use them do not know what they mean?

# **Emotions and coping**

"Emotion" is altered by Smail: it would already be partisan to use words such as "anger", "anxiety" etc, because they facilitate the abstraction of an individual from the field of power s/he both absorbs and transmits. The obvious way to use these words is my anxiety, his/her anger. Perhaps even distress makes this path too easy, although it does seem to carry the notion that the experience was not formed in a vacuum. I have introduced John, his narrative has perhaps felt hijacked with this crucial wider discussion and I have made it seem as though it is only now that these things become relevant to this research: not so. I read Smail in January 2013 at the time I was trying to decide how to approach emotions in this project. As mentioned in earlier chapters I had been reading a lot about emotions and especially "coping" from Lazarus and Folkman. Perhaps I could use one of a number of "coping" questionnaires? Suddenly I felt I should discard all of that reading. The way in which Smail introduced me to the individualisation of distress was a significant factor in the design of my political map. Pre-Smail I could not possibly have understood Steven Coles' statement that psychiatry and psychology may be a "hard spot the difference" (Coles et al., 2013, p114). As I nurse I always thought psychology was the antidote to the excesses of psychiatry, and I know that is a common nursing trope, but Coles refers to it as "the magician's assistant" (p111), since both individualise distress. As for coping: John, Wilkinson and Pickett, Smail and others who are found on the right of my experience map would ask how it was that we came to see coping as the necessary action towards emotions. Keep Calm and Carry On? Or Get Angry and Fight Back?

## **Kirkland and Masco**

The the most chilling chapter in all of the reading I have done during this research connects John, Smail and power in ways which I believe could not be described as "evidenced" and yet seems crucial. I'm not going to pretend that as a Quaker it did not move me in other ways too.

Anna Kirkland, the book's editor, introduced the volume, *Against Health: How Health became the new morality*:

From a Foucauldian perspective, American society's incessant talk about health produces and regulates itself and its subjects, while making it increasingly difficult to get outside of health. Such biopower subjugates utterances that we do not agree with and utterances that we do, both of which serve to remove us ever more from the possibility of real resistance. (Kirkland, 2010, p4)

These views clearly cement the book as one which views health as parochial/interactive/historical. In Joseph Masco's chapter I found this:

Such emotional management required a two-pronged approach. First, citizens were asked to "take responsibility for their own survival." Second, enemy status was displaced from nuclear war onto public panic, such that the main threat was perceived as inappropriate reactions to detonation, rather than to the bomb itself.

(Masco, in Kirkland, 2010, p180)

Masco is describing the manner in which the nuclear threat (a pinnacle of external threat, now perhaps rivalled by climate change) was recreated from the 1950s as a personal and individual problem, finding itself in the need to control one's feelings of panic; panic being the real enemy. The chapter explores the methods by which this (and acceptance of the irradiation of testing) was achieved and charts the rise of the use of anti-psychotic medication during the same period. The "civilian soldier", it seemed, brought mental experiences more common within the military to the general population. It is, of course, impossible to evidence the claim that the growth of the nuclear deterrent and the use of anti-psychotics are causally bound together; there must be too many factors to confound any bold statement about the two. Yet with all of its attendant understandings about the technologies involved to make individuals responsible for managing their emotions (such as government information television about panic, drills in schools and even nuclear tests which showed that a freshly painted house with a tidy garden reflected heat the best) it is a narrative I cannot seem to shake; it has me returning to it over and over as a means to understand just how it might be that distal and proximal powers may work, as well as the relationship between the modern neoliberal state, war and individualism. I find it speaks to me of a kind of mass dissociation required to live under such extraordinary threat each day. That those who cannot successfully achieve this are then "ill" seems incredible. Now I am connected to guestions about whether being "well-adjusted" in such a society is any kind of health at all. And what does it mean to have been part of the system which has nursed it into being? Does part of the relative absence within psychiatry of the idea of voices as dissociation have something to do with psychiatry being a tool to increase dissociation in society? And this sudden opening out of the idea of dissociation, from being the psychological mechanism described by Claire and Angela to being something which might occur at societal level reveals that so far I have not viewed dissociation as a story. Yet surely, that is what it is: an emplotment method, writing in or writing out for a purpose, with varying levels of consciousness. Here dissociation is something more like the target of E.M. Forster's only connect (Forster, 2012) rather than a personal mental phenomenon.

This is a perspective so far from where I started, and so inflated on Smith's chart (it could hardly be more morally polarised, more global in reach, or describe more sinister powers of action) that it seems to compel me to run away from mental health nursing. On May 8th, 2015, I was in London for a conference about emotions. The morning election results had left me stunned. I looked

around me on the Underground at the commuters and felt the most powerless I have ever felt in my life. I left the conference early and walked through drizzle from Southbank up to Charing Cross. At about 4pm I found myself standing outside Downing Street. There was some kind of armed forces memorial crowd further down Whitehall, but in front of the railings of Downing Street it was quiet, more open, with a line of about twenty policemen. I stood facing them, staring. I was thinking about Masco, about war, Harvey, Syria, Calais, Smail, and about some of my participants, about inequality and choices... I felt rage fizzing through my limbs. I felt dangerous. It was very frightening.

Within John this set of narratives, which contain Smail, Kirkland, Masco (with Foucault arguably the founding-father of the idea that health is a discourse of power) seems to find an explanation that is powerful and yet unhelpful. Narratives John may need are struggling to hold their own: Smail's necessary illusion. I am also found at the intersection of powerful stories which make it seem one minute that I am performing the role of an oppressive state using concepts of "health" to judge John, part of Foucault's "government of individualization", and the next that I am being drawn into a set of radical sociological views which might serve to further disable John as an individual. Yet even the phrase "further disable John as an individual" can be valued positively within that story! Perhaps John is indeed part of a medical experiment, that the place to start to help John is not so much with his own thoughts and feelings but rather with the *jack-booted Nazi bunch of scum;* that the object to be nursed into health is society. Perhaps Wendell Berry is right that the smallest unit of health is a community (cited Goodman, 2015, 1011), in fact, I feel certain of it. But perhaps John could be happier if he *also* developed the illusion, the narrative habit, of an internal locus of control; "[s]aying that capitalism ... is the problem does not help me get up in the morning" (Svetkovich, cited Blackman, 2015, p29).

Before giving John the final word, I defer once again to Michael White, who, as ever, seems to have anticipated my difficulties, and in this he critiques Smail's undoubted insights, too:

This idea about stories living us is a significant part of the equation. However... if the idea that stories "live us"... leads to the notion that persons go about life rather mindlessly reenacting or reproducing their stories, then I think that it is a problematic idea. Stories provide the frames that make it possible for us to interpret our experience, and these acts of interpretation are achievements that we take an active part in. Also, a single story cannot live us in any complete sense because there isn't any single story of life that is free from ambiguities, contradiction, and that can handle all of the contingencies in life. These ambiguities, contradictions and contingencies stretch our meaning-making resources. We work really hard to resolve or make sense of these contradictions and ambiguities... to make sense out of significant experiences that cannot be so readily interpreted through the dominant stories we have about our lives, to make meaning out of experiences that threaten to leave us flummoxed or confused or puzzled. In this process we often elevate or invoke some of the sub-stories of our lives, and it is this multi-storied nature of life that requires at least a degree of active mediation on our behalf (White, 1995, p15).

Me: Thank you. I'm glad that we used the cards, and that you did relate to quite a few of them. I'm thinking a bit about... Well, one thing that you haven't mentioned at all, and that is... is hearing voices. And I wonder... If you could just tell me a bit about that?

John: Well, hearing voices... I get that when I start to feel at my lowest ebb each day. Especially when I wake up. I think that's probably the worst time. That's when I start getting visions and hearing voices. Start getting the urge to do myself in again.... It's... It's a huge hurdle to overcome. All of a sudden, you come round and its.... Again. Each day. The past, the present and the future. That's the worst bit of the day. So... you start getting visions, little voices telling you to do horrible things to yourself. And it gets worse, and they tell you to – urgently, they tell you to do that stuff to yourself.... Some of the therapy I have had here... I've had meditation, dozens of different groups here, and at various other mental illness clubs I've been to, the confidence building classes, the meditation, a dozen different classes, talking therapy... CBT... they tell me that the devil makes work for idle hands. But when it comes to minds, the devil is 100 times more active there. He definitely makes work for idle minds. And at the key to this mental illness is, never be idle. Because if you're idle, that's when visions and voices come into your head and start trying to convince you to do horrible things to yourself again. ...And it can be extremely hard to find any reason... to see any reason to go on in life. You get such an extreme level of depression... it literally knocks you out. Can't get out of bed. That's when the depression reaches its worst level. You start getting voices in your head telling you... What type of life you've had, what type of life you've got. You compare yourself to others and that.

...I had suicide attempts in my early 20s when they first came on me. Somehow I managed to survive them. I went on through my 20s – I had like a woodwork job after a while as I got to my late 20s... I realised I was looking at 50 years on a building site, minimum wage basically.... job insecurity – it's massive! Those jobs... like a football manager's job. Because the job insecurity is so massive, it's more stressful, and you get laid off, made redundant here, laid off there, you put on short-time working somewhere else, you are always being let go, made redundant in one way or another, jobs are like that. one of the times I was on the dole... By that point I was doing agency work, doing odds and ends, bits and bobs and dribs and drabs of work, here there and everywhere, and... One of the many countless times they put me back on the dole, put me out of work again, I thought God what's the point of getting back into work, weeks went by, months went by... it eventually turned into 24 years. On the dole. For me. 24 years on the dole. Since I was 30. Once you are on the dole, time can fly past. Time flies....Yeah, that's what happened in my 20s.

## Jenny

#### Well, it's schizophrenia, isn't it?

From the beginning of the first interview, Jenny described herself as having an illness, spanning back more than twenty years.

Me: First of all, what is the illness? What is – Jenny: Well, it's schizophrenia, isn't it? I know that much!... But I don't know how the voices connect... Am I really hearing these voices, or is it just the illness? That's what I can't – I can't clarify.

This exchange contains several aspects which were reflected throughout. The first is the label, "schizophrenia", and the sense that it has been applied as expert outside knowledge. When I questioned her about it she seemed surprised, surely I must know that voices mean "schizophrenia"? And I surely cannot imagine that she does not? However, the second part, *how the voices connect* seemed not to be new puzzle brought about through very recent contact with a HVM group but a long-standing question about whether voices can or should be meaningful or understandable in some way. The third part, whether the voices are "real" or "just the illness" seems to relate to not being believed, that psychiatry by its nature seemed to be set up as a counter to her reality: again, more of that theme below. The final statement reflected her sense throughout that she found it very hard to reconcile the different ways of thinking.

Me: When did... This word "schizophrenia" first... come into your life?

Jenny: Mid-twenties... Because I was put on some tablets. And they said, "can help schizophrenia". And I said to the nurse... "I haven't got that schizophrenia have I?" She said, "Yes you have".... And one psychiatrist... difficult to talk to her... because she said... "I'm not saying you're lying but... these voices aren't really there". And I was trying to battle through that, saying, "well... I feel these voices are... in my mind and they are stopping me from going out." There was one point when I wouldn't go out at all – every day – I'd stay at home, stay in bed late, wouldn't want to go out at all – had to force myself. But when I went on, when I started volunteering, it gave me something to get up for and it was part of my recuperation because I sort of had a nervous breakdown... in my late 20s.... So I've been seeing a psychiatrist – different ones – for over – nearly – 20 years. But... Because I'm finding out that I'm not the only one it's... It's refreshing to know that they have also experienced these voices. And some people say they talk to their voices. I just try to avoid people. So I won't actually know whether they're actually saying anything or not. But it's usually when I am upset, and not 100% fit. Some of the time I just... I go out they are worse out than when I am inside but... Sometimes it can be vice versa.

I find it difficult to think about Jenny without noticing all of the statements she made in which it seemed that knowledge had been applied to her, in a way that seemed to invalidate her own thoughts, questions and experiences. In addition to earlier remarks about diagnosis, it seems particularly relevant to mention the sense in which diagnosis is "characterisation": "by transforming a particular malady into a general exemplar", (Sadler in Radden, 2007, p167), the focus of study is changed from one person to a selected group. This "permits scientific enquiry, indeed, is a condition upon which scientific investigation of illness depends" (ibid). Diagnosis is once again seen as a powerful story in Jenny.

Perhaps it is the juxtaposition with John, but I also found it ironic that several times she referred to herself as being a negative person and yet this was in contrast to her considerable commitments to charity work and volunteer roles, her general enjoyment of people and socialising, the value she placed on her relationships with her mother and friends, and taking physical exercise; yet she

described herself as the originator of problems. Later in the interview she clarified that being *negative* meant being interested in the voices, wondering if they were meaningful, being interested in other people's experiences of voices. Being positive was being clear that they are not "true". My understanding of this is that her story links the psychiatric concept of *insight* (which was not a word either of us used) to being positive and virtuous. It was statements like this that push me to trust my impression that Jenny is very much under the influence of an ideology which not only tries to invalidate her experiences and self-knowledge, but turn that denial into a virtue: Michael Freeden again.

Jenny: My first [psychiatrist], I must have had her for about three or four years. Then she had to go elsewhere. Then I have had a few male psychiatrists that have been just short-term. As the latest one, I just saw him in October for the first time. So he's upped my meds.

Me: He's increased them?

Jenny: Yes. So... That... He's... very nice. They have all been really lovely.

*Me: Has he increased them, do you think, because he hopes that they will stop the voices more?* 

Jenny: I think so.

*Me: Does medication change the voices? Does it change your emotions? How does it affect things?* 

Jenny: Well I'm still on medication, I think I will be for the foreseeable future.... Well, they help to a certain extent.... But I think I have always been a negative person, but I try not to be. I try to involve myself in things, so I don't think about the voices.... Are they really there? Or is it... in my... mental capacity?

Me: Do you talk to your voices?

Jenny: No.

Me: What would happen if you did?

Jenny: I think I'd end up going barmy!

Me: ... I know that you come to a hearing voices group -

Jenny: Highlight of the week!

Me: And you talk about voices, there, do you? What do you talk about in that group?

Jenny: Various different voices that I have, but because we are all the same in that room, because we have all got our own troubles and voices that are affecting us it's nice that we are all normal. Even though we've got mental health problems. There is nothing wrong with us physically, it's all in – inside. And because it's a small group you can... talk very easily. Because the group of people, even though they have got health problems – they hear voices – they are really nice, friendly happy people. So, if ever I've had a bad – say I've had a bad Thursday. And I wake up the next morning and think, "oh I'm going to see such and such today, that will be great!" And an hour and a half, it soon goes, because we all involved in what all of us have to say. and it – it gives you a light relief. And I work Friday afternoons at the [name of charity shop] so I always look forward to going there. I've got some close friends who work there too. But then, when I am ready to come home, I am ready, because I know I've had a good day. Me: Does talking about your voices change the way they feel?

Jenny: No, I don't think so.

*Me:* You mentioned that having everybody together is really good. When you talk about your voices, does it help you in some way?

Jenny: Yeah.

Me: How does it help?

Jenny: Because I'm not the only one. [short silence].

Jenny felt that voices did have a link to her experiences. The first is that she volunteered that they started in the context of a relationship breakup in her twenties. She also said that the voices "escalated" when she was "feeling down", when she has had poor sleep or when she is physically unwell, or during periods of low confidence. The content of the voices could change, so that they "turned against her" at such times and were "really malicious".

Me: Do you feel hopeful?

Jenny: I do.

*Me: Have you always felt hopeful?* 

Jenny: No.

Me: When did you start to feel hopeful? What things have made you more hopeful?

Jenny: Realising that I am not on my own. Coming to the first voices group... I'd never, I just sit there, I wouldn't say a word. Because I was a bit... I wasn't sure... How people would react. So I just listened... And I got an idea of... What is happening, and some people have voice-hearing – voices. ...So I'm gaining more confidence because... I am finding it... easier to talk about the voices. I think it's because I know I'm not on my own, that there are other people, like-minded, and there's nothing wrong with them. It's just the voices. And it's like – they all say nice things, like "hi, how are you doing?" kind of thing. Which is... Caring in a way, but it's not being nosy.

So... Yeah.

Me: And it has an effect of increasing your hope?

Jenny: Yeah.

Me: Yeah. So, have been periods when you have felt unable to talk about voices?

Jenny: Yeah.

Me: Why didn't you want to tell anyone?

Jenny: Because I wasn't sure that they would believe me. [Short silence]. And I'm on medication for it as well. But... I don't think that helps that much.

Me: No? It doesn't make voices go away?

Jenny: No. It lessens them slightly.

Me: They get quieter? Is quiet the right word? Or less frequent?

Jenny: Less frequent. [Short silence].

#### Second interview

The two interviews I had with Jenny were the shortest I had, at about thirty-five minutes each. We seemed to run out of things to say. The next time we met, about six months later, she was unhappy and worried, she had been finding both life and her voices more difficult in the preceding weeks. She was very concerned with the question of whether her voices were "real". She had managed to get an appointment with the doctor for the following day and was placing some hope on that meeting, although she could not say what it was that she hoped for. She described her doctor as someone who could listen without judging her, "a totally nice guy". She told me that she was on the highest doses of two medications. She felt that things had become more difficult because her support from her mother had suffered due to her father's deteriorating illness, that both of them found difficult. This time when she spoke about voices it was to say that she usually just swore at them.

It felt like a difficult time to have a conversation. I was left with a strong sense that it was not simply Jenny who was granted limited powers of action by her story, but her doctor too. I imagined his concern that, despite prescribing the most he could, he seemed to be losing ground against "the illness". After the initial "insight" of "schizophrenia" there seemed so few new insights available and this I feel is why the interviews were so short. I felt there was a lot more that Jenny could have talked about but it lay outside of the permitted story. When I asked (in either interview) about the content of the voices, Jenny changed the subject. I have no idea whether this was because she does not want anything to raise details which threaten the illness story, or that the voices speak of events which are very painful, or that she feels that the content is too upsetting or rude, or that she fears reprisals from the voices if she talks, or that she feels that to discuss the content is wrong, or that it would be too difficult to know if I was trustworthy, or a combination of these, or something else entirely.

## Rosie Gravy Boat

Me: How did you come to live here?

Rosie: I was brought here by [name], darling. [To care worker] Who brought me here?

Care Worker: I don't know.

Rosie: It's a mystery. It might have been Dr [name]. I'm not sure. Or gravy boat [laughs].

Me: Gravy boat?

Rosie: That's what I call Dr [name]. I christened him gravy boat.

Me: ... So, you've mentioned a couple of doctors there.

Rosie: Yes

Me:... How come they have been involved in your life, doctors? What is that about?

Rosie: Trying to sort out what was wrong with my head, darling. I kept on having nervous breakdowns...

Me: Okay... When did you first have a nervous breakdown?

Rosie: My mum caused two nervous breakdowns.

Me: She caused them?

Rosie: She caused them. Yes. Even psychiatrists didn't do that to me, they wouldn't, they're not that bad.

Me: How did your mum cause them, what happened?

Rosie: She put marijuana in my curry, darling.

Me: Did she?

Rosie: Yes.

Me: But she put marijuana in your food? How do you know?

Rosie: Dad told me eventually. Or God might have told me – God tells the truth sometimes [laughs].

Me: And what effect did this have?

Rosie: It did my head in. Causes unnecessary cartoons... In my head. [laughs, short silence]

Me: ...Someone who was hearing that might think, "that sounds fun". Was it fun?

Rosie: I thought it was... a bit queer. I had a vision of a cowardly lion. And a vicious black cat. I can still see it now. It was mum – she put marijuana in my curry. They did that to Pete Townsend, at Woodstock – somebody put LSD in his coffee. And he went berserk on stage. Nearly killed someone in the audience throwing his guitar... no he didn't, no he didn't, he just got nasty. That's why I got nasty.

Me: You got nasty?

Rosie: I got nasty, yes.

Me: What happened when you got nasty?

Rosie: I got nasty with [name]. I think he was as high as a kite. He might have been a robot – I'm not sure what it is that is causing all these hallucinations.

Me: Robot?

Rosie: Robot... he was high, he didn't know what he was saying. [Short silence].

...[My boyfriend] read the Bible backwards! [laughs] why did he do that for, exactly?

Me: Read the Bible backwards?

Rosie: [laughs] Never sure whether I got a snippet of information! [Short silence]... [Mum] told him to make some tea... she didn't think it was that bad. I was frightened of him, because he had penetrating eyes, and he stared at me. He had no respect for British birds. That's why I turned against him. I was frightened of him. Because he messed about with witchcraft, darling, that's why I was scared of him. I was scared of witchcraft... He dabbled in the bleeding occult.

Me: And this was when you were a teenager?

Rosie: 16 darling. He might have been telling the truth. I was frightened to death of him... Upsetting his family...

Me:... Gosh... So you have this boyfriend, but you were quite frightened of him -

Rosie: Because he messed about with the occult. shocking, isn't it?... Some people really do mess about with it, and it nearly kills them. Jimmy Page messes about with it as well. And he's frightened of [words unclear] in his house [Laughs].

Me: So when was it that you said that you started talking to God?

Rosie: I used to look for him in the clouds – I didn't know what I was looking at, I was too young. Mum might have – I think it was [woman's name] who mentioned God. But I had a neighbour who believed in God and Jesus and she converted me with zeal. So did a kind Jehovah's Witness.

Me: ... The boyfriend you mentioned, and then the marijuana. Was that at a similar time?

Rosie: Yes at a similar time. I'm telling you the truth. [Short silence] [laughs]. Mum did dob me in, she did have a violent temper – she was like her old father he never loved her. He

insulted her, he kept calling her bleeding ugly mug or something, and [name] did nothing about it. She just let him insult her. That's why she turned against me and dad. She was nasty with dad. She treated me well when I was seven. She trained her parrot – she had her parrot on her index finger, and talked to it. She showed me a picture of a parrot, in the botanical gardens, in 1966. That was back in '66. She went everywhere with it – she held my hand so tight she nearly hurt my little hand, that's how she held my hand....

#### [short silence]

*Me:...* And you were saying that the doctors got involved, because you had a nervous breakdown.

Rosie: It's abating slightly. It's just blobs now, darling. I like calling you darling – what's your name?

Me: Jonathan

Rosie: You might be married!

*Me: I am married – but you can call me darling, that's all right, it's friendly. [short silence]. did the doctors help?* 

Rosie: No. I can't get rid of the marijuana. Only God can do that. God can achieve the impossible.... It's tailing off. I just see purple blotches.... I wish I was a young girl again. I wish I was about 19. I'm 55 next year... how old are you, darling, about 20?

Care Worker: 41.

Rosie: 41?! You don't look it

Care Worker: Thank you.

Rosie was more than happy to talk. She told me about events, places and characters. She talked about the past and the present. She linked very few events in causal ways, such as the one above about cannabis. Yet, taken as a whole, there were many events but no particular plot. She invoked illness tropes; ideas about psychic powers and haunting; religious views; drug and alcohol issues within her childhood home; a boyfriend who was frightening and "into the occult"; a scene where her father stunned the dog with a hoe; a scene where a man who might have been a ghost or a faith healer or simply from Scotland may or may not have seen her naked and put his hands on her; a mother who was cruel because of her own parents' cruelty and had "no ambition but to get into a box"; voices that might be God; being bullied at school. Only Janis Joplin had really believed in her, she said. Conversation was full of references to rock music. Now in her mid-fifties, I believe Rosie has spent all of her adult life in care of one kind or another, and lives in a residential home. She has lost track of time; perhaps without the organising structure of plots and the institutional life, the passage of time, and the distance between events, becomes less knowable.

#### What of stories?

Rosie went through about 50 of the cards one-by-one, and described them, saying what they reminded of or whether she liked them, appearing to enjoy herself, remembering a school art teacher. She had an infectious smoker's laugh. Narratively, I believe Rosie is like an inkblot test. Others can find what we want there and what we find and emplot may say much more about our needs than hers; I also wonder if Rosie, and the kind of interaction I had with her, represents something that many mental health nurses recognise but that is not often found in books about "the voice-hearer". There is no idea that a more independent life will ever be possible. No one is suggesting the *Recovery Star* for her. She certainly could not be made into "inspiration porn" of the

sort that disability groups are increasingly disgusted with. Some might see trauma there, odd parents who were possibly abusive, some kind of sexual abuse, domestic violence and substance abuse, the need for God and the impossibility of knowing him, years of iatrogenic harm, high doses and institutionalisation. I imagine that her voices might be a good place to start, and maybe a timeline of some kind, perhaps a genogram, but I also look at the time that has elapsed, accelerated by tobacco and sedentary life and medications, and I wonder if it would be possible to begin. It feels wrong to try and more wrong not to. Others will see the tragedy of an illness, praise the care and patience of the staff, and go away and read the journals which tell them of being on the cusp of a new and bright age of healing possibility (Burstow, 2015, p151). Some might see the oppressed voice-hearer, a common human variation, brought to this life through pathologisation. Someone else might go away and try to further criminalise street drugs. Some might feel a great need to re-visit the medical notes to discover what "really happened": I do not. I could begin a section here about "disturbed ipseity" referring to the work of Louis Sass and Joseph Parnas (2001; 2003 and elsewhere), which takes a lot of explaining and sounds very explanatory but I do not want to; to present this interview and then make such analysis would be trying to create a mastery over her script, that has been done far too much already in her life and my feelings are that Rosie should be allowed to stand up in this research as she is, evoking feelings of care, tragedy, and yet still a woman able to be unique, memorable and warm. I am not certain that Sass and Parnas say anything that is not either said by or implied by Frank, but they tend towards the thin version of narratology that I have described elsewhere.

After this research is over, I plan to go back to see several of my interviewees and talk with them. I have no idea what I can say to Rosie, and I have a feeling she will not remember me. Perhaps she will hold my hand again and I will feel better, shabby as that may sound. There is not much else to say about Rosie. Her full transcript is in turns terribly funny (I believe she was consciously witty and I like to think of her humour as resistance) terribly poignant, and sometimes just plain baffling. The opening three lines above seem to me to be a perfect illustration of Franks's *a life that is not fully narratable is vulnerable to devaluation* (Frank, 2012, p75).

# The time when I heard a voice

What I need to explain is that I was brought up as a Christian. I don't mean that I was encouraged to go to Sunday school. I mean I was born again on Easter Sunday, aged 8, 1984; I asked to be baptised as a teenager; my parents were missionaries and my childhood was spent in Asia; I had a tendency to tell class-mates about The Good News; my family believed that the world was just 6,000 years old. We knew that most of what was said about natural history on the television (although we didn't have one) was a lie, we were "Young Earth Creationists". When I left home and came to England I went to live in an Anglican community where some members were life-celibates. At university I became the vice-president and then the president of the Christian Union. Everything I had, everything anyone had, was by the grace of God. I wonder if you understand what I mean? I mean that no one had any rights.

What might be referred to as "spiritual experiences" were not rare in my life, and many common occurrences in nature were spiritually symbolic for me. In fact, that was really the whole purpose of nature: Jesus speaking. Sometimes while praying I had a very strange feeling, that my legs and feet were miles away and my tongue had grown thick, my lips huge. I looked down at myself as if a few feet above my body. At a number of services at the religious community in the summer of 1994, aged 18, I was "slain in the spirit", a phrase we used to describe falling over whilst being prayed for by others: laying on of hands that then catch the faller to lower them safely to the ground. My hair stood on end during one of these experiences and my legs had a sort of vicious "pins and needles" so that I felt that I needed to beat them with my fists, only I couldn't move. I remember that I was lying on my back and tears trickling from the corners of my eyes were filling my ears. These memories strangely had no power to help me once it all began to fall apart.

A year later I was a student in London. I lived in a large hall of residence. It was a bit of a shock after Singapore and after the religious community. There were about twenty rooms on my floor. One day I went to a rally. I have no idea now how came to know about it but it was called "The March for Jesus". I spoke with Jesus every day, sometimes for an hour. He lived in my chest. When I opened my eyes each morning there were two of us, together. I loved him. I loved him more than I loved anything or anyone. I wanted to be with him, and I had a light touch on this world, a world that often felt mere "shadowlands". For me, "to live was Christ and to die was gain", although I would have felt unworthy to have put it like that.

After the march, which started in Hyde Park and finished in Trafalgar Square with worship songs, I went home and found myself in conversation with two fellow students in the communal kitchen. The conversation started with them asking me about my day. So I told them. The March for Jesus. Quite soon, the whole floor was listening, sat around the big table. I didn't intend for that to happen. When I look back on it now, I was making myself very vulnerable in front of a lot of people I mostly didn't know and was rather nervous of anyway. The air was thick with cooking and with dope. I was trembling.

I went to bed. I think I slept ok. As I was getting dressed the next morning I heard the voice of Jesus. Calmly, He said, "Thank you for saying that you loved me". I knelt down on the striped rug. I got up again. There was nothing else. I went on with my day. I have never heard anything like that again. It was not from outside of my head. It was inside my head but it was not my thought, it was as if it was being said audibly. It had a quality of being unbidden, from another mind. In the context of my faith it was pleasant but in some ways unremarkable (other experiences I had previously were, after all, literally hair-raising). In fact, it is only in more recent years that I have really thought about it at all. I think it highly unlikely that it motivated me to learn about voice-hearers. I did not know anything at all about mental health, psychiatry, hospitals, nursing, anything. I was a music student and it wasn't till over a year later that I decided to become a nurse. And I didn't know there was such a thing as mental health nursing even then; I trained initially to be a general nurse. I do not consider myself to be a voice-hearer. I forgot about this.

Two years later, in another student residence, staring at my eyes in the mirror above the sink, nothing made sense. Once again I remember kneeling down on the floor, it was the same rug that had moved with me, but increasingly I found I was alone. Nature stopped speaking to me. For many weeks I had chest pains, headaches and a constricting feeling in my neck. I couldn't sleep and ate little. I thought I might die, and, in a very real sense, I did. I became someone else.

## Amber

The following account is of meeting Amber. She was not recorded, does not have a transcript, cannot be guoted and made the choice to not take part. She withdrew from the research in the days between signing the consent form and the interview. Her reason not to take part was that she felt she could not cope with the emotions which the interview might bring up, and we left on warm terms. I feel that this research owes an acknowledgement to the very small part she played, that her story, while mostly untold, and the story surrounding her nomination as a possible participant, meeting, and choosing to withdraw can still be thanked for what it tells us. In presenting this section I acknowledge that here are two ethical "goods" in balance. The first is that participation should be linked to consent and that consent was given but then effectively withdrawn. The second is that this withdrawal of consent was due to the woman's perceived inability to cope with the interview despite her desire to do it, and that I would not want this to make her entirely absent. This goes further than an exploration of why consent may have been withdrawn, which in this case is probably rather straightforward. I think the events touch on something which is important, and has so far not been present in the research in this way. A further difficulty is that gaining some kind of separate consent from her to allow me to include this short piece would reveal to her something about the relationship between her and her care-team which would be an "intervention" on my part. I therefore present this section as something "illegal", an eventuality not considered in the preapproval ethics process, something unclear.

We really want you to see her. The thing is, we don't really think she does hear voices.

The team disclosed a number of details around her use of medications, the pattern of voicehearing across the 24 hour period, and that they considered that the arrival of voices was a bit too "strategic". They told me her diagnosis, and the one they felt should be given instead.

There was an implicit implication that I was an expert on voices (this was their phrase, used when one staff member introduced me to another) here to be a sort of "second opinion doctor". It was a bit difficult to know how to play this. Of course, in my mind were all the conflicts already described about voice hearing being judged to be genuine or otherwise, and for what purposes. Then again, here was an additional possibility that what the staff member was actually trying to tell me was that the participant was lying about the existence of any voices, "real" or otherwise. This would make this interview a sort of sham, although questions about why a person would invent fictional voices would remain.

I explained that, although I had been given an honorary contract with the local NHS trust to do this research, my work was from the University, and that this meant the work was confidential between the participant, myself and the research team, although the participant was perfectly entitled to choose to share information with whomever they wished. It was not until this moment that I realised that the honorary contract could potentially make this complicated, and a conspiratorial part of me had the sudden thought that I might have been duped. However, the staff accepted this, and I went through to be introduced to the woman. As a mental health nurse I have many many times been advised to meet someone with the warning that they might be less than trustworthy. Yet this was the first moment that I had been invited to meet someone on those terms as a researcher, and it didn't felt like being cautious and prepared, or experienced and not easy to manipulate; it didn't feel like good team-working, a consistent approach, clear boundaries born from professional experience: it suddenly felt revolting. I think that this was not only because of the idea that the "trustworthiness" of the participant should be questioned, but also that in no other interview had it been said that a third party "wanted" it to take place. I did not want my work to be part of the purposes of anyone else.

During a session to consider the participant information sheet and consent forms, Amber disclosed some vivid and disturbing abuse. I found myself several times staring uncomfortably down at the pieces of paper on the table between us. I had to tell her that the difficulty I had was that what she

was saying seemed hugely important and it felt wrong to just continue with the forms each time, but that I wanted to have the proper conversation after she had been able to sign them.

A few days later, I met her again and she told me that participation would be too difficult for her. I told her that I felt it was braver to withdraw than to continue from others' expectations, and that it was a good thing in that it represented her taking charge. We shook hands. As in every case, I did not set up the interview as something which was designed to look at or hear stories about the past, but to have a discussion about voice-hearing and emotions. I also often used the phrase, "things that you may feel strongly about", when asking about whether it might be difficult to speak about emotions, and I did in this instance also, but I do not say "events" you may feel strongly about.

This research is grateful to Amber for several reasons. The first is a number of ways in which her limited participation continues to shed light on the narratives of nurse vs researcher, about which there will be more to add after the insights of Mel and Ross. The second is very simple: to note that, just as with *every* person I asked about hearing voices and emotions, it was the past that was felt to be most explanatory.

## Mel

I've just come back from my second interview with Mel. I spoke, and she cried; it is going to be strange to transcribe. I felt the limitations of my researcher role keenly. In the fourteen months since her mother first took her to A&E, she has been prescribed three "anti-psychotic" medications and then clozapine. Finally, a dose was found at which she is no longer hearing voices: a strong sense of "panic over" for all concerned, utterly invested in "psychiatry as a hope technology" (Blackman, 2016, p267). She has become very overweight and lethargic and I cannot help but wonder how long it will be before the side effects become intolerable: echoes of Angela. Today I outlined to her some of the things that people have told me<sup>27</sup>. Mel has done a lot of Internet reading to try to understand her experiences, mostly about "mental illness". She broadly accepts that has been ill and that treatment is successful. It was when I mentioned that some voice-hearers have come to see trauma and dissociation as significant that things suddenly became upsetting. She explained that she had not told anyone certain things that have happened to her; that was when she started to cry.

The Participant Information Sheet<sup>28</sup> specifically suggests that people do not disclose such things for the first time during this research: she did not tell me, either. There was a lot of silence in the interview, at one point nearly a whole minute, but one question that she felt that she could answer without hesitation was that she did not have the kind of relationship with her "care-coordinator" that led her to feel able to talk about her experiences. I felt I should work hard to ensure that the interview finished by recalling her undoubted strengths and future hopes.

As I transcribed, I felt a great range of difficult emotions myself. I feel hugely disappointed in the nursing team. I do not trust them either and kept looking at what I had written and imagining how it would seem should there be questions asked about it later. This is the scenario I imagined:

Mel starts to ask the team who she can talk to about her traumatic experiences (whatever they may be). Either she does, and becomes upset and starts to hear voices again, or she just becomes upset. The team then wonder if my involvement has led to this "destabilisation". Mel was making such progress! What have I said? Perhaps Mel says that I told her that some people feel that their voices have come about through the way they have coped with trauma (I did tell her that). Perhaps the team will see this as just plain wrong - don't I know it is an illness like any other? They clearly are not used to talking about trauma and so they will be scared to do so (no doubt they would protest about that comment but I stand by it). They will tell themselves that listening to abuse disclosure is something only trained psychotherapists can do, they will even tell themselves that it is not exactly what they are there for, anyway. This was the fear of my Research Ethics Committee too. I can easily point to the safety nets in place, the transcript shows the conversation ended well. But maybe they will decide I was irresponsible or even plain wrong. Telling people about alternative views by its very nature undermines the full credibility of the one they already have, after all. The mental health team will not like to be exposed to different stories.

<sup>&</sup>lt;sup>27</sup> I have to be careful how I do this, because I do not want to make it sound like I am endorsing one idea or another. It is surprising how easy it is in these conversations to start to form sentences which imply that my study is a representative sample: "lots of participants have told me that...". I have to be careful to just talk about ideas that are around, or make it clear that one person said something.

One moment in the interview was particularly sad, and I realised that I might have misunderstood Mel's concerns. After I had explained about ideas of voices and trauma (and I also explained the word "dissociation", Mel said:

Mel: I thought I might have had some... dissociative... like that, Before, because usually, when someone has dissociative identity disorder then usually like, every other day, they like switch personalities – but I've only done it three or four times in my life, like only when I'm really angry, And then I won't remember it until, like, years later.

I realised that she felt that, in explaining something about other ways of thinking that had been useful to other participants, I was in some way trying to reclassify (or additionally classify) her from being "schizophrenic" to having "dissociative identity disorder", which she had read about. I tried my best to explain that was not my intention.

Eighteen months before, she had started to hear voices. It was the American National Security Agency. The NSA were not only monitoring her through the Internet and phone, but listening to her thoughts and speaking to her too. The first card she picked was a goldfish in a bowl; she was the goldfish and everyone could see her.

I want to be extremely careful in thinking about MeI as "delusional" or "paranoid" in this Assange/ Snowden era. If the ordinary citizen was encouraged to dissociate from their feelings about irradiation and annihilation from the 1950s (see John) then the today we are required to dissociate from the electronic intrusion of the State and the corporate world into our lives. Even our elected representatives may not know the details of secret trade agreements, such as the Transatlantic Trade and Investment Partnership (Wikileaks, 2015). When I started nursing on locked wards in the 1990s I thought that if I were ever to be detained under the MHA I would get out and no one would find me. Today, from credit cards to CCTV to GCHQ's ability to switch on camera and microphones remotely, undetected, this would be impossible, never mind "metadata" predicting where I would go and to whom. To know and care about freedoms in 2016 *is to experience a kind of paranoia*. It is almost as if those that rule us are daring us to try to cope with real knowledge of their lives and decisions; many of my friends have decided to stop reading the news. I think it is very important to consider Blackman's thought that a more feminist and more situated understanding of self can transpose "how do I feel?" into "how does capitalism feel?" (2015, p25), raised in John's chapter. In this case, "capitalism" might be replaced by "surveillance":

## *Mel: ...[J]ust had an overwhelming feeling of being watched. You know, when you have a bad feeling in your stomach, like something bad is going to happen...*

However, this was not the first time that Mel felt this way. At aged 9 she had a period in which she believed she was being watched by aliens. She decided not to tell anyone at the time, but her teenage years were characterised by a fascination with Greek and Egyptian mythology, Freemasonry, Rosicrucians, Jesuits, Illuminati, the Occult and Wicca. She knows "who the Rockefeller and Rothschilds are". She saw all of these as "sort of related". All of them are "stuff that people don't want to tell you". Mostly this was difficult because people did not want her to talk about her interests, and so she was quite isolated within them. She did not hear any "voices" until 18 months ago. She sees them as being part of the intense feeling of being watched, and they were mixed with some very frightening monochromatic visual experiences of angels and demons in her bedroom. The voices were a mixture of pleasant chat and highly personal insults. After being overheard screaming at them, her mother took her to hospital. However, it was not clear that she was frightened by these experiences; they fitted well with her beliefs and mostly she was just curious about them, intense though they were. She also suggested that her beliefs were driven by her experiences too. For example, she was not interested in religion until she saw angels. She felt her mother was right to take her to hospital but does not feel she was "mentally ill" as much as unable to cope with her low mood and isolation. Tablets helped her to feel much calmer, although it was a year before the voices stopped.

Mel felt that the voices were like bullies, and said things that bullies had said to her or others. She felt she was bullied consistently through school and feels it was part of her "bad depression" and attraction to smoking "weed" and heavy drinking from her early teenage years. Home was at times violent, especially when she was smaller and less able to defend herself, although this was ameliorated by periods with her father in prison. Mel's period of time being seen at a community mental health team and participating in a social group there is the first period of time she has socialised sober, and she feels this has been very beneficial. All of this is a summary of the things she told me when I asked her to tell me about voices and emotions.

Me:...What you think about the future?

Mel: I'm like, willing to go to school and stuff now.

Me: You'd like to go back to school?

Mel: Yeah.

Me:...What would you do?

Mel: I would do something like, something for the environment, or journalism.

Me: You have got a history of investigating things.

Mel: Yeah.

Me: Do you feel that you're going to stay well now?

Mel: Yeah

Me: There was like one bad period... You've made a... Do you feel stronger in yourself?

Mel: Yeah

Me: And... You still feel like this black-and-white card? [One of Mel's cards was half-white/ half-black]

Mel: I'm more at ease with myself. I'm just grateful not to hear voices. So anything – even like a normal day to most people is like a happy day for me because I don't go through so much emotional turmoil.

When Mel and I met for the second time, she agreed that her "breakdown" could be understood by a stranger from her first transcript in a number of ways: as a result of prolonged heavy substance misuse, as a result of getting into some rather extreme conspiracy/paranormal theories, as trauma relating to domestic violence and bullying, social isolation, or as an episode of mental illness (now treated), or a combination of the above. The improvements that she has experienced could likewise be related to safety and social connection, cessation of substances or the effectiveness of medication, or a combination. Mel said she felt the most marked change was that she had the confidence to introduce herself to people, and she felt that it was because people could not get away with bullying behaviour in the regulated social group of day therapy. She felt she was beginning to have her first friendships.

Mel: ... [B]efore I had my psychosis I had depression for a really long time. And I think the voices come from being depressed. So... I stopped being depressed, I was more social, Stuff like that.

*Me: okay....* When you say that the voices come from being depressed, do you mean that there is something about how you feel – your emotions – that is related to the voices?

Mel: Yeah.

Me: Can you say it more about that?

*Mel: I looked up psychotic depression. I have had depression for years and years. Depression stopped and it started to be psychosis....If you're stressed, it makes it worse.* 

Me: you think so?

Mel: yeah.

Me: how does that work?

Mel: My voices pick up on my emotions.

Me: go on...

Mel: If I'm having a bad day, The voices won't just be like conversation, they'll be putting me down. They'll be commanding me to do things.

Me: okay. So how you are feeling, and then how the voices-

Mel: – act –

*Me: – act, are related?* 

Mel: Yes.

*Me:* So if you are feeling better in yourself, the voices would be... less bothersome? Less frequent? Or...

Mel: Yes

Me: Saying different things, maybe?

Mel: Yes

Me: are they ever... I mean, you told me before that you did hear nice voices sometimes in the morning, and then later it became more insulting.

Mel: Yeah

Me: From the sounds of it you are also saying that to hear more nice voices at the times when you feel better. Is that right?

Mel: Yes.

Me: Okay. Where did you... Is that something that you have pieced together yourself?

Mel: Yes.

Me: You worked out that-

Mel: Yes... it's like a cycle. I feel bad, I have a nasty voice, I'll feel worse... a cycle.

Then came the part of the second conversation in which I outlined some of the spread of stories people have told me about hearing voices, and after mentioning the idea of trauma and dissociation, Mel began to cry.

My relationship with Mel felt like the beginning of something, but it was taking a long time to get started. I think the section in which she misunderstood me as trying to see not what other ideas, or stories, she might be connected to but *what other diagnoses* is very telling. Talking about experiences to her community mental health team, under this particular medical story, leads to fresh diagnoses. Feeling that there was anything yet undisclosed or unresolved only suggested she was not recovering, more ill than people had yet realised. To be well is to not have a troubling past, or difficult emotions, or be confused. And yet, without any particular emplotment Mel feels that voices have something to do with her emotions. Although she is on an extremely potent medication, she feels that mostly it is social factors, leading to a change in her emotions, that has led to a change in her voices.

# Something made me tell a lie (part 2)

Review the Hearing Voices Movement Story: Marius Romme is a conventional psychiatrist and then meets Patsy Hage (sometimes *Hague*), a voice hearer who challenges Romme to prove that hearing voices is not normal (Baker, 2013; Romme et al., 2009, p260). In the mid 1980s, Romme and Hage go on television together. They explain their predicament: Romme insisting that she has an illness called schizophrenia, Hage insisting she is not ill, and that hearing voices is not a symptom, not a hallucination, but a meaningful life experience related to trauma. There is a phone-in on TV and many voice-hearers "out" themselves, showing that there are voice-hearers who live without psychiatry in the general public. Hage is right. Romme *sees the light*. They found the HVM. The central message of the HVM is that of *Making Sense of Voices*. The central story is that voice-hearers have overcome and are overcoming the oppressive psychiatry and have formed a grassroots movement. I do not claim that this is exactly Romme's version of events, but that it is a story frequently told by and about the movement.

Here is a different story. Romme was very influenced as a trainee psychiatrist by Victor Frankl. Frankl; Auschwitz survivor, author of "Man's Search for Meaning" (2004, originally 1946), who formed a school of psychodynamic therapy, logotherapy, in which the driving force of the psyche was to find meaning even in the most adverse of circumstances. That part is not made up; Romme told me so himself. Romme was always steeped in psychodynamic thinking. Not only is this made clear by his early attachment to Victor Frankl, but when I asked him to recommend a book on dissociation in 2013 he suggested I started with Anna Freud's Ego and the Mechanisms of Defence (1992, originally 1936). By the mid 1980's and probably some time before, Romme is finding that none of his colleagues are talking about ego defence, dissociation, trauma or suppressed emotions, but instead they are only interested in brain chemistry and tablets; psychodynamic explanations increasingly leaving psychiatry during the 1970s (Sayce, 2016, p41). Romme meets Hage, who, perhaps not so uniquely, illustrates this conflict that Romme has with his colleagues and the wider world of psychiatry. Romme stages the conflict, literally staging it on national television, to provoke discussion. He, a psychiatrist already into his fifties, founds the Hearing Voices Movement, claiming that Hage and other voice hearers have driven this agenda. Yet the movement has Victor Frankl running right through it. It is all about making sense of the most adverse of circumstances and standing against the brute random events of a psychiatry obsessed with a brain chemistry no more meaningful than decisions about who went to the gas chambers on any given day, chambers Burstow and Read have already told us was indeed enabled by psychiatry. It has a strong psychodynamic theme of trauma and suppressed emotions. of dissociation and defence of the psyche, which have become more developed over time and are now articulated by new authors such as Eleanor Longden.

Is it a grassroots movement? It is founded by a psychiatrist and is not particularly democratic. It is full of professionals, some of whom seem uncomfortable about being there and pretend that they that they are only peripheral. This extends a little beyond that which might be thought admirable in a movement in which professionals are trying to promote "expert-by-experience" knowledge. Not only was the Hearing Voices Movement founded by a psychiatrist, most Hearing Voices groups are founded and facilitated by professionals even though in every group I have witnessed there is a story that this is the exception and not the norm. The chair of the Hearing Voices Network England admitted as much to me while at the same time being reluctant to train two recently qualified mental health nurses who wanted to start groups; they were the wrong people, although there were no voice-hearers ready to take on the role. There is a need to uphold the story that the Hearing Voices Movement on the *outside* of psychiatry (although I also believe that the best groups probably are facilitated by voice-hearers and one I visited appeared to be particularly well-attended and dynamic).

Without the professionals there is no HVM<sup>29</sup>, which is not to say that this will always be the case; some would argue that in order for a disempowered and marginalised group to form themselves and become powerful, they needed the conferred power of professionals (Smail's view, I imagine). Were this to be the case, then as time goes by, successive leadership of the HVM might contain proportionally fewer professionals as voice-hearers become more empowered. *Why would professionals need to create the Hearing Voices Movement in order to house the arguments they need to have between themselves?* Perhaps none of this is quite right, either. Recently, I read yet another version of this story, one in which Hage is presented as far more active and Romme the white middle-class male professional who later received the credit: "Her tenacity and persistence have been replaced by the heroic actions of her male psychiatrist who has been canonised as responsible for the development and shaping of the network" (Blackman, 2015, p30).

Perhaps, instead of examining the different actors, there is more to be gained by seeing persons as secondary to the stories that are struggling against each other. The "Overton Window" of psychiatry became so narrow that it forced psychodynamic explanations into a "beyond the pale" zone, and in doing so made them all but invisible. Since they were not available, they had to be re-invented and this gave rise to a HVM of voice-hearers and professionals. One could even argue that the HVM is where psychodynamic thinking is hiding, awaiting a second time in the sun (see Burkeman, 2016, describing a possible resurgence of psychodynamic thinking).

Perhaps that idea still misses something important. Is it psychodynamic explanations *per se* which became invisible? Or is it trauma-based explanations more generally? If this is the case, then it is tantamount to saying that from the 1970's, psychiatric narratives made experiences and emotions themselves somehow "off-limits" as causes. Emotions could certainly be "symptoms", they could form descriptions. But could they be explanations? Even if one suspects Romme (or others) of massaging a certain image which turns out to be more complicated on closer inspection, it is understandable that he should have seen the need for it: how did we arrive at a psychiatry in which emotions and trauma were somehow hidden or even disqualified? Professionals may know that psychiatry is hugely controversial and they have to go somewhere else to tell these stories.

*That is what I did.* Ever since it's mid-1980's origins, the HVM can be seen partly as an argument that is going on *within* psychiatry between professionals, yet staged *as if* between psychiatry and an underground movement. So much of what I was expected to do and think as a mental health nurse seemed wrong to me that I went and found a group to make me feel less alone. The tears I have shed at HVM Congresses have always felt as much about me, about my stories of psychiatry, about my desire to say sorry, to come home, as they are about the often very moving stories of those voice-hearers I have met there. I want to tell them about all the horrible things I have done, or was made to do. There are always a few key events that return to me and that I know I have tried to bury; I want to say them, to confess them. Suicides. The Clifton Suspension Bridge. A terrified young woman I had to chase through the hospital carpark. There are more. And then perhaps it is natural to downplay that, because it really does seem very hypocritical to play the *I'm a victim too* card. I got to go home at the end of each shift. Giving injections under restraint might have been upsetting for me, but it certainly has nothing on the experience of receiving them.

Yet, for a grassroots movement a surprising number of people have privately volunteered that they find its leaders to be intolerable and several have told me that for a movement which professes acceptance there can be a distrust or even a rejection of voice-hearers who's stories are not quite in step. Just how one can be "out of step" with a movement which claims that it can accept and promote a multitude of stories about voice-hearing is a very interesting question. For the people I have spoken to about this, Angela, Claire, and others who are not participants, it seems that it often hinges on *recovery stories.* The theme I present in the chapter with Claire, that somehow her

<sup>&</sup>lt;sup>29</sup> Which feels a similar comment to Angela's: that without being in psychiatry first, the HVM would have had no appeal.

understandings are both acceptable (because voice-hearers are always "good enough") yet simultaneously inadequate and partial, likely to be storing up future trouble, seems to me to be part of a common problem. Another voice-hearer told me of Romme insisting that she re-visit childhood trauma or else her "recovery" was inadequate, and also that "there was nothing to learn from unrecovered voice-hearers". Romme writes that Patsy Hage has only a 'partial recovery' (2009, p261). Is a feeling that once within the movement, the expectation is that distress will diminish, and where it persists there is a sense of personal failure? Why does that sound familiar? And once more it may be at the boundary of the internal and external that so many accidents seem to occur. Blackman says that "Patsy's [Hage] account exceeded the capacity of a subject who could be present to herself and required a distributed form of perception", and that this "exceeds the kinds of confessional technologies and narratives that have become so ubiquitous within neo-liberal cultures" (2015, p31). Is there something about Hage and other voice-hearers which defies the neoliberal authentic self: the "whole" self, the "true" self? Having the power to show us some of the fallacies of individuality? Is this where the real danger for the HVM is? That as it tries to present itself to a world that is still in the thrall of such right-wing individuality it will have to translate its many "distributed forms of perception" into a leftwards move on my map for the sake of credibility or coherence, that ultimately stifles what it is? Or is this conflict not so much between the HVM others, but between members (and leaders)?

I would not wish any of this to take away from the value of ideas that have come from the HVM and I write it from a position that the HVM is about the most exciting thing that has happened to psychiatry, perhaps in its whole history, as far as I can tell. To be present while the Thessaloniki Declaration (appendix 5) was read out loud for the first time was a privilege I will never forget.

## Ross

I call it going further down the rabbit hole. Alice in Wonderland, yeah? But then a lot of the time I can rationalise it, I can rationalise my way out of it. If I don't trust anything voices say, it's... It's my subconscious.... I think... most people have got their subconscious, it pops up every now and again to give them emotional thoughts and things, but in the sense of psychosis and schizophrenia it's almost as though the subconscious has taken on its own persona, personality or multiple personas. The subconscious is there and it is almost screwing with me. It is messing me around, it has got its own agenda. So, if I believed the things [the voices] say.... Or if I looked at it from rational perspective where I'm thinking it is just my subconscious, then I can listen to voices and sometimes I do, and I listen to the things they say but I take them with a grain of salt... it is almost a metaphor. So if the voices saying this thing to me, like this is this and this, then I try to look at it in a metaphorical sense. That it is trying to make me deal with emotions that I might have previously repressed. Or if it appears as someone's voice. It has come from that person's personality. then it might be someone I don't like, or I wouldn't want to talk to, and it's almost like it is making me trying to deal with the reality or possible reality of trying to deal with that person....That's if I look at it from say, a medical perspective, where I accept the fact that it is just my subconscious...

Had the concept of *data saturation* been a useful one for Dialogical Narrative Analysis, then meeting Ross would have given me sleepless nights. Suddenly, with this last participant, came ideas which were using narratives in a way which I had never seen before. The mind-body interface assumes a new shape in Ross, who has been diagnosed with "psychosis" for less than eighteen months. We sat in a tiny room in an unremarkable area of urban sprawl in England, and this young man played with concepts in his head that I believe he had no idea were the subject of countless articles, books, arguments and academia. He spoke at high speed and in re-reading the nearly 24,000 transcribed words I am struck by his extraordinary eloquence: one sees that he is captured by stories and yet that he is becoming able to recognise that process self-reflectively, leading the reader to be moved by his confusion and then awed by his mental agility. I was continually reminded of a phrase by philosopher of phenomenology Giovanni Stanghellini about "experiencing one's experiencing". I could not find that quote, but I found one better, that, to me, also speaks directly to the questions at the end of the previous chapter.

This supposed incomprehensibility (Jaspers 1913) has been for decades a cast-iron alibi for many and has been taken by some as a legitimate reason to give up understanding and to look for causes and explanations.... What is challenging and tackling my capacity to understand these experiences is that they reveal a special kind of non-understanding. If I try to understand them, I will also understand some basic features of my own way to experience and to make sense of my experiences, and by doing so I will feel displaced from what holds fast in my life and seems intrinsically obvious and convincing. Schizophrenic "abnormalities" exhibit usually unnoticed conditions of normal daily experience.... When 1 listen to my schizophrenic partner, I may have the opportunity to see in front of me what I cannot be aware of when I am turned to the life-world in the so-called "natural" attitude. If I try to follow him, I am at risk of seeing that most (if not all) of what I consider "natural" is indeed not such and can be put in brackets, suspended. If I turn away my gaze, as he does, from the life-world, I will become engaged in perceiving, almost as concrete objects and material processes, what was hidden to me when I was immersed in the life-world, as a part of it. I will nearly see my self, my body, and my world from another place. If I was previously feeling, perceiving, and acting, I will make these feelings, perceptions, and actions into external objects to be explored (Stanghellini in Cheung et al., 2007, p129).

Ross has explored two conflicting narratives, sometimes simultaneously. Using his terminology they are called *the rabbit hole* and *medical*. Each story has its own aetiology of voice-hearing, its

own past, present and future and its own agency. Each has quite a different effect on Ross, altering his daily activities and contact with others. Each casts others in new roles and shows the world in a different light. Crucially, each story alters Ross' whole experience of voices, *altering the voices themselves*. One sees glimmers of this providing Ross with the understanding he needs to promote himself from being passive in the experience of "psychosis" to more frequently being an agent in his own mind. Ross seems to have worked most of this out from his bedroom. I think the quote above is enlightening, because it foreshadows Ross' belief that his mental health team will not want to know about his explorations. However, in one very significant regard I disagree with it. I do not believe it to be a necessary and sufficient part of "schizophrenia". I believe it to be part of living narratively. I believe it is not so much "schizophrenia" as Deleuze's "schizoid man", a different thing entirely (Colebrook, 2002, p5). Or, to put it in another way, it is back to that moment that I referred to in John's chapter, when upon reading Frank I saw fully that stories are both wrong *and necessary*.

Narrative:	The Rabbit Hole	Medical
Where do voices come from? What are they?	Voices are telepathy from real people. They can be heard both inside and outside the head. New voices may be heard all the time. People whom Ross is with may suddenly start to use voices to communicate, and the voices tend to be of people he knows. This story has the effect of altering the perceived location of the voices and makes them <i>more like</i> <i>people</i> . The content also changes. Certain people learn how to communicate telepathically. This is a complicated process with complicated rules. It is something that Ross is supposed to learn (the voices tell him this) but has difficulty with. For example, at times he broadcasts all of his thoughts indiscriminately, including embarrassing and private thoughts, without wanting to. These can be heard by everyone. Voices can be commenting, conversing between themselves, directed at him or commanding. Under this story, the voices often try to instruct him about telepathy or lead him towards answers. They can range from lighthearted to insulting. "Psychosis" could be thought of as a developmental problem at the point at which people are supposed to learn telepathy.	Voices are voices, and they originate from Ross's "subconscious" mind. This story gradually has the effect of altering the perceived location of voices, such that they do not seem to be separate people anymore and only <i>parts</i> of Ross. The content also changes. In Ross's view, since voices are generated by Ross, it stands to reason that they say things which are important about himself. In listening to the voices he is listening to his own memories and thoughts, but ones which he would not otherwise have access to. Sometimes this is just useful - it expands the reach of his memory, for example. However, in being able to discover (through the content of the voices) the things which his subconscious focusses on, Ross may also learn about things "he has not properly dealt with".

Narrative:	The Rabbit Hole	Medical
What are the implications of this story for the present?	For this story to be true, there must be a significant secret that many others share about telepathy. Ross is likely to be a special person, because of his access to this secret. Being special can be positive or negative ("a targeted individual"). This aspect increases Ross' anxiety. He gets lost in thought, often not sleeping, is socially withdrawn, increasingly anxious. May walk the streets at night following voices. Others become concerned. He might embarrass himself. Although he can get very lost "down the rabbit hole", he finds that as others are describing his behaviour he can quite quickly see himself as having been "irrational". Ross feels antagonised by the often negative things the voices say, which become increasingly "offensive and rude" in this story. Makes him special. Feels it is possible he will make a gnostic breakthrough. This purpose feels as important as anything else in his life, and the voices are as real talking to anyone else. The more time spent "down the rabbit hole" the more likely Ross is to view what the voices say as believable. The voices also proliferate. In this narrative, strong emotions are the understandable response to the frightening nature of the experience of voices, and feelings of being a "targeted individual".	Accepting that the voices are "medical" and "not real" allows Ross the possibility of what he calls "an interpretive" approach. In a number of ways he showed that this is the ability to think about thoughts - metacognition. The content of the voices can be viewed as interesting rather than directly upsetting. In so doing, the content of the voices gradually changes to be less confrontational and insulting. Ross notices that he becomes less anxious the more he believes this story. He also notices that he gains in power over the voices, and is able to control them. They become quieter and more pleasant. In this narrative, voices are permitted to stay in the longer-term. The story changes them from being somewhat apocalyptic in nature to being more mundane. He is more able to socialise and commit to his studies. He seems to miss something of the previous intensity, however. In this narrative, emotions are not the response to voices only, but also their origin.
what are the implications of this story for the future?	There is a "make or break" aspect to this narrative. Either he must resolve the problem of telepathy, or else he would like to be rid of the voices. The future is frightening and uncertain.	While operating from this story Ross could say that he "accepts" that he will hear voices, probably for the rest of his life. The voices afford him opportunities to understand himself in new ways, that is both to "deal with" the past and also a sort of enhanced future ability, with access to memory and thoughts which might not be available otherwise to him, or to others.
What ideas decontest this story?	The narrative of being special or targeted decontests the idiosyncratic nature of his experiences; the lack of confirmation from others is because this is all secret.	Strangely, it is also the idiosyncratic nature of Ross' experiences which decontest this story too; the different experiences of others (their voices are quite different) suggests to Ross that it must be from his head.

Narrative:	The Rabbit Hole	Medical
What ideas lower the genre of this story?	One of the biggest threats to this story is that other people experience psychosis but have entirely different sets of meanings, as he has found out through talking to other young people. This reduces the high conspiracy genre of Ross' telepathy story into a local and idiosyncratic account. Also, he sees that this story affects him adversely, in that he becomes very anxious. The beneficial effect that the "medical" story has on his anxiety in some way suggests to Ross that it may be a better story than this one.	This is already a lower-mimesis story. However, there is a tension between a "hallucinations" account of voices, perhaps held by his team, and Ross' sense that he has learning to do to be able to use his voices as a key to self- understanding and augmented memory. This "Quest" narrative, while not as urgent as the <i>Rabbit Hole</i> could be lost with more of a hallucinatory story.

#### **Medical story**

In the discussion that follows I would like to draw attention Ross' skill as a narrator. He is a natural pluralist; one of the key parts of Ross' understanding is his unusual ability to allow himself to not only "go down the rabbit hole" but to stand back and see it from other's point of view. To explore two stories simultaneously in the way that Ross does feels related to the Stanghellini quote and it feels uncommon. My experience is that these too frequently become the "patient's" story held against the doctor's story, but, although Ross has a clearly articulated lack of trust in psychiatry, this positioning has not occurred. The reasons for this I can only speculate about, but I suspect Ross to be a person of high integrity who has avoided the projection of these different accounts onto others. I also suspect he has been both lucky and skilful in maximising the benefits from his contact with mental health services and avoiding the kinds of loss of autonomy which would have impinged upon his impressive ability to explore and evaluate both stories freely. I also think he has not noticed that his understanding of "medical" is different.

For Ross, if the voices are "medical" then it follows that they are *psychological* (although he never used that word):

Medical = subconscious = meaningful and reflexive.

The reflexive part is one of Ross' key realisations: the character and content, even the perception and location of voices is altered by the manner in which he thinks about them. Noticing these elements of emplotment arguably does three things for Ross. Firstly, it undermines the story that the voices first told him, about telepathy, by making it much more likely that they are located within himself; the very fact that the voices behave in a storied manner makes them less likely to be actual telepathy. Secondly, it seems to make it possible to be "interpretive" or view the voices "in a metaphorical way", making Ross able to take a step back from his voices that he could not otherwise. Thirdly, it provides him not just with an explanation but agency: "Hopefully, in the future, I think I'll be able to incorporate them into my life in a positive way". He can make choices to alter his experience. He can make himself better. He talked in strategic terms. This kind of agency does not exist in the "rabbit hole", where it is the voices who are the agents.

I have found that is the most helpful way of thinking about it, it's to interpret it. If I listen to the voices I listen to what they are saying, and I will try to interpret it in almost a metaphorical sense. Sometimes I will talk to them literally, so sometimes I might just be bored, and I might just – sometimes they'll just say something funny... It might be an attempts to mock me, or it might be an attempt to mock somebody else, but it might be quite funny. I can be walking down the road on my own and then I just burst out laughing – a voice will have said something funny that will have completely tickled me – nothing I would be able to come up with myself, almost like someone else has just told me this joke ... I don't take everything they say metaphorically, Sometimes I just think of the things they say, but a lot of other times like when I said they're saying things like stand up for yourself, or insulting me, I try to interpret that as like being part of the bigger metaphorical picture.

An example of this interpretation Ross gave was that through insulting him the voices might be telling him that he should stick up for himself more. He is aware of times in the past when he did not stick up for himself and was taken advantage of, he said. Sometimes the voices might actually say, "stick up for yourself", too, perhaps in response to the question, "why are you insulting me?". I felt it possible that there were other examples that Ross is as yet unable to articulate. I wondered if these kinds of voices were heard more at times when Ross felt threatened, but he said that no, it was more or less unrelated to what was happening at that moment.

The fact that most people do not associate this kind of thinking with the word "medical" did not come into our conversation. For me, very much based in years of nursing experience and conversations with voice-hearers, the term medical goes with "hallucination", and this in turn implies something which is random in content and *not useful*, very much with Jaspers' understanding/explanation split discussed elsewhere. For Ross, "medical" implies *not real*, but this use of "real" only extends to mean that the voices are not actual telepathy, but not that the voices themselves are of no meaning. So, whereas others have claimed their agency (and recovery) came from recognising that the voices *are real* (e.g. Ron Coleman, in Romme et al., 2009, p12), Ross finds that it comes in recognising that they *are not real*. Oddly, both men are referring to stories whereby they feel liberated to see the voices as personally meaningful.

There's lots of different languages and, funnily enough, as I am saying this the voices at the moment at telling me now to not share any information because it is part of a secret society. And I should not give it out, because everyone who wants to learn telepathy needs to figure it out for themselves.

Ross was even able to say that the voices tell him that they are not part of his subconscious, that he is being deceived into thinking that, but that he can see that this may confirm that they are part of his subconscious since it is an expression of his own doubt about whether the "medical" way of thinking is right. A complex place, Ross' mind! He described this back and forth like an "angel and devil thing" in his mind. He sometimes writes notes to himself to find later to try to ensure that he remains in one narrative *or the other*. While admiring Ross' thinking I would not want to imply that he does not suffer.

Ross: Sometimes I can go from one state of mind to another just in the space of a few days or a week, so...

Me: Into the rabbit hole and back out again?

Ross: Yeah. So next time I have a conversation I could be in a completely different state of mind and believe something completely different.

I wanted to know where Ross had got his ideas. I felt it unlikely that anyone in the mental health team had been using phrases such as "it's almost as though the subconscious has taken on its own persona, personality or multiple personas". He had looked at a HVM Facebook page, he said, and had been recommended to do so after telling his "care-coordinator" that sometimes he quite liked his voices<sup>30</sup>. However, what he found there was more of the "rabbit hole" - people posting their conspiracy theories about telepathy and being a "targeted individual". This phrase became interesting to Ross and he was later surprised to hear me say later that, actually, the HVM also comprised many ideas which were more like his other "medical" thoughts about the "subconscious", about voices representing events and emotions which were problematic and

<sup>&</sup>lt;sup>30</sup> I asked Ross more about this interaction: what did he think this nurse knew of the HVM? Ross thought that it was just something that the nurse had heard of, nothing more.

needed attention, and that it was possible to change the relationship one had with them. As far as I can tell, he worked out all of those ideas for himself; he uses rather different language from the HVM, and was unaware of the way in which many voice-hearers claim that "medical" implies a reduction of meaning (in the manner of Angela, for example).

One of the aspects of a story which locates voices as part of the self in some way, is that the voicehearer may be left needing to explain why one part of the self is being so difficult towards another, issues which have been discussed prior to this with Claire and Waddingham's *taboo voices*. Becky concluded that there must be a link to traumatic experiences and parts of her past which were not "dealt with". Claire was more dismissive of voices as "internal saboteurs", to be countered with better evidence. Angela talked of dissociated parts, Lisa felt she had not been abused enough to justify viewing voices as echoes of trauma, but that in connecting them with her emotions came the understanding that looking after herself was a way to make her voices better too. Ross is still trying out these ideas:

There might be part of my brain which is completely masochist and wants to trip myself up and wants to see myself fail.... I think that, for the most part, I am trying to understand it and put them into life in a way that's – ...When it comes to developing in life, that they don't get in the way.

#### Thinking with, thinking about

Ross had never spoken to anyone in depth about his voices before, and he was enthusiastic to do so. He found talking helpful. In our first recorded conversation, I largely just summarised what he was telling me, yet in talking about his two different narratives, laid out in the table above, he became clearer about their differences. At the beginning he spoke very quickly, often rather confusingly, and there were clear examples of *thinking with* the different narratives. As the conversation progressed, he slowed down and was more able to *think about* them. When we met for our second recorded conversation about 3 months later he said that the first had been like "therapy", more useful than many hours of talking to other people, to "structure his beliefs". He described it as "a weight lifted off me". He also said that talking about the possibility of taking a more interpretive attitude to his voices, and being less controlled by them, made it more possible. He did not find this mysterious, but said that he felt it would be the natural consequence of talking about other things, too. In case all this appears a reason for my self-aggrandisement, I should also mention that he said that the conversation would have been just as beneficial had he had it with a brick wall! Ross seemed to have swung more strongly in favour of his "medical" narrative, although he had "gone down the rabbit hole" one more time for a couple of weeks about a month after our first conversation (he did not feel that this was related to our conversation, but rather just something which happened one night when he could not sleep). This time, however, he had managed to "keep a rope tied to help him get back up".

I have learned quite a lot about certain ways of thinking just through having psychosis. Through going down the rabbit hole, believing things in that delusional way, I believed what I heard was real, being in that mindset for so long sort of helped me to work things out more. So, once I did come to terms with it being part of my subconscious, I was able to look back on the experiences that I had in the past when I had believed the things that I heard and interpret them in a different way. What would have been an embarrassing moment in the past, I can look back at now and laugh. There were things that the voices would have said to me and would have convinced me that were real– things like that I had special powers, or something. The voices would constantly tell me things like "you are special", or "you are unique", "you have some sort of ability that other people don't". I believed that for so long, but I can look back at it now... The first thing I would think of when looking back is that I would be slightly embarrassed, or I would cringe at the memory. But now I can laugh about it to myself, And I do that quite a lot now – Just walking down the street I will laugh– and I look back and I think,"well why did I believe that?". I think that's quite interesting, that I was so convinced that I would believe something so outrageous. Like having special powers....

...Well the main thing is that if I had heard a voice saying, "don't do this", in the past, I would've believed it. For example, in the past I've heard a voice saying, "don't take the medication, it will screw you up". In the past I would have completely believed that.... But I've become more confident and more in control of it.... And I thought... If I can control my thoughts just by the way I think then obviously, it can't be other peoples' voices. I have to have, I think that belief, that delusion, go down the rabbit hole completely, and almost lose my mind, to actually come out the other side more confident that it was the opposite.

I'm looking it it in less of a literal sense, I am interpreting the voices more. I'm learning more about the things they say, even though they are less common as a result. And I think that because of the fact I am looking at them in a different way, that they also behave in a different way. So in the past, when a voice would have said something outlandish and I would have believed it, as a result they would then say more outlandish things that I would then go ahead and believe. But now, I am more in control, and the voices are now not pretending to be other peoples' voices so much. In the past they would always identify as the voice of the person I knew in real life. Now, if I give that voice a name, and the voice says,"Why are you calling me that name?". Since I have come to accept that it is just a voice in my head, it now behaves more like a voice in my head. Which is quite interesting... it's also quite refreshing...

...So before they were conflicting, provoking, Pushing my buttons... Now, because I'm not letting them push my buttons they are now more helpful. And I'm not getting wound up by them and they are now behaving differently as a result.

The voices had gone from being a source of anxiety to being less dominant and often being a comfort. This led to an unexpected difficulty: the voices had also become quieter and there were now times when he found it hard to hear them distinctly. Yet, their new role in helping him with his anxiety, including saying things from a range of perspectives he felt that he would not have had access to otherwise, meant that he was concerned that they might become too quiet. Thus they seemed to have gone from something to be feared, to something which could be accepted, to something which could be cherished and even mourned.

#### **Relationship with services**

Ross' relationship with mental health services was striking to me. The first question surrounds medication. In this account, and in Ross' own mind, the role of different ways of thinking is promoted as having a causal effect on his experiences and his well being. What of medication? Secondly, If he could have been helped by talking with a brick wall, why was it that up until our conversations he had not told anyone the details of his voice-hearing experiences?

I have tried three; Aripiprazole, Risperidone, and Olanzapine. Olanzapine was similar to Aripiprazole in the way that it was quite long acting, but as soon as I was taking it after half an hour I felt physically like I was drunk. I'd walk around and I feel – it messed my balance up, like my physical sensations, I felt physically drunk, I'd slur my words, I felt like it was slowing me down. It felt like I was drunk but without any of the positive effects of being drunk. But both Aripiprazole and Olanzapine... they gave me this in emotional sense of being numb... My whole creative ability. I study [an arts subject] at college. In my free time I like drawing. That's basically my main thing, it's the main thing I have got going for me. I love art, I love drawing, anything creative... that's my passion. And when the medication killed that off I really didn't want to take it any more.

Ross said he felt that his creativity and his emotions were linked together.

I have been on... next to the highest dose of Risperidone every day for about eight months solid. And there has been no dent in it. I accept that they are going to be there.

...all the medication does is it makes them a bit quieter. A bit less intrusive but I have accepted the fact that...they will probably be there for the rest of my life.

I have found that there is no real correlation between when I am on the medication, when I would be off it, no correlation between being more psychotic or less psychotic.... Taking the medication over a long term has meant that the voices are a bit quieter, but even in the past when I have been feeling more psychotic, the medication would be working, In the sense that it would be dampening down the voices, but as long as I was still able to make out what they were saying then they would be able to make me feel anxious.

...The way I understand the voices is completely down to my own personal thinking.... I think the medication just stops the voices from becoming too intense. So, if I was in the more delusional mindset, it stops the voices from getting too powerful, or too loud. Because, there was a brief period where the voices were so loud that it was almost like there was just constant noise surrounding me all the time. I did hit cars driving past that weren't there. I was hallucinating. I wasn't just hallucinating voices, I was hallucinating sounds. I would hear music. Not just like you can hear music in your head, it was like there were speakers next to me and I could hear the music. A few days I couldn't go to sleep completely, because it was just too loud. I think the medication, in that situation, it stops it from getting like that. In the short-term, anyway. I think in the long term it does just generally quieten down the volume as well. So, I think it has been helpful tool, But the main tool has been my own understanding and thinking. The medication has just been like another tool to help.

One final comment that Ross had about medication was that he felt there had been times when the lethargy associated with taking it (especially early on, before building up a degree of tolerance to the sedation) actually gave him less strength to avoid the "rabbit hole". He was more willing to sit for long hours and engage with the voices than he would have been otherwise, he felt. Eleanor Longden has claimed that medication led to a proliferation of her voices and an increase in their intensity (2010), and I wonder if Ross' description helps me to understand how that might occur. It is only possible to establish the detail of Ross' subjective experience of medication, not to objectively verify either its efficacy or lack of it. Perhaps it is not right to say that his understanding of the voices has been "completely down to his own personal thinking", or perhaps the medications have in any case altered that thinking. There is simply the additional (unknown, narrative) account of his psychiatrist, whom it seems reasonable to suspect does not know significant parts of Ross told me.

Given that Ross so appreciated the opportunity to talk, and claims to have found it so helpful, why has this kind of conversation not taken place with mental health professionals, with whom he spends weekly contact (nurses) or monthly contact (psychiatrist)? I decided to ask him. Firstly, what was the team's response to his recent "trip down the rabbit hole"?

...I think somebody said, "you are a bit quiet lately", but I just said "nothing is wrong". I think other than that, I was just generally a bit more withdrawn.

I think, and I have been told by some of the care-workers that I am more independent compared to a lot of people who seek our psychiatric help. I think that because of the fact that I am so independent, I do pretty much everything on my own, going to college, apart from living at home, I think that they don't see me as like the high risk member.... so I am not given... as much one on one help as other people might be.

Yet he also expressed doubts that others might be getting more from the service:

There's no real talking about peoples' individual experiences. And like I said, if there is a problem, if people seem to be acting a bit differently or saying different things, then the response is to quickly increase the medication. I'm sometimes apprehensive about talking to some of the staff members here about my experiences because it might affect my treatment. So, for example, I might not want to have my medication dosage upped. So, I won't complain that I'm feeling more psychotic of late... My biggest fear at one point was being hospitalised. I didn't want that, I didn't feel that I needed it, but there was a point when I did go through a short breakdown and the doctor said to me, she said 'we can offer you hospitalisation'. And I really didn't want that, and she said that they would keep me at home. And I thought – "that was too close!" The last thing I wanted to do. It's probably biased but I have maybe some expectations of that hospital experience being quite negative. It is something I have desperately tried to avoid. I think that fear has put me off expressing things openly because I feel it might affect my treatment.

And as I said, I wouldn't be more open here, because I wouldn't want stronger medication thrown at me and to go through the whole period of having to deal with the side-effects of medication all over again.

I think a lot of the time... you are just seen as your diagnosis. The doctor sees that you've got psychosis, you've got schizophrenia, you've got bipolar or whatever so I think the doctor a lot of the time sees you as your diagnosis. Perhaps not seeing the whole person.

I don't think I had any preconceived notions of what psychiatry was going to be like. All I remember was that the first thing that the doctors said to me was,"We'll be able to help you but only as long as you keep taking your medication". You must take medication otherwise you will get in trouble. If I didn't... I have always thought it was like a battle, you are expected to take medication and if you don't take medication then we can't help you.

Me: The good will disappears?

Ross: Yeah

Me: Sounds a bit threatening, really?

Ross: I almost felt intimidated by it. What if I don't want to take my medication? The belief is that you have to to all you will definitely get worse. And I don't think that is going to be the case.

There was another barrier:

Ross: You are accepting that [voices] are a part of yourself. The more you fight with them, The more you try to suppress them, the more problematic they seem to be. It's like the whole thing I said, you can't control your thoughts but you can control how they control you.

Ross felt that the team conceptualised voices as basically pathological, and therefore unacceptable. I noticed that the only time he consistently used the word "psychotic" was in relation to what doctors say, in contrast to the "medical" story he has discovered for himself. He described an inability to trust the intentions of the team, and agreed that it was only the confidential nature of this research interview which made it possible to speak. If readers agree with Ross that there is something vital about his journey to understand his experiences and gain agency through connection to new stories, then they will feel that this represents something fundamentally awry with the service he has received, whatever the manner and intentions of the staff providing it. Ross' use of "medical" as a story with a quite different meaning to psychiatry's use of "medical" has led me to an idea which is really a simple way of expressing so much of the debate about the science about psychiatry: Is biology nothing until it is storied? Many contrasting *oughts* from some (decidedly doubtful) *is's*? Ross has a non-pathological bio-story, psychiatry has a pathological bio-

story. Perhaps the "common human experience" of the HVM is yet another. Do any of them have a shred of good biological science in support? This is a question I will return to in the final chapter.

Ross seems to be doing very well. However, I am left with two concerns about him. The first is that he hopes to ask the team to reduce his medication. He has already said that the team may be friendly but it seems conditional on taking medication. His plan is to tell them that he wants to reduce the medication because he feels that sometimes he cannot hear the voices properly and he misses them. What they will make of this reasoning? Secondly, if we are to take seriously the critique of medications discussed in response to Angela's story, then there is even a sense that a clock is ticking somewhere, that it may be that Ross' new ability to take some control over his mental experiences and his emotions are conditional on preventing longer-term medication use.

Me: do you think they'll see it that way?

Ross: Well, I hope so, otherwise it... changes the goodwill. I want to be in control of my own treatment. I don't want to be told that I have to receive medication if I don't feel like it.

## Section 3 Limitations and evaluations

... [t]here is not, nor should there be, any method of narrative analysis, if method is understood as a prescribed set of steps that the analysis should follow. A method, in the prescription model, serves as the guarantee of its final production: a guarantee that findings will both turn up on schedule and meet collegial standards to publication, that publication being the accreditation of the work as worth taking seriously... (Frank, 2012, p72).

The above quotation makes it difficult for me to reflect on this project as a whole and say anything easy about its limitations. It is tied to an epistemological position and to certain kinds of refusal, I hope very defensibly, but, as such, many of the things one might question are more of a criticism of the whole approach rather than this specific work. It would be difficult to investigate those without also giving the whole thesis once more as an answer.

One of the first questions is whether I might have extended the interviews to mental health professionals, the public, "carers", film, or something else. This is rebutted by saying that with an approach that choses not to ring-fence what is seen to be relevant then certainly *resources will be an issue* and, although other choices could have been made, they would have been made at the expense of what is here. "[H]istories of madness often omit the voice of the person living with the experience", something for which even Foucault is criticised (Sayce, 2016, p18). A greater mix of participants would not have made this "sample" more "representative", since that kind of representation is not a goal.

Secondly, it might be noted that a great deal of what is brought into dialogue with my participants relies upon me, my reading, my views, my own stories. This is rebutted by saying that yes, that is exactly what has taken place, but that it is not seen as a weakness of itself in this research. I tried to give of myself while keeping others central, I wrote much more material and deleted huge sections, and it will be up to the reader to judge whether that has been done well, since there is no template for me to follow, unless it is the goal that people should be helped in some way. I tried to give of myself in a way that upholds others' value and dignity, emphasising what we share, meeting people, not categories. If that is *nursing* then I would be happy to call it that.

Therefore, for me there are other ways to evaluate this work. As they read, does the reader care about and identify with the participants? If the reader does not agree with my views, have I at least given them enough for them to understand something of how I became recruited into them?

Perhaps the largest single barrier that some will have to this research is the handling of literature. I asked a PhD supervisor from a different discipline, Latin American studies at Cambridge University, about my handling of literature. The clear message was that none of her students do something like a "strategic review" and that, in her view, such handling of published material belongs particularly to the natural sciences. The fact that this was such a concern of mine causes me to wonder again if it shows something about the uncomfortable interface of the sciences within the world of Mental Health, my home-culture. From deciding that a "strategic review" was not right, and in combination with my realisation that I needed a map try to reveal why there is such heterogeneity, it was but a short step to dispense with a separate literature review chapter and make the literature flow through the whole text, along with the transcripts of interviewees, as stories to consider. However, I know that this will be seen by some as unsuitable. My head-of-department expressed horror that I was following academics on Twitter as part of my research; it would skew the literature towards certain users of social media (rather than the "unskewed" results of a database search). I simply do not agree (a) database searches are "unskewed" or even

qualitatively better and (b) that DNA should be less interested in Twitter than in any other form of published material.

Fundamentally I hope that the choices I have made about literature in this thesis reflect the DNA desire to "open up" rather than close possibilities. I hope that my approach is seen as more honest in this contested field and I also think it is likely that attempting to catalogue and comment on the literature in the manner of a strategic review would have left almost no words for the interviews. The truth is that I am *still* reading, and not merely newly-published material to ensure I "have it all": I have not got it all.

The research failed to engage the non-patient population of voice hearers, as already described. Perhaps I should have used the Internet rather than print-media. Perhaps the non-patient population is very small. It would have been valuable to find them, however.

#### Originality

The question I have struggled with most, from conception to completion of this project, is that of originality. The American Gail Hornstein's book, Agnes' Jacket (2012) was published the year I began this research. It is a book dedicated to first-person narratives from people within the Hearing Voices Movement. Many of her key findings are duplicated here: that "psychosis" is often meaningful and even positive, that diagnosis in no way predicts outcome, which may often be one of recovery, that people diagnosed with psychosis can build warm and trusting friendships and can help each other, often more than they are helped by professionals. Like me, Hornstein even argues for the futility of scientific attack on the DSM and suggests that first-person narratives make it irrelevant, hugely shifting the frame of reference (Hornstein, 2013), although I have tended to make the case that arguments about the science tend to mask the politics. Added to this is the question of whether this work adds anything to the expertise of the Hearing Voices Movement in general. In answer to that all I can say is that (a) I am not responsible that the same arguments may still be glaring; (b) this work is a DNA of literature and interviews, and also suggests problems between stories which are not unique to psychiatry but are part of the HVM's difficulties too, which may make it a less common kind of text; (c) this work is about me, a nurse, and a particular group of people, and so in that sense its local nature makes it unique, just as Hornstein's book was unapologetically personal to her.

And finally, the title: I am not sure that "hearing voices and emotions" remains the right title. The piece became more about the politics of experiences that surround voice-hearing. However, my suggestion is that one led to the other, and I would like to leave it to the reader to decide if the title is right, or not.

## Possibilites

Dialogue refuses what monologue aspires to.... Finalisation (Frank, 2012, p97).

Non-dialogical social science methodology seeks validation for analyses: interpretations must have some guarantee that excludes other possibilities. Dialogical analysis has little interest in excluding – it welcomes the proliferation of possibilities, which confirms that the story or stories can never be finalised. From a dialogical perspective validation risks imposing... "Somebody else's rules". The dialogical position is that interpretations are valid when they are responsible.... interpretation is responsible when it opens, not closes; when it creates links to more stories, anticipates effects, and asks why some stories affect judgements rather than others (Frank, 2012, p110).

But above all, one sees that the focus of critique is essentially the cluster of relations that bind the one to the other, or the one to the two others, power, truth and the subject. And if governmentalization is really this movement concerned with subjugating individuals in the very reality of a social practice by mechanisms of power that appeal to a truth, I will say that critique is the movement through which the subject gives itself the right to question truth concerning its power effects and to question power about its discourses of truth. Critique will be the art of voluntary inservitude, of reflective indocility (Foucault, 2007, p263).

These three opening quotations foreshadow the style of my final section. They suggest that there is an important choice not to "conclude": the reason for the title of this last chapter. To be responsible, dialogue should continue, providing engagement rather than assertions (Frank, 2012, p197) and no definitive story (Carr, 2008, p30). Unlike some other qualitative research methods, establishing causation is not especially a goal of narrative research (Glaser and Strauss in Wertz, 2011: p56). Yet DNA is not resigned to moral relativism (see below): stories can and should be evaluated, although not in an effort to exclude them. I need to make some suggestions about what might happen if dialogue is to become more prevalent between the various stories about voice-hearing and emotions I have encountered. There is a call to remember that none of this happens outside of systems of power which may actively discourage dialogical ideas.

This chapter follows the following structure .:

- Firstly, I will re-assert that this research shows that more dialogue is responsible and imperative, and here I will also allow myself to draw together some thoughts about the monologue of psychiatry.
- Secondly, I want to make some suggestions about what more dialogue might look like.
- Finally, although there are many themes I might chose to bring into a summary, I focus of the role of "researcher" versus the role of "nurse".

#### 1. More dialogue is responsible and imperative

The existence of strong monologues which may make dialogue very difficult in a field as contestable as mental health, with such high stakes for individuals and society, makes the suggestion that more dialogue is imperative very obvious. My experience as a nurse and now as a researcher is that dialogue between stories is more respectful, validating and enabling of those in distress, and monologues do much to promote the interests of professionals and institutions: the two sets of interests do not seem to overlap enough. Frank (2002) is not alone in noting that the storied nature of experience leads directly to ethical questions:

If... our lives are constituted through narrative, it really is not possible for us to take the position that 'one story is a good as another'. Moral relativism is ruled out. Instead, we will be making it our business to attend to the real effects of those stories which constitute

persons' lives....I don't think there is any constructionist position that can escape a confrontation with questions of values and personal ethics. In fact, according to my understanding, the constructionist position emphasises these questions, and elevates this confrontation (White, 1995, p14).

### **Responsible biology**

I feel that it would be irresponsible if I failed to draw attention to a suggestion raised in the chapter with Ross about biology, and also with Lisa and elsewhere. This focusses on one specific monologue within the set that comprises knowledge about hearing voices and emotions: biomedical psychiatry. From the moment psychiatry appears as one extreme position on my map in a way which may implicate it with a particular politics (and certainly with a very particular notion of selfhood and agency) that conclusion was predictable; *it would be strange if a philosophy which disregarded so much could have a science that did not.* 

Background reading to this study has included as much genetics and neurology as I could justify. I have not, however, recognised the stories I have witnessed as upheld by biology, the science. From this research and my previous reading in the philosophy of science, I find that it makes sense to understand the use of biology within these participant stories, and those around them, primarily as stories. For example, the term "hallucination", Ross' unusually liberating "medical" and the "common human variation" story of the HVM show us that one can tell different biology stories about the same bodies and achieve very different narrative outcomes. I am aware that this is a controversial thing to say. Even as I write another article (BBC, 2016) has appeared in the mainstream media that claims that 108 genes are implicated in schizophrenia and that mental illness is inherited<sup>31</sup>. I am not a geneticist, but I do know that (a) again, the category "schizophrenia" is considered invalid (Insel, 2013; Bentall, 2006 and many others) and unreliable (Johnstone, 2014 and many others), and (b) my suggestion is that none of the stories are actually altered by the addition of knowing "genetic markers", neural pathways, etc., because it is the story that creates a priori the design of the research and the meaning of such findings, which, in any case, are usually future-myths, old refuted myths, or contain mythologised possibilities<sup>32</sup>. In just the same way. I am not aware that the "neuro" of "neurodiversity" contains much neurology. If it did it would fall foul of all of the various problems which might be summarised as difficulties of correlation and causation. It is just another storying of biology for certain ends, yet that does not prevent its proliferation. Although my first chapter began with Dennett's assertion that there is no philosophy-free science. I think I may make these points about "biology" without entering the more difficult realm of whether there is ever fact without value, science without story, since we are talking about the grossest possible storying imaginable: for some the "biology" is proof of pathology and exclusion from the set "normal"; for others the same data is proof of legitimacy, non-pathology and the basis for inclusion in the set "normal". Perhaps I am using slightly different language, but I think this conclusion about psychiatry not using biology-the-science but merely "biology stories" is essentially the same as others noting that the power of psychiatry is broadly ideological (Morgan et al., 2015, p72).

Therefore, within a chapter that aims to consider the responsibility of stories, I begin as I began the whole thesis, by saying that few biological stories about voice-hearing as they are currently formed can be responsible because they claim not to be stories at all, monologues hiding or decontesting

<sup>&</sup>lt;sup>31</sup> I notice that critical psychologist Professor Richard Bentall has already referred to it as "bollocks" on Twitter, and some suggest that he write another letter (see Bentall, 2016, for a slightly more developed argument!).

<sup>&</sup>lt;sup>32</sup> The "108 genes" story falls into this last category, because the real message of that finding, were it to be reputable, is that it suggests that we are further than ever from able to alter the experience of "schizophrenia" genetically yet the implication of the article is that the finding is a breakthrough which will lead to cures. See also a recently released a short video by the influential neuroscientist blogger "Neuroskeptic" on "The Myth of the Brain" (Neuroskeptic, 2016).

that which is most distinctive about them: personal and cultural valuing, and in a manner which hides the idea, strongly suggested by my participants, the HVM and by work such as Lurhman's (2014) that voices are culturally reflexive, interactive/historical/parochial *storied* kinds. For a responsible set of stories, we need a new biology of distress found from within a more enlightened political philosophy of biology. I think this is as true for "common human variation" as it is for "schizophrenia", and, for that matter, sexuality; uses of biology in these debates so often turn out to be biological stories rather than biological science. What I have seen on all sides are various "appeals to nature" at the philosophical level of shampoo adverts.

Mercifully, ideas suggested by Stewart & Cohen (1994), authors who influenced the beginning of this thesis, are now gaining traction year on year: emergence (complexity and simplicity), epigenetics, recently discovered Lamarckism, and neuro-plasticity; these are all words which convey that the monological "biology" of experience invoked by medical models in psychiatry, such as the ones articulated by Becky, Angela, Lisa and Mel (and, I feel, the key factors in the stories surrounding John, Jenny and Rosie) is not modern biological science at all: biology in the 21st century is already dialogical. Khalidi (2010) produces an rigorous exploration of Hacking's *interactive* that suggests that some natural kinds are interactive too: philosophy of science that once again directs us to the idea that such binaries break down and each time they do, dialogue emerges as yet more essential.

Other researchers in the field of mental health are writing about this, with Blackman providing a rich commentary about the possibilities of epigenetics with questions of "embodiment"<sup>33</sup>. Cromby writes from the need to "facilitate an embodied psychology" (2015, p8). Thomas & Longden raise possibilities for the "Traumagenic Neurodevelopmental" model, in which, through synaptic plasticity, the role of neurology as a *determining* factor in experience is greatly reduced and must be placed in dialogue with experience (2013, p2). The key point for these texts is that there is no body without embodiment and this makes dialogue essential. I want to emphasise that this is not simply as an adjunct to science: the argument is not that a dialogue *between* science and culture is needed, but that scientific biology *is* dialogical.

However, I cannot claim that biology seems so often to be nothing until it is subject to emplotment, without anticipating that many of the ideas above, including Dias and Ressler's Lamarckism (2014), will be rigorously used for entirely opposing purposes. If there is a complex relationship between genome and environment, including the acquisition of characteristics through the environment of ancestors, then some will say that this proves the environment is the only really important factor, and others will find it confirms their belief in genes as causal. Hidden in this (not far below the surface) will be all of the usual fears about blame and responsibility, and various kinds of notions of individuality and agency, mind and body, probably leading to an array of responses found right across my map: they are fundamental stories we use and they are deeply problematic. On this cynical note, I think my map would also endorse the view that if there is money to be made from certain emplotments then those will be the ones which are most successful at decontesting themselves.

## 2. What would a dialogical approach to hearing voices and emotions look like?

I very much hope that a more dialogical approach to hearing voices and emotions would look like the kind of work I present in this thesis. Such work could lead to radically different experiences for voice-hearers in the UK, who would (inevitably) be presented with many more ideas and options. I particularly recall Angela's assertion that alternatives - their mere presence - change everything. Lisa reported something like an awakening from ten years of stasis as she began to hear other

<sup>&</sup>lt;sup>33</sup> Blackman also speaks to the problems I have referred to as the "thin version" of narrative self - a replacing of the "molecularisation of persons in biology" with "atomized conceptions of the autonomous, bounded psychological subject" (2016, p260).

stories, even if the initial stories she found later became less important. The stories of my participants suggest strongly that currently it is by leaving mental health services that voice-hearers increase dialogue. In general, that echoes my experience too. I have tried very hard to hold back, but this is one moment I will allow myself to say what must be obvious: my belief that for Becky, Claire, Angela, Lisa, Matthew, Steve, John, Jenny, Rosie, Amber, Mel and Ross there is reason to understand stories as being not at all coincidental to their experiences, and that it is within storying that a future with less suffering may be found, with a great deal of caution and with diligence to prevent others' interests taking charge, and ensuring that narratives neither become too thin/ internal nor indeed too thick/external, deflated or inflated. Perhaps readers can imagine a safe way to do this *without* a pluralist practice of dialogue within a re-politicised landscape, aided by one-to-one and group discussion, in a non-individually pathologising manner, but I cannot.

#### Medical and Legal power

Actions, powers and professions that are currently possible because of the monological nature of the field would be highly challenged by dialogue. Coercion would be much more obvious and more difficult to justify. Grounds for using the Mental Health Act would be difficult, since it relies upon the monologues of medical stories: one is detained by virtue of a combination of "nature" (that is, diagnosis or suspected diagnosis), risk and that the condition is "treatable" (almost exclusively medical treatment). Under a more dialogical mental health system, if voice-hearers were detained, it would not automatically follow that forced-treatment would be possible, since the existence of other explanatory stories and possible actions would make it difficult for the actions required to medicate someone against their will to be justified: as Smith reveals, the genre has to be apocalyptic to take a democracy to war (2010, loc 340). More dialogue alters the sense of what is a last resort or the choice of least restriction. This would drive a wedge between detention and "treatment", which, in turn, alters whether hospitals with doctors and nurses remain the obvious first choice as a place of safety. Often, the severe side-effects of psychiatric drugs are accepted because the stories produce the idea that there is no alternative and this means that we could expect there to be a growing sense that psychotropic drugs are risky and not the first option, not only for voice-hearers under the Mental Health Act, but more generally. Long-term use (perhaps unless requested by the recipient) might be a casualty of dialogue, too, since what can be justified to combat an immediate risk or need is less possible as a long-term response.

Joanna Moncrieff's replacement of "disease-centred" with "drug-centred" models (Coles et al., p214) may provide psychiatrists who are feeling uncertain about "mental illness" with a means to disconnect their role as prescriber from the political and aetiological problems of diagnosis. Psychiatrists could recommend drugs and voice-hearers could accept them, without anyone needing to manage the narrative conflicts they might feel if they also find it helpful to view voices as part of other stories. This would be liberating both within the mental health system and within the HVM. It might be that this will be either a vehicle for psychiatry to continue to legitimise itself even after accepting more dialogue, or it might lead to an inability for psychiatry to retain the power of their stories, or even increase their reach, with all kinds of consequences, intended or otherwise<sup>34</sup>. Nevertheless, in her work I feel Moncrieff provides a template for what might be called *dialogical prescribing*. One in six people in Blackpool cannot be prescribed anti-depressants (Easton, 2013) under a "drug-centred" model *and that be the end of the conversation*.

Yet once a set of monological stories are enshrined in law, increasing dialogue seems a great challenge. Is dialogue really possible under the power of the Mental Health Act? Currently the law supports and demands "treatment" for diagnosed "mental illness" and "treatment" (especially for concerns such as hearing voices) generally requires the law: that is a lot of infrastructure, expectation and very well paid jobs. The law is the only safe recourse for a professional needing to defend their practice. Pilgrim and Tomasini provide a fascinating critique of the Mental Health Act

<sup>&</sup>lt;sup>34</sup> For example, a *greater* proliferation of medications if they cease to be tied to diagnoses. See Neuroskeptic (2015) for discussion of another suggestion beginning with drugs rather than diagnoses.

(Coles et al., 2013, p77), as does Bob Sapey (forthcoming) which also draws our attention to the concerns that the United Nations have and conflicts with the European Court of Human Rights. But whereas their critiques focus on the many dubious concepts of risk assessment and overstated risk relative to the general population - a "legalised discrimination" (Sidley, 2015, p62) - and the conceptual medical framework upon which it rests, this DNA raises the notion that without this law, monological psychiatry could not exist and without monological psychiatry, the current law is unusable. I think it shows this because (a) other stories exist in which voice-hearers are so interested and attracted that they form international movements to promote them, and (b) those stories in large part remain unacceptable within mental health services (and connection to them detrimental, as Jenny and Ross reveal so well), and (c) the story of the Mental Health Act belongs to the left of my map and not to the whole of it. It is hard to imagine how a change to a less monological approach to voice-hearers could be smooth, could happen without Foucault's voluntary inservitude and reflective indocility. This understanding of the role and primacy of the Mental Health Act is not in any way original to me. Bracken and Thomas brought it into focus in their 2001 article entitled, Post-psychiatry, a new direction for mental health (2001, p724). Fifteen years later I can confirm that psychiatrists, social workers and nurses are still shocked (tearful, even) when the ethics of the Mental Health Act examined by a lecturer.

Put simply, there would be a monumental shift in the balance of power between voice-hearers and State under a more dialogical system. This is why so many are beginning to use the phrase "paradigm shift". One does not need to be a Smail recruit to suspect that incremental change cannot achieve what is needed (Sidley, 2016).

## Increased visibility of trauma

If dialogue about voice-hearing increased, one could expect a shift in understanding in the mental health service and within the public towards more trauma models. One of the strongest counter narratives to the ununderstandable psychosis of psychiatry is "voices-as-dissociated emotions", currently most strongly driven by the HVM, especially by writers such as Dirk Corstens (Corstens et al., 2014). This essentially psychodynamic perspective could lead to a shift in the "Overton Window" of the psy-disciplines, making Freud, Lacan, Jung and their modern counterparts, such as Darian Leader (2012) possible figures for mainstream study for the first time in forty years. There is some evidence that this may already be taking place (Burkeman, 2016), but, beyond some of the critical perspectives I have introduced, the dominance of CBT within psychology (Coles' "hard spot the difference") remains prevalent at this time. Dialogue would also help us retain concern about over-emphasising or universalising the role of trauma, just as it did with Lisa and me.

This shift might include suggestions that "diagnoses don't work for everyone". Some of this work is being done already by the British Psychological Society's *Division of Clinical Psychology*. They have created several documents which advocate a less monological approach to distress in society, including voice-hearing (Cooke et al., 2014, Cooke, 2016). They are currently finalising a short information booklet for service-users and carers exploring diagnosis as something that is only one way of understanding persons and something about which caution is required. All of these documents represent a growing confidence and power for psychology in the UK, and it is gratifying to see that some of the authors are as ardent in their criticisms of individualising and pathologising stories of psychology as they are about the evidence and effectiveness of psychiatric diagnosis and treatments (Coles, for example, is the chair of the "Beyond Diagnosis" committee writing that leaflet). A relatively new textbook (Cromby, et al., 2013) completely excludes the phrase "abnormal psychology" for the first time, preferring terms such as "distress". How different Angela's life might have been had that been her A-level textbook.

However, just as nuanced versions of psychiatry tend not to counter illness storying, it is probably wisest to assume that most psychology tends to "psychologisation". At the time of writing, the security firm G4S is advertising for CBT therapists to conduct 'back to work advice and guidance' in UK job centres (G4S, 2016). Authors such as Freidli and Stearn (2015) make their views clear:

The use of psychology in the delivery of workfare functions to erase the experience and effects of social and economic inequalities, to construct a psychological ideal that links unemployment to psychological deficit, and so to authorise the extension of state—and state-contracted—surveillance to psychological characteristics (Freidli & Stearn, 2015, p40).

In addition, I have not forgotten that it was problematic notions of "coping" and "resilience" that first alerted me the political nature of emotions and psychology, leading to Smail and in turn to the creation of my map. Psychology depoliticised is just as dangerous as any other monologue. Trauma and psychology stories require very careful dialogue too:

"Stop calling me resilient. Because every time you say 'Oh, they're resilient', that means you can do something else to me. I am not resilient" (Diprose, 2014, p54).

## More visible philosophical problems

In the opening chapters I suggested that much of this work spoke to contemporary versions of

- The mind-body problem
- · Freedom of the will/agency/theories of action
- The philosophy of personal identity/selfhood.

My map suggests ways in which the three problems are not possible to hold apart. So much of Frank's DNA is about the ways in which stories make certain actions describable and possible, virtuous or otherwise. So many of the different stories evoked by voice-hearers here alter who or what may be considered responsible or hold agency for their experiences. Psychiatry is seen to be both product and producer of particular stories about "the will", "individuals" and "bodies". Changing *the will* into Smail's distal and proximal power, individuality from *the psyche* to something more distributed and socio-narratological, *bodies* to embodiment: these are all bound together. Perhaps more dialogue for voice-hearers will make visible these philosophical problems from within the stories in which they have been hiding. The section above about dialogical biology is essentially the mind-body problem articulated in contemporary language. Some will say that, surely, I cannot be suggesting that mental health nurses need to learn *philosophy*? It is exactly what I am suggesting: or we can be bad philosophers.

I feel conflicted about nursing interest in Fulford's extensive work on "Values Based Practice" (1989; 2006, ch20; in Radden, 2007, ch14). Fulford's analysis is driven by Hume's is/ ought dichotomy (Fulford, 2006, p126) and leads him to an ethic that voice-hearers are treated well when they are offered many options, or that diversity of values is recognised. From his first published work on the subject (Fulford, 1989) Fulford has always claimed that within the field of health, values are "legitimately diverse". That might seem perfect, dialogical, but is that interpretation political enough? Is this diversity innocent? I believe this is a significant question for mental health academics to be addressing, even while we may welcome such publications as his recent high-calibre multi-authored collaboration (Morgan at al., 2015), representing a growing awareness about the ideological nature of evidence and the philosophies upon which it depends. Does this suppose too much that voice-hearers have a firm "is" to have "oughts" about? If so, that would not reflect the necessary reflexivity, Hacking's looping effects or the extent of Blackman's embodiment. Fulford certainly acknowledges that science is not a value-free enterprise, but for him the general direction of flow is that new science leads to new and more involved values-based decisions, such as with fertility treatment (ibid, p47). Can psychiatry really be compared with something like fertility treatment? People certainly feel that fertility treatment contains difficult ethical issues, fertility treatment occasionally has serious side-effects too, but are groups of infertile couples forming international political movements to protest about the *concept* of infertility? It is not until the fifth chapter of Fulford's new collaborative work that political concerns are raised, with the

sentence, "[u]p to this point in the book, we have largely considered the issues of ethics and values as though they occur without a societal context" (ibid, p69). What, then, is the reader to do with the first four chapters? It seems to me that the reader is left with the hard work, with the possibility of a de-politicised idea of values being promoted (because they are *legitimately* diverse) and a depoliticised version of evidence too (because I do not feel that evidence is treated in the same manner as values - a legitimate diversity leading to the need for dialogical practice - but rather as something which values should be considered alongside).

I wonder if my unease at Bracken et al.'s (2012) "technological" has the same root: despite the clear political view of the authors, does it risk painting the science as brave but mistaken, or in need of updating, rather than suggesting it is not, and never was, particularly scientific at all? I think it makes more sense to think of this "technological" being all about maintaining certain kinds of power and privilege from the very beginning, and if those involved felt they were being "scientific" it shows the extent to which they were recruited into certain self-serving stories, metanarratives or politics<sup>35</sup>. And, if this is the case, can Fulford's idea of "dissensus" be the right one? "[D]ifferent values remaining fully in play to be balanced sometimes one-way and sometimes another according to the particular circumstances of a given situation" (Morgan et al., 2015, p59)? As Lucy Johnstone said to me recently: "I hate the word balance. Balance means not challenging the status guo". If there is to be a paradigm shift towards the hermeneutic, where is the evidence that current mental health professionals will be the people needed to champion it? As well as considering Frank's Chaos, Restitution and Quest (Frank, 2012, p118), we need to think more about what I have described as mechanical narratives, and ask why they are so prevalent in psychiatry. We need to get good at identifying them and all of their associated language and actions, care plans and regimes, and ask whom they suit and what politics they belong to.

## More visible political struggles

The above leads to the most obvious of suggestions in this chapter, yet, in a field where "evidence" is often considered to be the quest to hone the perfect "health" monologue (a close relative of "best practice") it is still far from obvious to many that politics are relevant at all. The HVM are a political movement and documents such as the 2014 Thessaloniki Declaration (appendix 5) make no sense at all if answers for voice-hearers will be easily found within existing structures. Inclusion of the right of my map is re-politicisation: externalising "...brings the world into therapy and... makes the personal the political" (White, 1995, p50). Indeed, an intriguing guestion to consider is what effect a more dialogical approach to emotions generally might have on the politics of society. If "mental health" services became more dialogical, would there be a change at Westminster? It seems certain that the "Overton Window" of emotions would be altered. There could be an increased sense of the importance of collectivity and systemic explanations. Perhaps mental health nurses will even one day lose their strong affiliation for promoting "an internalised locus of control". On a recent internet forum, a socially-minded survivor expressed delight with a Tweet by Lynne Friedli; Eleanor Longden famously has said that voice-hearers should be asked not "what is wrong with you?", but "what has happened to you?" (Londen, 2012, p136), thereby moving from extreme left to middle-left on my map. Friedli's Tweeted response was "Why did that happen to you? What configurations of power & privilege map our fates?" (Friedli, 2016), thereby moving considerably further to the right of my map.

<sup>&</sup>lt;sup>35</sup> I do not want to accuse all psychiatry of "bad faith", as authors such as Burstow do (2015, p164). If I accuse psychiatry of that, then how can I also argue that Becky's use of stories (for example), which might appear to some to be deliberately manipulative, is really an attempt to find her way through the poor quality or conflicted nature of the stories she has been offered? And how can I say that psychiatry is also a product of society's trouble with deeper philosophical problems? I think it is better to make stories the villains, and people only responsible for the extent to which they perpetuate them: closer to White's view (White & Epston, 1990, p40).

I offer my own journey as an example of the kind of difficulty with which a re-politicisation of voicehearing may take place. As I explained in John's chapter, standing in front of Downing Street last year I felt a moral compulsion to get myself arrested. In what way, I have no idea: was I supposed to throw something? It may seem ridiculous, but I walked away very shaken. Searching the Internet for articles on "freedom vs equality" is an instructive thing to do, the resulting heat perhaps being best described by noting that, given their normally positive connotations, the terms have *rhetorical power making them suitable as political slogans* (Gosepath, 2011): as Freeden would say, they *decontest* themselves, housing complex and competing narratives, with the prerequisite of each being a cost to the other. I admit it: revolted by decontested psychiatry I was pulled/allowed myself to be pulled to the other pole. It made me feel powerful, perceptive and with insider-knowledge (like a psychiatrist?). Full of Smail-storying, I found it hard to prevent.

In its prescriptive usage, "equality" is a loaded and "highly contested" concept. On account of its normally positive connotation, it has a rhetorical power rendering it suitable as a political slogan.... At least since the French Revolution, equality has served as one of the leading ideals of the body politic; in this respect, it is at present probably the most controversial of the great social ideals (Gosepath, 2011).

Angela helped me to reconsider the "salvation" stories of the HVM, including my own. Lisa helped me to realise that the trauma and dissociation story to which I have been so attracted (and so useful for Becky, Claire and Angela) had strengths but could be dangerously simple. With Gosepath and my "Downing Street moment" another narrative spell seems to have been broken: I was frequently using the politics of the far-left to critique psychiatry and, as with a number of others currently<sup>36</sup>, I had been drawn into a metanarrative which swiftly became super-inflated and supersystemic. I do not regret this, although the anger that I have experienced has been extraordinary. Nor do I regret my involvement during these three years with the radical psychiatric survivor group, Recovery In The Bin, who reexamine, often brutally, their own experiences of psychiatry through the lens of similar politics, or at least through a rigorous critique of neoliberalism. Many members of that group are being pushed towards genuine destitution by current cuts to welfare and stories of "resilience". Arguably, nurses were naively led into the world of "evidence", trading our better instincts about hermeneutics and our "vocation" for a positivist quantifiable "professional" world; those of us awakening to this abuse of "evidence" must be careful we do not step into political philosophy with the same naivety: once one arrives at the point that the only answer to the question "how can we improve the lives of voice-hearers?" is "have a socialist revolution!" then at very least there is a lack of short-term pragmatism, even if pragmatism does not satisfy Smail (too proximal!). There is a strange realisation here that moderation is valuable. I wonder if this DNA, my map of experience, and my own journey, make it clear that we are attracted to the extremes because of their ability to alter who may be considered agents. Do we dream that without agency there will be no distress? Is that compassion or utopianism?

However, I do not want to mislead: I may be finishing this research with an awareness that equality is another story to hold in dialogue, but at this moment I feel it likely that I will remain of the view that most voice-hearers are caught up in a politically right-wing enterprise which uses the language of biology (but not the science) and tends towards eugenic ends that suit the powerful in society. It was the social justice of John Rawls that most affected me as I first read any political philosophy in 2010 (Miller, 2003, p89). I believe that Hacking's *Cultural Vectors* (2002, p51), Dennett's *narrative self* (1992) and Frank's *socio-narratology* paved my way to being vulnerable to Smail's brilliance. I'm not sure whether reading David Graebber (2014) was strictly on-topic, although David Harvey (2007) was. None of these authors burst like balloons with the realisation that one needs care at both extremes of my map. I sometimes wonder if I am destined to walk from one fundamentalism to another, but this research has got me through some huge and compelling ideas without too much harm: in the final analysis, I hope DNA has kept me from dangerous simplicity, and allows

<sup>&</sup>lt;sup>36</sup> Psychologists Against Austerity, for example, who march under the banner "Equality is the Best Therapy".

me to present this work as unsettled, incomplete and unfinalised: I hope DNA will continue to change my views and direct me to new reading. Next I want to understand further how my critique of psychiatry may have been influenced by the socialist traditions of Britain and continental Europe, and to learn more about why North American scholars write from libertarian stances when they critique psychiatry and we seldom do. This DNA suggests a strong role for culture in the production of 'mental health', and the possibility is that its critiques are similarly produced. A DNA of 'critical mental health' would interest me greatly.

## 3. Voice-hearers, nurses and researchers

In 2012 a young woman for whom I had been community nurse for six months told me that I had been able to help her because I had "treated her as an equal". She was not "a voice-hearer" but had experienced terrifying beliefs accompanying a period of elated mood and sleepless weeks. When I qualified in 2001 I would have said that I treated service-users as equals, of course. But when "mental health" problems are located within persons they are not equals.

I was trying to hear voice-hearer's stories long before I started this research. It is possible as a nurse. Yet in this research there were many indications that my participants were not having, or had not had, relationships with their mental health team that enabled them to say the kinds of things they were telling me. I met some of those nurses. Two of the participants attended a youth centre to meet their mental health team, along with perhaps 25 other young people with "psychosis". There were healthy snacks, sports, acupuncture, an inclusive social environment. The psychiatrist came to the centre and met with people in a side-room. I could see the nurses were proud of the space they had created. They cared about their service-users. They were relaxed, experienced, enthusiastic and creative. Yet they were, as far as both voice-hearers were concerned, untrustworthy.

Lisa's history, her experiences, her voices and emotions: what else would we have talked about? And yet in 10 years of contact with mental health services, these two conversations were the only times she had been asked directly about the experiences we discussed. I see no reason to believe that Lisa was lying. I can only suggest that the stories of the mental health team do not make such conversation important or possible, and, yes, I do think that is astonishing.

Becky had shown me - it hit me very hard - that as a nurse I often blamed individuals for the contradictions within the stories that they are given when they seek help. I was very struck by Claire's use of diagnoses as stories, and my suspicions that she would not have talked about them in that way to a nurse. Nurses uphold facts, apparently. Does that mean we stifle stories, we do not *let them breathe?* Claire and I met for a coffee a couple of months ago; she has become a friend. I had been at a conference in the same city about "What is new for UK Early Intervention Services", but I left early. There had been a large sign in the lobby from Janssen-Cilag, claiming that its sponsorship of the event was "non-promotional" and nothing else needs to be said about the conference, or about the educated professionals milling about in front of the sign with coffees. Claire was deciding whether she should publish her work under her own name or not. She concluded that it would be most unwise; once expertise is labelled "service-user" expertise, it can be treated very differently.

Alec Grant, a mental health nurse academic and Narrative Reader in Mental Health, writes candidly on the Critical Mental Health Nurses' Network blog:

It seems to me that institutional psychiatric treatment spaces create possibilities for already damaged bodies to perpetuate unkindness on other bodies. Mental health nurses and other state psychiatric workers are systematically stripped of their capacities to be kind through, among other things, being neoliberalised, classed, gendered, Psydisciplined, and socialised to institutional psychiatric custom and practice (Grant, 2015).

This is a chapter of possibilities, not conclusions. I am looking into the possibility that being a researcher may benefit voice-hearers more than being a nurse. I do not mean voice-hearers *en masse*, like a quantitative researcher might. I mean individual voice-hearers. As has been clear, I hope, my concerns about psychiatry's science have been with me a very long time, perhaps brought to a head in this DNA, but if this four years can be reduced to a simple story it would be that this DNA has shown me that mental health is not merely a set of scientific arguments, *it is a political nightmare*.

I will lead student nurses away from *docile servitude*, or as Burstow describes, "the serviceable underling" (2015, p159). I have continued to use the map I created as a DNA of the professions and literature as a teaching aid for student nurses, social workers and Approved Mental Health Practitioners. Many were able to use it to understand *the personal is political* (Hanisch, 1969) for the first time. I have been asked to present at a large critical mental health conference later in 2016, and I will be writing a paper based on this research about nursing and violence.

I keep thinking about Angela, aged 17, alone, in her school library. Of all the moments I have witnessed in this work I would want that one to remain in the reader's mind.

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## Appendix 1

**Press release** 

#### New research on hearing voices

Researchers at Birmingham City University are looking for people who hear voices that others cannot hear. For a long time it has been assumed that anyone who hears voices must be mentally ill. Doctors call these voices 'auditory hallucinations'. Medical treatment has often been of little help, and recent research suggests that many (or even most) people who hear voices are getting on with their lives without seeking help from mental health services.

So, why are some voice hearers very distressed by their experiences, while others not? What skills do voice-hearers who are outside of mental health services have that enable them to manage? Do they understand and cope with their voices and emotions differently? If so, how? Do they even benefit in some way from hearing voices? What can voice-hearers learn from each other? Is it helpful to think of hearing voices as an illness, or is another way of understanding it better? The new research is being led by Professor Mervyn Morris and PhD student Jonathan Gadsby, both of whom have been listening to voice hearers talk about their experiences for many years: 'We are going to be talking with people who are involved with mental health services in Birmingham, but it is crucial that we meet people who are not, who perhaps have never talked to anyone about hearing voices before'. Although both have backgrounds in nursing, they are keen to stress that this is not medical research. 'No one is going to describe you as 'ill' or worse still, 'mad'! In fact, from our point of view, you are the expert. The research will involve sitting down with a friendly and experienced researcher and telling stories about your life and emotions. It is not a kind of test. You will get a chance not only to tell your stories, but help us think about some other peoples' stories too. It is completely confidential.'

If you would like to take part, please be in touch. You can let us know either by email, by phone or by letter.

## Appendix 2 Participant Information Sheets and Consent Form

There were two versions of the following forms, with only two minor differences. The first was that for participants who were in the "non-patient population", the part under section 3 "you are in contact with mental health services" was changed to "you are not in contact with mental health services", and the part about "medical care" on the consent form was removed. The second difference was that for those participants who were seen within mental health services (for which I was given an honorary contract with the Trust) I was required to put my forms under their letter head.

Title of Project: A Dialogical Narrative Analysis of Voice Hearer's Emotions

Name of Researcher: Jonathan Gadsby



#### PARTICIPANT INFORMATION SHEET

We would like to invite you to be involved in our study, which is part of PhD research for the main researcher. This information sheet is to let you know what it is about and what your involvement would be, so that you can decide whether you want to take part. This is important, and so there will be time to discuss this together and ask any questions that you want to. We suggest that this might take about 20 minutes.

#### 1. What would I need to do?

Participation in this research is voluntary. It consists of two conversations of approximately an hour in length on separate occasions, likely to be several months apart. The first conversation will be longer because of the additional need to discuss this information sheet and sign a consent form. You can take a break at any time. The conversations will be recorded and transcribed, and you can have copies. What you say in both conversations will be confidential.

#### 2. What is the research about?

The research is about the emotional lives of people who hear voices. We want to find out how the different stories people have about their voices and emotions affect how they think, feel and make choices. We will be talking to people who have very different kinds of stories.

In the first conversation, the researcher will use some simple pictures and ask you a few questions to help you tell stories about your life, particularly about your emotions and things you feel strongly about.

We also want to know what you think about other people's stories. In the second conversation we will talk about the kinds of stories other people have told and discuss how you think they may be similar or different to your own, and whether their stories change the way you think about your stories. A third conversation can be arranged if you feel there is more you want to say.

### 3. Why have I been chosen to take part in this study?

You have been chosen to take part because you hear voices and you are in contact with mental health services. About one third of those who are taking part are also in contact with mental health services. By having participants who are in both groups we can think about some of the differences there may be between the stories of those seeing mental health services and those who are not, although this is only a part of what we hope to learn.

## 4. What will I gain by taking part?

We hope that you will have a good experience of talking about your emotions. We hope that you will find the process of thinking about other people's stories interesting, and possibly even beneficial to you, although this is not guaranteed. You will be contributing to a greater understanding about emotions and voice-hearing, and the effects of different ways of thinking about them. Your knowledge and thoughts will have an impact on the outcome of the final research.

## 5. Are there any risks for me in taking part?

It is up to you what you choose to tell us, but talking about emotions and things which you feel strongly about can be emotional in itself. This is not a problem for us, but if you feel that it will make you upset in a way which would be hard for you to recover from afterwards, then taking part is probably not for you. If you are keen to take part but think you might need support afterwards, we can talk about this carefully before you decide, and make appropriate plans. You are welcome to bring someone with you for support, although they will not take part in the interview. There is one further consideration: Although what you say is confidential, if you tell us something which suggests a crime either has taken place or is at risk of taking place, and if this is something you have not previously disclosed or reported, then we would have a duty to consider breaking confidentiality and to inform the proper authorities. This would likely be discussed with you. This research is probably not the best opportunity to disclose something like that for the first time.

## 6. What happens after the research?

After the first conversation, we will arrange a further date for the second conversation. About two weeks after each conversation you can have a transcript. After the second conversation, your part in the research will be finished. When the research is published, you will be notified and either given copies of the text or directed to it. Your contribution will be made anonymously, unless you do not wish it to be, which we can discuss. It is anticipated that the research will be published in academic journals and in other more accessible formats.

## 7. Giving consent

To take part in the research, you will need to sign a consent form.

## 8. If I agree to take part, can I change my mind later?

Yes. Even though you have signed a consent form, you can withdraw at any time. All you need to do is contact the main researcher by email or at the address given in section 12, stating that you wish to withdraw.

## 9. Payment

There is no payment for taking part. However, expenses for travel can be reclaimed. Please discuss this with the researcher.

## 10. Who has reviewed the Study?

The study has been reviewed by Leicester Research Ethics Committee, and Birmingham City University.

### 11. Complaints procedure

If you wish to make a complaint about any part of your participation in this research, please contact the Patient Advice and Liaison Service (PALS) of the Mental Health Trust:

Customer relations, Freepost RLXJ-XLRU-GGYY, Birmingham and Solihull Mental Health NHS Foundation Trust, Ardenleigh Centre, 385 Kingsbury Road, Erdington, Birmingham, B24 9SA.

Alternatively you can contact Birmingham City University:

Lucy Land, Chair of Research Insurance and Indemnity Committee, Birmingham City University, Westbourne Road, Edgbaston, Birmingham, B15 3TN

### 12. Further Information

Further Information can be obtained from Jonathan Gadsby, 219 Bevan House, BCU City South Campus, Westbourne Road, Edgbaston, Birmingham B15 3TN. jonathan.Gadsby@mail.bcu.ac.uk

Thank you for taking part in this study.

Title of Project: A Dialogical Narrative Analysis of Voice Hearer's Emotions

Name of Researcher: Jonathan Gadsby Participant ID Number:



#### PARTICIPANT CONSENT FORM

Please initial all boxes

- 1. I confirm that I have read and understand the information sheet dated 26.4.2014 (version 004) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason without my any medical care or legal rights being affected.
- 3. I understand that what I say is confidential and will be made anonymous. However, if I disclose anything which might suggest a crime has taken place or that someone is at risk in a significant way then this may need to be reported to the appropriate authority, breaking that confidence. I can expect this to be discussed with me if it arises.
- 4. I have discussed my support needs with the researcher.
- 5. I understand that the interview will be recorded on an audio device and that this data and transcripts will be kept in accordance with data protection policies.
- 6. I understand that I can have a copy of the transcript of the interview.
- 7. I agree to take part in the above study.

Name of Participant:

Name of researcher taking consent:

Date:

Date:

Signed (participant)

Signed (researcher)

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#### **NRES Committee East Midlands - Leicester**

The Old Chapel Royal Standard Place Nottingham NG1 6FS

Telephone: 0115 8839368

22 April 2014

Mr Jonathan Gadsby PhD Birmingham City University Birmingham City University 219 Bevan House City South Campus Westbourne Road, Birmingham B15 3TN

Dear Mr Gadsby

Study Title:	A Dialogical Narrative Analysis of voice-hearers'	
	emotions.	
REC reference:	14/EM/0132	
IRAS project ID:	138763	

The Research Ethics Committee reviewed the above application at the meeting held on 04 April 2014. Thank you for attending with Professor Mervyn Morris to discuss the application.

#### **Documents reviewed**

The documents reviewed at the meeting were:

Document	Version	Date
Evidence of insurance or indemnity		11 February 2014
Interview Schedules/Topic Guides	001	10 March 2014
Investigator CV		14 February 2014
Letter from Sponsor		06 February 2014
Other: Non NHS SSI	138763/575588/6/840/218357/293971	06 March 2014
Other: Press release	001	24 February 2014
Other: CV - Professor Romme		
Other: CV - Professor Morris		
Other: DBS		07 February 2014
Participant Consent Form	002	24 February 2014
Participant Information Sheet	002	24 February 2014
REC application	138763/575465/1/508	03 March 2014

#### **Provisional opinion**

- The Chair introduced himself and the Committee and thanked you for attending.
- The Committee informed you they liked the press release as it describes the study well. You thanked the Committee.
- The Committee asked you to clarify if this study is part of a PhD. You confirmed it is. The Committee informed you this needs to be stated on the Patient Information Sheet.
- The Committee asked you to describe the procedure if a participant becomes distressed. You stated there is not one procedure as part of the research as patients who come from the NHS will have a support team in the NHS service and will be known to the team. The patients involvement in the research will be discussed with their care coordinator first. If that in itself is too distressing it will be suggested they do not take part. For those patients who may find it distressing the conversation will be about what support they feel they need. You explained the meeting will be at the Community Mental Health base and will be introduced to them by the care coordinator.
- The Committee asked you to clarify the length of the interviews. You explained the initial interview will be about 20 minutes to go through the Information Sheet and Consent Form and then the second interview will be about an hour.
- The Committee informed you there is potential to cause distress in the interview. You stated not really as most of what will be discussed is volunteered by the individual. You said you will be asking them about their emotions and telling stories, which is a recall of their life and it would be strange if they did not tell you about any distressing issues. You said you will rely on your judgment to talk these through with them. The Committee asked you what about the participants who are not in the NHS service. You explained talking to public participants will be self-identified. The Committee asked how these participants will be supported in the event of distress. You stated they will have the same consent process, interview and research and the effect it will be for them may be different but it is difficult for you to recommend what support they may need. You can talk about the options that are available to them. The Committee informed you that if someone becomes so distressed and are not safe, you cannot just let them leave, there needs to be immediate support available to them, and there needs to be a robust process that will be followed. You agreed with the Committee and stated that if this were to happen you would need to clearly inform the Committee of this process.
- The Committee informed you if a participant discloses something during the interview that it must be made clear you will not be able to ensure confidentiality as you will have a duty of care to report it to the appropriate authorities and this needs to be included on the Information Sheet.
- The Committee asked you to clarify at what point participants will have had the Information Sheet and the choice to Consent. You stated you imagined both as some people will be volunteering to take part which shows the willingness to take part, or do I need to offer people the chance to go away and think about it, the only problem with that is some people who come to see me, may not want to come back again. The Committee asked you what is your clinical practice and how often do you see participants. You stated it is different for each group. The Committee suggested to you that you send the Information Sheet and Consent Form once a participant has shown an interest to take part. You agreed this can be done.
- The Committee informed you although you will anonymise the interview, if people wish to have their name on it, the participant will need to consent to this and suggest there be a separate Consent Form for it.
- The Committee informed you there are no complaints procedures on the Information Sheet and this needs to be added.
- The Committee asked you to clarify if you will need an honorary contract. You

confirmed you will which will be done as soon as ethical approval has been given.

- The Committee asked you to clarify where will the interviews take place. You stated the
  interviews for participants in the NHS services the best place will be at the Community
  Mental Health base and for participants in the Community the interviews may be
  conducted at the University.
- The Committee asked you to clarify when participants withdraw from the research, is this
  just the data. You stated on the IRAS form you selected the full withdrawal and the
  interview as they can remove their story so the limit can be chosen. The Committee
  explained to you normally participants have up to 1 week after the interview if they wish
  to withdraw the details.
- The Committee suggested to you there should be two different information sheets for the different groups. You asked the committee to be more specific about what information is specific to a particular group. The Committee explained in the section 'Why have I been chosen to take part in this study?' The information in this would be a different statement depending on which group they are in.
- The Committee asked the researcher to clarify why in the section 'What is the research about' on the Information Sheet it does mention voices. You explained this is not an accident, it has been left out as some research has been done that voice hearing to give their story, this research is different although there may be a crossover this is by way of emotions as well as voices so you have deliberately kept it open in that statement.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

#### Further information or clarification required

- 1. You must provide information as to how you will support Participants who become distressed both for those Participants who are recruited from an NHS setting and for those who are not.
- 2. Provide a detailed support procedure for those who are being interviewed outside of an NHS setting.
- 3. Please confirm you have an honorary contract as discussed with the Committee.
- 4. If persons are to be identified within your analysis this would need to be specifically consented to by those individuals.

The following changes are required to the Information Sheet:

- 1. Provide two Information Sheets one for each group.
- 2. Add in details of the complaints procedure.
- 3. Add in at the beginning that this study is part of a PhD.
- 4. Clearly explain in the 'Why have I been chosen to take part in this study'.
- Please add if a participant discloses something during the interview and that it must be made clear the researcher will not be able to ensure confidentiality as they will have a duty of care to report it to the appropriate authorities.
- 6. Clearly state what the withdrawal process is.

## If you would find it helpful to discuss any of the matters raised above or seek further clarification, you are welcome to contact Wendy Rees REC Manager.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise using tracked changes showing the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 22 May 2014.

#### Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

14/EM/0132

Please quote this number on all correspondence

Yours sincerely

p. W Rees

Professor Geoff Dickens Chair

Email: nrescommittee.EastMidlands-Leicester@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Sponsor - Lucy Land Dr Paul McDonald, Birmingham & Solihull Mental Health NHS Foundation Trust

#### **NRES Committee East Midlands - Leicester**

#### Attendance at Committee meeting on 04 April 2014

#### **Committee Members:**

Name	Profession	Present	Notes
Professor Geoff Dickens	Research Manager & Head of Nursing Research	Yes	Chair
Mr John Baker	Radiation Protection Advisor and Senior Lecturer (retired)	Yes	
Miss Sue Ainsworth	Magistrate	Yes	
Miss Alison Armstrong	Consultant Orthopaedic Surgeon	Yes	
Mr Steve Barrett	Research Coordinator	Yes	
Dr Paul Beeson	Senior Lecturer	No	
Margherita Carucci		Yes	
Miss Stephanie Deveney	Occupational Therapist	No	
Mrs Sandra Hall	Principal Lecturer in Clinical Pharmacy & Pharmacy Practice	Yes	
Dr Sally Hinchliffe	Medical Statistician	Yes	
Dr Nicola James	Independent Research Consultant	Yes	

#### Also in attendance:

Name	Position (or reason for attending)	
Miss Andrea Graham	Deputy Regional Manager (Nottingham)	
Wendy Rees	REC Manager (minutes)	
Miss Joanne Unsworth	REC Assistant	



**NRES Committee East Midlands - Leicester** 

The Old Chapel Royal Standard Place Nottingham NG1 6FS

Telephone: 0115 883 9368

02 May 2014

Mr Jonathan Gadsby PhD Birmingham City University Birmingham City University 219 Bevan House City South Campus Westbourne Road, Birmingham B15 3TN

Dear Mr Gadsby

Study title:	A Dialogical Narrative Analysis of voice-hearers' emotions.
<b>REC reference:</b>	14/EM/0132
IRAS project ID:	138763

Thank you for your letter of 30 April 2014, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Ms Wendy Rees, NRESCommittee.EastMidlands-Leicester@nhs.net

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <a href="http://www.rdforum.nhs.uk">http://www.rdforum.nhs.uk</a>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (<u>catherineblewett@nhs.net</u>), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of insurance or indemnity		11 February 2014
Interview Schedules/Topic Guides	001	10 March 2014
Investigator CV		14 February 2014
Letter from Sponsor		06 February 2014
Other: Non NHS SSI	138763/575588/6/840/218357/2 93971	06 March 2014
Other: Press release	001	24 February 2014
Other: CV - Professor Romme		
Other: CV - Professor Morris		
Other: DBS		07 February 2014
Other: Managing Distress	001	25 April 2014
Participant Consent Form	003	26 April 2014
Participant Consent Form	004	26 April 2014
Participant Consent Form	005	26 April 2014
Participant Information Sheet	003	26 April 2014
Participant Information Sheet	004	26 April 2014
REC application	138763/575465/1/508	03 March 2014
Response to Request for Further Information		30 April 2014

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

#### Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- · Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### **Feedback**

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

#### 14/EM/0132 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

"After ethical review - guidance for researchers"

With the Committee's best wishes for the success of this project.

Yours sincerely

R.

#### Professor Geoff Dickens Chair

Email:NRESCommittee.EastMidlands-Leicester@nhs.net

Enclosures:

Copy to:

Reader Lucy Land

Dr Paul McDonald, Birmingham & Solihull Mental Health NHS Foundation Trust







Research & Innovation Department Suite O Radclyffe House 66/68 Hagley Road Edgbaston Birmingham B16 8PF

> Tel: 0121 301 4330 Tel: 0121 301 4327 Fax: 0121 301 4340

18 November 2014

Mr Jonathan Gadsby PhD Birmingham City University Birmingham City University 219 Bevan House City South Campus Westbourne Road, Birmingham B15 3TN

Dear Jonathan

#### A Dialogical Narrative Analysis of voice-hearers' emotions

Thank you for providing us with the documentation to support your application for R&D approval. We have received notification of a favourable ethical opinion and following a review of all the documentation this study has been approved by the Trust. You may therefore commence the work.

Please note that the Trust's approval of this research is given on the understanding that you are aware of and will fulfil your responsibilities under the Department of Health's Research Governance Framework for Health and Social Care, including complying with any monitoring/auditing of research undertaken by the Research & Innovation Department.

In particular, whilst conducting your study you should respect the confidentiality of data obtained from participants.

Please do not hesitate in contacting the Research & Innovation Department should you require any advice or support on any aspect of your project. When contacting us it would be helpful to quote our reference number for this project: NRR1286.

Yours sincerely

Professor Swaran P Singh Interim Director of Research & Innovation Chair: Sue Davis, CBE Chief Executive: John Short

PALS Patient Advice and Liaison Service Customer Care Mon – Fri, 8am – 8pm mhft.nhs.uk Website: www.bsmhft.nhs.uk Text: 07985 883 509 Email: pals@bsmhft.nhs.uk Tel: 0800 953 0045



Improving mental health wellbeing

# Appendix 4

Original systematic review of the literature: The following is taken from my university's in-house research proposal, submitted in 2013. It details my first attempt to systematically review literature by categorising it into different schemata. On page 11 I describe this as a 'failed attempt' and explain why.

#### The literature on hearing-voices and coping

The proposed research is sited within a conceptually uncomfortable field; one which cannot agree in which branch of science it best fits, or even if science is the right field at all. In reviewing the literature one could contrast the different approaches to hearing voices that have existed through history and across cultures (Longden et al., 2011). One could contrast the recovery stories of service users (Romme et al., 2009) and the outrageous scandal implied by longitudinal studies of the effectiveness of Western psychiatric interventions (Whitaker, 2011) with the latest research in neuro-psychiatry. One could focus on theories of dissociation and trauma, and see voice-hearing as a result of childhood abuse (Dillon, 2010, Read et al., 2005). One could scan the science journals for possible genetic coding of schizophrenia, yet find other eminent authors calling for a ban on further research on schizophrenia because of lack of concept validity (Bentall, 2006), or indeed others who argue that it is not so much that one diagnosis is flawed but that diagnosing itself is the wrong type of process, a debate which is highly topical in the reactions to the publication of DSM-V. After all of that, one would still have the task of looking for clarity on the subject of coping style, which is also not well defined, with measurements which also reflect the collision of differing concepts. It is therefore the baffling spread of the literature which demands initial attention, more than the merits of any one particular set of research findings. This is the reason for the need for a philosophical review and analysis of the literature, without which a further piece of research, even with an original focus, seems unlikely to be aware of its own assumptions and cannot hope to significantly further the state of knowledge in this field.

This process has been commenced with an initial analysis of 69 articles, the result of a strategic search for peer-reviewed discussion or research into voice-hearing and coping style. As a result of conducting this review, it can be seen that there are different concepts of voice hearing which are situated in at least two opposing schemas. These schemas could be categorised in a number of ways, such as 'technological' vs 'hermeneutic' (Bracken et al., 2012), or perhaps less neutrally (in the tradition of philosophers of science such as John Dupré) as 'reductionist vs anti-reductionist' (Dupré, 1983). There is a suspicion that these schemas are a kind of contemporary re-phrasing of the mind-body problem of philosophy (Robinson, 2012).

A main finding of this review was that what counted as *coping* depended upon the starting assumptions of the researcher(s) about voice-hearing to such an extent that statements about it were valued oppositely. For those who considered coping with voices to be found in reengaging with a dissociated aspect of one's self or experience, then coping was primarily a problem-focused enterprise in which a voice-hearer sought to understand or re-understand the meaning of their experiences (life experiences and voice-hearing experiences). However, for those who considered hearing voices to be illness, or part of an illness, the key insight to be gained was that they were not to be integrated into the self, but instead to be considered as 'auditory hallucinations', and with this came the view that the experience of voice-hearing was best coped with when viewed with the insight that it has no specific meaning or relationship to life-experiences. Under this approach, coping with voices was more usually an emotionfocused enterprise, alongside pharmaceutical *treatments*, although the relationship between these schemata and emotion vs problem focused coping needs further exploration. In other words, coping and concepts of aetiology (of voice hearing) were significantly linked. This is inevitable, but problematic because there are highly opposing views about aetiology. Further to this, the concept of coping was often not defined, and slightly concealed by use of different language, which once again reflect differing philosophies. Functioning was one such a word, and the relationship between coping and functioning requires further examination. In some of

the literature, neither word was used, with *management* or *recovery* seeming to take their place.

Often coping was used to describe a different kind of subsidiary concern, techniques of coping such as *distraction* - things to do, or suggested cognitions when troubled by voices. Studies in this tier link struggling to cope with hearing voices to depression, *maladaptive* coping such as alcohol ('self-medication'), or perhaps studies showing that positive self-talk can balance the negative comments of voices. Articles with these kinds of concerns are listed in table 2, 4b. Describing this as a *subsidiary* tier is not denigrating such research as unimportant but rather that it has a narrower scope than the previously mentioned views which make coping into something more like a general stance to the whole experience of voice hearing.

Table 1 is an initial analysis of the main two schemata found in the literature, with table 2 being the method by which the table 1 was constructed: a breakdown of the the often contradictory assumptions within each of the 69 articles.

	Schema 1:	Schema 2:
hearing voices	normal for a minority, possibly a trauma coping strategy or the result of a trauma coping strategy (i.e. dissociation), psychological causes	abnormal, a symptom of illness, psychosis, something to cope with, traumatic, biomedical causes.
non-clinical populations of voice hearers	included, relevant, visible	excluded, irrelevant, unseen
metacognitions about voices	a causal role in voice formation and/or a key role in coping/ recovery	a measurement of 'insight', a possible cause of depression/ anxiety, may alter ability to cope with voices
accepting voices as real, normal	Therapeutic	lack of insight
listening to voices, engagement with voices	Therapeutic	loss of reality
attributing meaning to voices, forming beliefs to explain voices	finding a new sense of self	becoming delusional
voices held as separate from self	(continued) dissociation	a key insight
integration into self	Therapeutic	delusional

#### Table 1: Two schemata and their characteristic values

Table 2

Theme and value:	Articles
1a. Inclusion of non-clinical voice-hearer populations	Andrew et al. (2008), Campbell and Morrison (2007), Cardano (2012), Castillo (2003), Conway (2004), Cortstens et al. (2012), Daalman et al. (2011), Escher et al. (2003), Escher et al. (2005/6), Escher et al. (2004), Escher et al. (2002), Garcia-Montes et al. (2003), Goldstone et al. (2012), Jones et al. (2003), Krabbendam (2008), Longden et al. (2012), Meddings et al. (2006), Ruddle et al. (2011), Thornhill et al. (2004), Varese et al. (2012)
1b. Clinical population only	Berman et al. (2012), Berry et al. (2012), Brewin and Patel (2010), Cather (2007), Coffey et al. (2004), Davidson et al. (2009), Dixon (2008), Dorahy et al. (2009), Farhall et al. (2007), Favrod et al. (2004), Favrod et al. (2007), Fenekou and Georgaca (2010), Ferrer and Jadapalle (2011), Granholm et al. (2012), Hatashita-Wong and Silverstein (2003), Hazipetrou and Po Oei (2010), Hayashi et al. (2007), Jenner et al. (2004), Jenner et al. (2006a), Jenner et al. (2006b), Knols and Corstens (2011), Langer et al. (2010), Lee (2005), Lee et al. (2004), Mackinnon et al. (2004), Mann and Packenham (2006), Marder (2012), Mawson et al. (2011), Newton et al. (2007), Nothard et al. (2008), Penn et al. (2009), Perivoliotis et al. (2007), So and Wong (2008), Sommer et al. (2012), Tsai and Chen (2006), Tsai and Ku (2005), Veiga-Martínez et al. (2008), Wiersma et al. (2004), Wykes at al. (2005), Zimmerman et al. (2011)
2a. Voices part of normal human or normal spiritual experience	Cardano (2012), Castillo (2003), Conway (2004), Cortstens et al. (2012), Daalman et al. (2011), Dillon (2010), Escher et al. (2005/6), Escher et al. (2004), Escher et al. (2002), Fenekou and Georgace (2010), Jones et al. (2003), Knols and Corstens (2011), Longden et al. (2012), Meddings et al. (2006), Thornhill et al. (2004)
2b. Voices are abnormal human experience	Berman et al. (2012), Berry et al. (2012), Farhall et al. (2007), Brewin and Patel (2010), Cather (2007), Coffey et al. (2004), Dixon (2008), Dorahy et al. (2009), Favrod et al. (2004), Favrod et al. (2007), Ferrer and Jadapalle (2011), Goldstone et al. (2012), Granholm et al. (2012), Hatashita-Wong and Silverstein (2003), Hayashi et al. (2007), Jenner et al. (2004), Jenner et al. (2006), Jenner et al. (2006b), Lee et al. (2004), Mackinnon et al. (2004), Mann and Packenham (2006), Marder (2012), Newton et al. (2007), Perivoliotis et al. (2009), Place (2003), Shawyer et al. (2007), So and Wong (2008), Sommer et al. (2012), Tsai and Chen (2006), Tsai and Ku (2005), Wiersma et al. (2004), Wykes at al. (2005)
3a. Acceptance of voices (as 'real' or as having meaningful content) as a means to better coping or greater agency	Berry et al. (2012), Campbell and Morrison (2007), Cardano (2012), Castillo (2003), Conway (2004), Cortstens et al. (2012), Dillon (2010), Dorahy et al. (2009), Escher et al. (2005/6), Escher et al. (2004), Fenekou and Georgaca (2010), Goldstone et al. (2012), Jones at al. (2003), Knols and Corstens (2011), Krabbendam (2008), Longden et al. (2012), Mawson et al. (2011), Meddings et al. (2006), Newton et al. (2007), Norton (2006), Ruddle et al. (2011), Thornhill et al. (2004)

3b. Acceptance of voices (as 'real', or as having meaningful content) sign of lack of insight or loss of agency	Berman et al. (2012), Cather (2007), Coffey et al. (2004), Dixon (2008), Farhall et al. (2007), Favrod et al. (2004), Favrod et al. (2007), Ferrer and Jadapalle (2011), Granholm et al. (2012), Hatashita-Wong and Silverstein (2003), Hazipetrou and Po Oei (2010), Hayashi et al. (2007), Jenner et al. (2004), Jenner et al. (2006a), Jenner et al. (2006b), Mackinnon et al. (2004), Penn et al. (2009), Perivoliotis et al. (2009), Sommer et al. (2012), Tsai and Chen (2006), Tsai and Ku (2005), Veiga-Martínez et al. (2008), Wykes at al. (2005)	
4a. Voices primarily viewed as a result of coping style (such as dissociation)	Andrew et al. (2008), Anketell et al. (2011), Anketell et al. (2010), Berry et al. (2012), Brewin and Patel (2010), Campbell and Morrison (2007), Conway (2004), Cortstens et al. (2012), Dillon (2010), Escher et al. (2005/6), Garcia-Montes et al. (2003), Goldstone et al. (2012), Knols and Corstens (2011), Karabbendam (2008), Longden et al. (2012), Meddings et al (2006), Thornhill et al. (2004), Varese et al. (2012)	
4b. Voices primarily viewed as something to be coped with	Berman et al. (2012), Cather (2007), Coffey et al. (2004), Daalman et al. (2011), Dixon (2008), Escher et al. (2003), Farhall et al. (2007), Favrod et al. (2004), Favrod et al. (2007), Ferrer and Jadapalle (2011), Granholm et al. (2012), Hatashita-Wong and Silverstein (2003), Hazipetrou and Po Oei (2010), Hayashi et al. (2007), Jenner et al. (2004), Jenner et al. (2006a), Jenner et al. (2006b), Lee et al. (2004), Mackinnon et al. (2004), Mann and Packenham (2006), Marder (2012), Ngo Nkouth et al. (2010), Penn et al. (2009), Perivoliotis et al. (2009), Place (2003), Shawyer et al. (2007), So and Wong (2008), Sommer et al. (2012), Tsai and Chen (2006), Tsai and Ku (2005), Wiersma et al. (2004), Wykes at al. (2005), Zimmerman et al. (2011)	
5a. Voices viewed as part of self given positive value	Anketell et al. (2011), Anketell et al. (2010), Cardano (2012), Conway (2004), Cortstens et al. (2012), Dillon (2010), Escher et al. (2005/6), Escher et al. (2002), Fenekou and Georgaca 2010), Garcia-Montes et al. (2003), Jones et al. (2003), Knols and Corstens (2011), Longden et al. (2012), Ruddle et al. 2011), Thornhill et al. (2004), Veiga-Martínez et al. (2008)	
5b. Voices viewed as part of self given negative value	Berman et al. (2012), Coffey et al. (2004), Dixon (2008), Farhall et al. (2007), Favrod et al. (2004), Favrod et al. (2007), Ferrer and Jadapalle (2011), Granholm et al. (2012), Hatashita-Wong and Silverstein (2003), Jenner et al. (2006a), Mackinnon et al. (2004), Penn et al. (2009), Perivoliotis et al. (2009)	

#### Table 3: Articles by schema and design

The following table shows how many articles divided into each schema. There are a few caveats. Firstly, there were articles which did not fit well with either schema, and a 'best fit' approach had to be taken, although two were impossible to decide and became 'other'. This lack of perfect tessellation between schemata and articles introduces a more subjective element to this part of the review. Does this mean that the two schemas are a dichotomy found more within this analysis than within the literature? This seems doubtful, given the number of articles which did fit the schemas well and the supporting philosophy. Instead, the articles which were more difficult to place are more likely to be an indication of the poor acknowledgement of starting assumptions and resulting internal confusion of some studies.

One further point to be made is that it was not correct to imply simply that Schema 1 was *psychological* whereas Schema 2 was *biological*. There were many items which fitted within

Schema 2 which promoted psychological approaches for coping with voice-hearing. Broadly they tended to be more Cognitive Behavioral Approaches, whilst those of schema 1 tended to be more psychoanalytic: describing this difference more fully requires further work.

Finally, the numbers in the final row cannot be taken as an indication of the general percentages of research carried out within each schema. This is because of the exclusions mentioned above of articles primarily concerned with aetiology of voice-hearing would have added to the percentage of articles in the second schema.

#### Table 3

	Schema 1	Schema 2	Other
review	1	5	
quantitative study	8	18	
qualitative study	13	8	1
commentary, essay or opinion	9	5	1
total number of articles	31	36	2

#### Search method limitations:

This review has been described as an *initial* review: further work is required. Firstly, restricting the search to English language and to recent work are more pragmatic than philosophically defensible; perhaps other cultures or eras have found ways of examining voice-hearing without such polarisation between schemata. Secondly, it is a little difficult to say exactly what is the literature which should be searched. This initial review makes the assumption that peerreviewed journals are the correct resource, and there is some safety in this approach. Yet according the organisation Intervoice there are now 27 countries with established networks of 'hearing voices groups', peer support groups for people who hear voices (Intervoice, 2013). Very little of this kind of evidence is represented in peer-reviewed journals, and yet could a review of hearing-voices and coping style be considered complete without using such a resource (and its literature)? Whilst questioning if the peer-reviewed literature is representative, one might also ask how it came to include such opposing findings, the schemata outlined above. One possibility is that certain issues are presented as value-neutral when they may not be. The above analysis portrays the literature as conflicted but equally valid. A further review may need to make decisions about inclusion which is more sophisticated, or at least, further critical analysis. Finally, excluding some articles on the basis that they were primarily concerned with *aetiology* and not *coping* may be a little arbitrary in some instances, especially when the both schemas contend that understanding the aetiology of voices is key to making them more easily coped with.

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# Appendix 5

Thessaloniki Declaration, 2014 (<u>http://hearingvoicescymru.org/about-2/thessalonika-hearing-voices-declaration-2014</u>)

#### DECLARATION

"It was worth existing, so that we could meet" G. Ritsos

We met in Thessaloniki because our lives have value. Our voices have value and acquire meaning when they encounter other voices. We demand and we create safe spaces for our dignity and our quality of life together with others and not against others. We consider ourselves a part of a living movement of solidarity and mutual respect, which comes as a response to the one-sidedness of biological approaches. We are, thus, a political and a multi-cultural movement. The experience of voices is not a personal, but a collective matter: it concerns family, friends, professionals, the whole society.

We live in a continuously changing world, with precariousness spreading to all aspects of our lives. Particularly in Greece, at a time of complete collapse of the public health services, the empowerment and participation of persons with psychiatric experience at all levels of human rights advocacy, influencing policies and decision making is of outmost importance.

#### We demand

- · Safeguarding human rights in the field of mental health
- · Adopting approaches which focus on experiences and their meaning
- · Abolishing stigmatizing and un-scientific terms, such as schizophrenia
- Developing a simple and experiential discourse, that can describe our experiences
- · without labels and diagnoses
- Undoing the myth of the omnipotence of psychotropic medication
- · Information on alternative ways of managing our experiences
- · Possibility of choice of the care, support and treatment we might need
- · Connecting up with other social movements

Our struggle is a struggle for the self-determination of our lives.

We walk together in crisis, we seek common paths of recovery in an Odyssey where the personal becomes collective and the collective becomes personal.